PATIENT EXPERIENCE OF TELEHEALTH FOR THE SELF-MANAGEMENT OF CHRONIC DISEASE: APPLYING A VALUE CO-CREATION FRAMEWORK

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I dedicate this work to my beloved parents,

Dr Adrian and Pik Jan Go, to whom I owe so much

and

Mark Walters,

for making everything we do a part of a wonderful life together

Abstract

This thesis is a study of patient experience of telehealth services for self-management of chronic disease. It investigates the use of technology-based services to address the social and managerial problem of unsustainable demand for scarce resources by focusing on the understudied patient perspective. Chronic disease care is a 'wicked problem' affected by complex interdependencies that are difficult to change, such as rising demand from ageing populations, unhealthy lifestyles, spiralling healthcare costs and economic contraction weakening the financial foundations of healthcare systems. Studies suggest that using technology-based services installed in patient homes can play a part in safely reducing demand for in-clinic appointments and emergency hospitalisations.

Conceptualising the research problem involved unpacking extant patient experience concepts. The thesis applies marketing theoretical perspectives to explicitly question the assumptions in the healthcare literature relating to patient experience and argues for application of a service-dominant logic (S-DL) (Vargo & Lusch 2004; 2008; 2016) to address provider-led biases. The perspectival shift enables patient experience to assume patients participate in service experiences as social actors rather than objects. In committing to marketing perspectives, the thesis draws on explanations of consumers agentically experiencing service interactions through resource integration aimed at deriving value from their consumption experiences (Arnould et al. 2006). It also conceptualises telehealth as a self-service technology (SST) (Dabholkar 1996) within a multi-interface, multichannel service context. Using an S-DL approach grounds the study of patient experience in their interactions with various aspects of services based on patient goals and interests. This is consistent with the S-DL's explanation of value emergence by advocating attention to structure and agency in order to account for value as it is subjectively determined by the patient in context.

Applying the S-DL perspective is consistent with the critical realist (Bhaskar 1978) standpoint adopted in the thesis (Löbler 2011; Peters et al. 2013). Critical realism is capable of maintaining consistency between the ontology of patient perspectives of service experiences while accounting for the influence of provider-led social structures. As a philosophical background, critical realism also provides epistemological tools for investigating the interaction of agency and socio-technical structures of healthcare services to explain social change. Its theory of morphogenetic social action (Archer 1995) provides a methodological route to logical conjecture about the generative mechanisms that explain the structure of interactions between patients and providers implicit in service structures even if the actors involved are unaware of them. Therefore, the conceptual framework is philosophically equipped to engage with debates between epistemological approaches in the healthcare literature about the role of individual agency and deterministic service structures. Critical realism also provides analytical tools useful for adducing the potential of telehealth services to disrupt ingrained attitudes and behaviours. The theoretical stance adopted in the thesis suggests that identification of generative mechanisms at the micro level of telehealth service experience can be used to theorise about changes introduced by patient use of telehealth to trigger meso-level structural change, toward transformation of wider healthcare

service interactions in different service channels. Transformation is argued to be signalled by the selection of alternatives that challenge the relationship dynamics sustaining ingrained interdependencies that contribute to the problem of unsustainable demand for chronic disease care.

An in-depth case study of an NHS telehealth service informed by multiple case studies of experienced telehealth users provides rich empirical data. Employing interviews and participant observations with a heterogeneous sample of 27 complex chronic comorbid adults, data collection took place in patient homes in a large English city over an 18-month study.

The findings show telehealth to involve effortful experiences challenging the prevailing view that telehealth is convenient, easy to use, cost-saving for patients, and that it extends the 'objective' clinical lens on the patient condition in non-clinical settings. The thesis highlights the relationship between telehealth and wider healthcare service relationships by showing that the outcomes from telehealth use are valued by patients as they compensate for inappropriate functional outcomes and poor relational outcomes that result from full-service interactions. Telehealth is a resource that enables patients to manage service relationships with healthcare services. Patients are shown to regain control over what happens to them through customising clinical decision-making processes. Patient participation in decisions about access to further healthcare resources is argued to be transformative because it makes healthcare interactions patient-led.

The core contributions of the thesis are a patient-centred framework improving the construct validity of patient experience and patient value research. By studying disadvantaged and vulnerable consumer experience of SST in a highly institutionalised healthcare service context, it contributes to the SST literature by moving beyond psychology-based focus upon 'use' and applying a S-DL to consider the role of 'experience'. It contributes to the S-DL literature on consumer-provider value misalignment by showing the importance of service channel affordances as opportunities for patients to co-create subjective value. The findings contribute insights into debates about patient choice and autonomy and evidences strategic value from loosely integrated multichannel services in order to counteract effects of misaligned provider and patient value systems.

Practical implications include support for continuing telehealth provision, and acknowledgement of non-economic costs of use for patients by ensuring availability of full-service options to provide much-needed support and feedback in response to changing needs. Additional resources are needed to guide users to learn more about clinical measurement and interpretation of vital signs to develop their practical self-management skills. This could improve patients' ability to derive improved value from their healthcare service interactions. Managers should understand that telehealth is valued by patients because it increases patient autonomy which is missing from full-service experiences. Customisation is an important part of the value that patients derive from using telehealth, enabled by provision of multichannel services. Work is needed to transform organisational culture and values currently focused on clinical outcomes at the expense of the functional and relational outcomes valued by patients.

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Part I

Chapter 1 Introduction

This chapter explains the thesis topic and the scope of the research undertaken. It explains the motivation for the study by explaining the research context and the gaps addressed by the thesis. This is followed by a summary of the approach taken, including the research aim, questions and objectives followed by an outline of the thesis chapters.

This thesis is a study of patient experience of telehealth services for self-management of chronic disease. It addresses the real-world problem of the global chronic disease epidemic (WHO 2011) creating pressure on healthcare systems. Failure to provide affordable care poses a risk to societies because debility and permanent disability from poor chronic disease management affects productivity and well-being for individuals, households and societies. Policy makers recommend transformation of healthcare systems to foster behaviour change among providers and patients by shifting emphasis from treatment to prevention of illness (Epping-Jordan et al. 2004). Prevention of complex comorbidities through good daily care is critical for avoidance of difficult treatment involving prolonged stays in hospital due to increased susceptibility to serious infection (Steventon et al. 2012).

Technological innovation is increasingly important for managing demand for scarce medical resources across geographical distances (Koch 2006). Telehealth is an umbrella term for the application of information and computing technologies (ICT) (Cruickshank & Winpenny 2012) enabling remotely located expertise to inform and guide the actions of non-medical personnel. Initially developed to serve military contexts (e.g. the battlefield and space exploration), it has been adopted for civilian applications to manage incidents in transit and serve rural areas with low population density and poor access to healthcare (Bensink et al. 2007) and increasingly to address chronic disease care.

More than 20 years of medical research has studied the effects of telehealth interventions in heterogeneous contexts (Wootton 2001; Bahaadinbeigy et al. 2010). The majority of studies focus on effects to organisational telehealth service users on system infrastructure or medical personnel work processes. The vast majority of the literature is clinical studies using a randomised control trial (RCT) design to test a telehealth intervention's effects on patients, primarily assessing risk of adverse effects on clinical effectiveness or patient safety, and the impact of telehealth on healthcare resource utilisation. These often include nested patient opinion studies to capture satisfaction or acceptance using validated questionnaires. A small non-medical telehealth literature is comprised of provider-focused research studying the effects of telehealth services on healthcare resources. Of that literature, a tiny proportion is dedicated to studying patient experiences of telehealth. The slow turn to patient-centred research is partly due to patients being the latest group of users to handle

telehealth equipment. This combined with increased use of telehealth in the form of direct-to-consumer health technologies (Katz & Rice 2009) make researching patient perspectives timely.

Patient-centred studies are encouraged by policies responding to high profile scandals make it more common for service quality improvement initiatives to incorporate elements of patient and public involvement (Coulter et al. 2014), and the importance of patient experience research has been widely acknowledged (LaVela & Gallan 2014), although work establishing its practical usefulness to service improvement processes is still at an early stage (Fitzpatrick et al. 2014). For example, there is no consensus on standards for measuring, analysing and interpreting patient experience data (Coulter et al. 2014) necessary for healthcare service improvements (Bate & Robert 2007).

In response to these issues, the thesis considers the theoretical underpinnings of patient experience and highlights the weak construct validity of current approaches because the concept is paradoxically provider-led rather than patient-centred. The paradox is illustrated by comparing patient experience articles from the healthcare and marketing literatures to make explicit the assumptions by showing the former takes for granted that the environment of the service interaction constructs patient experience, while the latter assumes that patients construct patient experience agentically. By clarifying the importance of the structure-agency dialectic in patient experience research designs, the thesis is positioned to advance an alternative patient experience ontology developed from a marketing perspective. Therefore, an objective of this thesis is to contribute a different philosophical and epistemological approach to conceptualising and studying a patient-centred patient experience of telehealth.

The thesis is based on an empirical case study of a telehealth service commissioned by an English NHS organisation from an independent third-party provider. Unlike passive monitoring systems, this case study was purposively and theoretically selected to involve a type of telehealth which cannot function without patients actively co-producing the service. Co-production occurs through a series of linked service-based interactions between patients, clinicians, and other networked actors (human and machine) in the community-based healthcare service setting. These actors are involved in three processes: (a) using medical equipment and telehealth machines to transmit patient data, which enables (b) remote computer-aided decision-making to occur, that (c) is the basis for decisions concerning patients' access to further healthcare resources.

Reasons for choosing to study this critical management issue of unsustainable demand in a complex healthcare context are partly because efforts to improve healthcare are universally relevant, and also because the problem of chronic disease is analogous to other sustainability challenges with far-reaching implications if they are unresolved. Therefore, an objective of this research is to generate theory that is applicable to other contexts where it is necessary to shift unsustainable consumer demand for necessary but scarce resources toward more sustainable levels of consumption through

the use of technology. By framing sustainable demand as a service management problem, it requires the study of interactions between organisations, individuals and socio-technical environments. An appropriate theoretical perspective to conceptualise the research problem is the service-dominant logic (S-DL) (Vargo & Lusch 2004; 2008; 2016), which advocates consideration of structure and agency to account for the person in context (Chandler & Vargo 2011). This approach is more patient-centred because it considers the contextualised person holistically and not only in reference to the healthcare service.

The S-DL is a systems-level pre-theory of value generation (Winklhofer et al. 2007) based on the integration of resources by generic actors. It is primarily concerned with interactions that involve the integration of intangible operant resources, such as skills and knowledge, which are needed in order that service-for-service exchange can take place. Mutually beneficial exchange is conceptualised as part of a normative value co-creation process, where the value outcome is subjectively and phenomenologically determined by the interacting beneficiaries. In recent years, S-DL's refinement in response to criticism (e.g. Schembri 2006) suggests that it is well-suited to avoiding the provider-led bias that is argued in this thesis to characterise patient experience research in the healthcare literature. Historically S-DL can be seen as part of a movement to coax managers away from thinking that only firm-value mattered. Hence the S-DL perspective encourages firms to frame customers as intrinsic to a firm-customer dyad that is centrally important to firm value (Vargo & Lusch 2004). Later articulations extended beyond the dyadic relationship to frame a service ecosystem with networks of generic actors influencing firm- and other beneficiaries' value generation processes (Vargo & Lusch 2016). The refinement of S-DL to include a democratic view of actors, theoretically flattens differences in power between actors, making it sympathetic to the framing of socio-historically disempowered actors to act agentically within the relevant context of interaction, and is able to recognise marginally subjective value as valuable (and potentially marketable to) -- even if what is valued by these actors is not currently understood to be mutually beneficial to firms.

Although the S-DL has been criticised for its theoretical abstraction, it is a managerial framework where applicability to strategic firm value generation is assumed. This is because market orientated firms understand that facilitating the emergence of customer value can be mutually beneficial. Although the current articulation of S-DL describes ecosystems and networked actors, it does not preclude applying it to focus on dyadic firm-customer interactions as instruments of value generation, it just encourages this investigation to be nuanced with consideration of institutional arrangements as a context that potentially influences the process of interaction and the ontology of the value generated. A theoretical perspective that suggests the extent that provider value and firm value are dynamically and subjectively determined is highly relevant to the healthcare context, where it is recognised that there is likely divergence between how interaction outcomes are valued.

For example, judging healthcare quality based on what a patient wants and what a patient needs may lead to different evaluations of a service experience (Berry & Bendapudi 2007).

As the S-DL perspective is rooted in resource-advantage theory (Hunt & Madhavaram 2006) it frames service consumption as involving resource integration (Arnould et al. 2006; Baron & Harris 2008; Baron & Warnaby 2011), and this conceptualisation is useful for identifying the key components and activities underpinning telehealth usage as a value co-creation process. Applying Arnould et al.'s (2006) consumer resource integration framework enables the research to structure the problem in the following patient-centred way: If a chronic disease patient's personal goal is to minimise the effects of their illness, and achieving this goal is usually associated with accessing professional help as a resource to treat disease symptoms, then access to telehealth must be salient to achieving this goal. *Is this the case, and if so, what are the conditions that enable this to occur?*

To answer these questions, the thesis applies a sociological approach to the conceptualisation of conditions as social structures. As mainstream use of telehealth services typically targets chronic disease patients (May et al. 2005) in order to avoid unnecessary admission to long-term institutional care (Darkins et al. 2008), this study contributes consumer insight into vulnerable service users who are invariably under-resourced and under-researched (Rosenbaum et al. 2015). Vulnerability and illness are both social constructions according to the sociology of health and illness literature. Therefore, this research is informed by the substantive contribution of streams of sociology related to the understanding of people as patients, vulnerable social actors, and thence service users, who are relatively powerless given the ingrained and hierarchical social structures organised to support relationships of control over patients and their actions. Healthcare is often characterised as having persistent hierarchies of power that maintain that control in order to serve interests other than patients' (Parsons 1951; Freidson 1970a; Illich 1975; Scott 2008). These social structures in turn affect the experience of everyday life for the chronically ill (Corbin & Strauss 1988; Mol 2002; 2003; 2008; Bury 1982), frequently portraying patients as disempowered and victimised. However, given the constraints of a doctoral thesis, this literature's substantive contribution to the abductive and retroductive analytical processes applied in this thesis is acknowledged, although it is beyond the scope of the thesis to discuss them in depth. They are discussed briefly in the telehealth for self-management literature (Rogers et al. 2009; May et al. 2014; Rogers et al. 2007; Rogers et al. 2011; Ong et al. 2014) where the review highlights the centrality of the structure-agency dialectic and explains the basis of the thesis' engagement with it.

Elaboration of S-DL-compatible ontologies, epistemologies and methodologies have been undertaken by anthropology- and sociology-based scholars from the marketing subfield of consumer research, working under the label of Consumer Culture Theory (CCT). These scholars have advanced an epistemological approach to the study of consumer experiences that are

complementary to S-DL, because they account for the value emergent from experiences as contextually determined through interactions with culture (Arnould & Thompson 2015). The partnership between S-DL and CCT provides the scaffolding through which a full and adequate conceptualisation of telehealth can be studied as a material object (or operand resource), and an intangible resource resulting from the user's experience of a technological system (operant resource) which is influenced by and has the ability to influence other actors, and subsequently as a technology-based service, i.e. as an entity or actor, interacting within a multichannel system of other services provided by a network of actors (Akaka & Vargo 2013).

In order to integrate these views with the research aim to consider how patient experience of telehealth affects existing relationships with healthcare service providers, the thesis conceptualises telehealth as a self-service technology (SST) (Dabholkar 1996; Meuter et al. 2000) embedded in multi-interface healthcare services, or services involving different forms of virtual and face-to-face interactions (Patricio et al. 2008). Although the introduction of different types of SSTs in varied service sectors has been shown to significantly change, or instigate a break from, reliance upon interpersonal service interactions with front-line personnel, there is scant research considering the role of SSTs for value generation in multi-interface services (Ostrom et al. 2014; Patricio et al. 2008) in the context of professional healthcare services, although healthcare has been established as a setting for the investigation of patient value co-creation practices (McColl-Kennedy et al. 2012; Helkkula et al. 2013; Witell et al. 2013; Elg et al. 2014; Hardyman et al. 2014). Furthermore, despite considerable resistance among healthcare management scholars to viewing the healthcare sector as an appropriate context for strategic marketing thinking, the use of service marketing approaches is apparent in the sociology-based healthcare literature framing telehealth as a service process innovation. This literature considers its implications on an organisation's (or geographic region's) IT infrastructure in handling patient data via the internet; telehealth's effects on organisational resources, or capabilities, such as implications on the diffusion of skilled work to lesser skilled operatives, including patients (A. Rogers et al. 2011), and workforce management (May et al. 2005; May, Rapley, et al. 2006; May, Mort, et al. 2006; Nicolini 2006; Nicolini 2011; Oudshoorn 2008).

Certainly in adopting a marketing perspective, the thesis recognises that marketing practices have commonly been criticised for their role in creating the problem of insatiable demand, overconsumption and increased risk of disease, and notes their use to redress these issues (Andreasen 1994). Similar duality applies to increased availability of health information to consumers via technology, argued to enable individuals to do much more for themselves, while recognising that it often presents unwanted effects on the process of delivering expert services efficiently (Lustria et al. 2011). Therefore, rather than transporting assumptions about consumer choice and agency from schools of thought in the marketing discipline, their applicability to the healthcare sector is explicitly questioned. Paying heed to literature considering the marketization

of healthcare that concerns itself with the inherent differences between healthcare and commercial (i.e. market-based) contexts (Stacey 1976; 1984; Greener et al. 2006; Galbraith & Laing 1996; Laing & Galbraith 1995), means that, although these issues are not explored further within the scope of this thesis, the thesis acknowledges these debates and uses them to avoid applying service marketing perspectives as a worldview that is blind to the sociological arguments about the particular social construction of actors and interactions in the healthcare context.

By conducting an exploratory study of telehealth from the patient perspective, the research responds to a significant research gap. Through its research methodology, the thesis makes several interdisciplinary contributions. It contributes to the healthcare management literature by highlighting the limitations of current approaches to patient experience research, while offering an alternative based on the experiential perspective developed in the marketing subfield of consumer research. It offers a plausible account of patient experience and patient value from telehealth that may help to provide an empirically-based theoretical account for the consistently high measurements of patient satisfaction reported in the literature. It develops theory on patient agency and explains how autonomy and choice are determinants of patient value in paternalistic healthcare services. The thesis contributes to the marketing field by providing empirical examples of value co-creation by physically resource-disadvantaged consumers using SST, and shows how four approaches to value co-creation link contexts of resource availability with subjectively experienced systems of value determination. Finally, it contributes to our understanding of technology as an operant resource leveraged by users to change the structure of interactions in order that subjective value can emerge. The implications on service system transformation are explained.

The theoretical contributions are enabled by the adoption of a critical realist perspective. A realist perspective agrees with a structurationist theory of social action (Giddens 1984), which is argued to be evident in both S-DL and especially CCT approaches to our understanding of service consumption. A structurationist perspective suggests that agency and structure are mutually constitutive. However critical realism takes issue with structuration theory's fallacy of 'central conflation' (explained in Chapter 4). Realists argue that it is necessary to maintain analytical duality of structure and agency in order that our understanding of social change gains specificity, i.e. identifying in what ways and under what conditions does individual agency contribute to structural change. In order to study the experiential effects of telehealth on patients' self-care, critical realism offers an ontologically consistent treatment of patient agency in the construction of experience as real and co-existing with different perceptions of the same interactions by other social actors. By applying realism's concept of a stratified ontology to patient experience, this view is consistent with S-DL's many actors perspective, where different actors potentially experience the same interaction outcome but simultaneously determine its value differently (Helkkula et al. 2013). An outcome of

applying an S-DL perspective is an explanatory matrix to show how patient experience relates to the use of telehealth to co-create subjective value in a multichannel healthcare service.

1.1 Research Aims, Questions and Objectives

The aim of the research is **to investigate patient experience of telehealth services for chronic disease self-management**. The thesis addresses the following research questions through meeting the research objectives listed in Table 1.

TABLE 1 RESEARCH QUESTIONS AND RESEARCH OBJECTIVES

Research Questions	Research Objectives
How do patients co-create subjective value with telehealth services? How does patient experience affect co-creation of value with telehealth? How does value co-created using telehealth influence relationships with healthcare service providers? How does the debate about structure/agency relate to the context of patient use of telehealth?	• To describe patient experience of telehealth in relation to the contexts and conditions of chronic disease self-management • To explore how patients co-create value with telehealth • To examine the resource implications of telehealth services on patient experience • To identify the dimensions of subjective value that is co-created • To examine the influence of telehealth on patient agency • To examine how telehealth use affects patient-provider relationships in a multi-interface, multichannel healthcare service

1.2 Thesis structure

Chapter 2 explains the policy background and its dependence on critical transformations in: (a) the aim and matter of social interactions between patients and healthcare providers; and (b) the reconceptualisation of positive healthcare service outcomes as delivering clinical and functional value. Functional outcomes are understood to result from productive interactions between patients and providers. These are depicted as supporting self-management to help patients maintain their health and ability to function and perform activities of daily life with chronic disease (Wagner et al. 2001). Prospects for successful policy implementation are then argued through a critical review of the literatures on telehealth and patient self-management of chronic disease showing a large gap in our knowledge due to the under-studied patient perspective. The review also positions the

research to address the debate between schools of thought about the role of structure and agency in service interactions and their outcomes.

Chapter 3 conceptualises the research problem of studying patient experience to account for structure and agency. It argues that current approaches to studying patient experience are paradoxically provider-led. By comparing healthcare and marketing approaches, the chapter argues that the discipline of healthcare research takes for granted that providers are empowered with agency and patients are passive, whereas research from the marketing discipline assumes that consumer agency applies generally to patients. By making these assumptions explicit, the thesis argues that applying a marketing perspective enables the patient experience concept to be patient-centric.

This is followed by an introduction to the field of service marketing to foreground the conceptualisation of the telehealth service according to an SST understanding. This positions telehealth as a technological resource with implications on provider and user value, and contextualises it squarely within a multi-interface, multichannel service, rather than discussing this context as an after-thought. A consequence of applying the SST to conceptually frame telehealth is that the decision not to apply the frequently cited customer experience perspective to studying the use of SST requires justification. Although this literature usefully explains further dimensions of the experience concept beyond the cognitive, and usefully explains how experience relates to agency, customer experience as a conceptual framework for this study of patient experience is discounted due to the practical issues for analysing patient experience of telehealth. Furthermore, as a broadly psychology-based approach, customer experience has not been developed to consider the structure-agency dialectic required for this research.

The chapter then explains the S-DL as an analytical framework. Its theoretical underpinnings, ontological assumptions, the elaboration of its foundational principles, its critical reception and development are provided. To support the use of S-DL to explore the themes of structure and agency in the context of telehealth services, we use Arnould et al.'s (2006) consumer resource integration process model, which maps relevant resources in a flat ontology, rather than theoretically privileging the influence of one over another, and which explains a patient-centred conceptualisation of what patients do as influenced by their access to resources and their personal goals and life projects. Resources are understood to be embedded in socio-cultural contexts, hence the applicability of these integratable frameworks to consider the interplay between structure and agency.

Chapter 4 explains the choice of a critical realist research methodology. It outlines the ontological and epistemological assumptions of the thesis and explains the approach to analysing, identifying

and discussing related concepts of structure and agency. It offers a philosophically consistent approach to the existence of multiple realities (patient and provider) and tools for generalising from the micro level empirical findings toward the macro level theories of social action for social change using realist retroduction.

Chapter 5 explains the qualitative research methods used to conduct the study. It discusses sampling methods, the use of semi-structured in-depth interviews and observations and their limitations. It also provides information about the study context, ethical considerations and sample characteristics. The analytical processes are discussed and an illustrative coding summary is provided.

Chapter 6 discusses findings from thematic analysis of micro-level interactions between actors (machine and human). It introduces the context of the patient lifeworld in which technology consumption is ubiquitous and targeted to counteract the experience of losing control in familiar environments due to illness. It then explains prominent themes of effortful use of telehealth leading to the introduction of customisation processes and the development of clinicised self-knowledge as an outcome. Using illustrative cases, the chapter explains the value co-creation process and the determinants of value in the context of telehealth use.

Chapter 7 discusses findings from thematic analysis using illustrative cases to explain the role of patient experience of healthcare services in the use of telehealth services. It explains how the value derived from telehealth is mainly oriented toward the avoidance of negative hospital-based service experiences.

Chapter 8 discusses findings from iterative cross-case analyses identifying four approaches to value co-creation according to the contexts and conditions that precede the use of telehealth. It provides a resource-based explanatory matrix of patient agency for value co-creation to synthesise the findings and explain their relationship with the results of the realist retroduction analytical process.

Chapter 9 synthesises the key findings and discusses their significance in relation to the SST and S-DL literatures.

Chapter 10 presents reflections about patient experience of telehealth for value co-creation and discusses methodological implications from the research. The key findings are discussed in terms of their theoretical and practical implications, and provides suggestions for future research followed by closing remarks.

Chapter 2 Literature review

The literature review first explains the real world problem of chronic disease and the health policy response advocated by the World Health Organization (WHO) and adopted by the UK National Health Service (NHS). In successive iterations, the policies focus on the importance of supporting patient self-management with telehealth services. Reviewing telehealth and patient self-management literatures identified two research gaps. The first is the lack of telehealth research from the patient perspective. The second is a debate about the role of structure and agency to support patient self-management.

2.1 The problem of chronic disease

Chronic diseases have reached epidemic proportions (Sloninsky & Mechael 2008; WHO 2011; Yach et al. 2004). Excluding communicable long-term conditions like HIV/AIDS, chronic disease is the world's largest killer, causing more deaths than any other causes combined (WHO 2011). In 2008, 63 percent of global deaths were caused by chronic disease, principally cardiovascular disease, diabetes, cancers and chronic respiratory diseases (WHO 2011). As incidence of chronic disease increases, combined with ageing populations, annual death rates from chronic disease are forecast to rise globally. Chronic disease includes a non-exhaustive list of progressive, incurable but treatable mental and physical diseases. They require daily care in order to reduce the risk of developing complications of morbidity (acute illness, permanent disability) and increased mortality (premature death). Chronic diseases can be congenital or acquired and their progression has been linked to ageing and risky health and lifestyle behaviours. Policy imperatives include the development of population wide and individual interventions focusing on prevention, early detection and treatment at primary care levels (WHO 2011).

In the UK 15 million people (Cruickshank et al. 2010), including 58 percent of adults over the age of 60, have a chronic disease and 25 percent of people over 65 years of age have two or more chronic illnesses (DH, 2012a). The number of people with multiple chronic diseases will rise to 2.9 million in 2018 from 1.9 million in 2008 (DH, 2012a). People with chronic conditions are typically high users of primary and acute health services, sometimes referred to as 'frequent flyers' (Hamilton 2012) borrowing terminology from a customer loyalty perspective. This is because poor daily disease management can result in exacerbated conditions which require emergency hospital admissions and longer than average stays.

To counter the effects of rising demand for chronic disease care, the policy response recommended by the World Health Organization (WHO) (Epping-Jordan et al. 2004) and adopted by the Department of Health (DH 2005a) is to focus on prevention and early stage management of chronic

disease by introducing fundamental changes to healthcare systems. These issues are detailed in the Chronic Care Model (CCM) developed by Wagner et al. (2001) and pictured below (Figure 1).

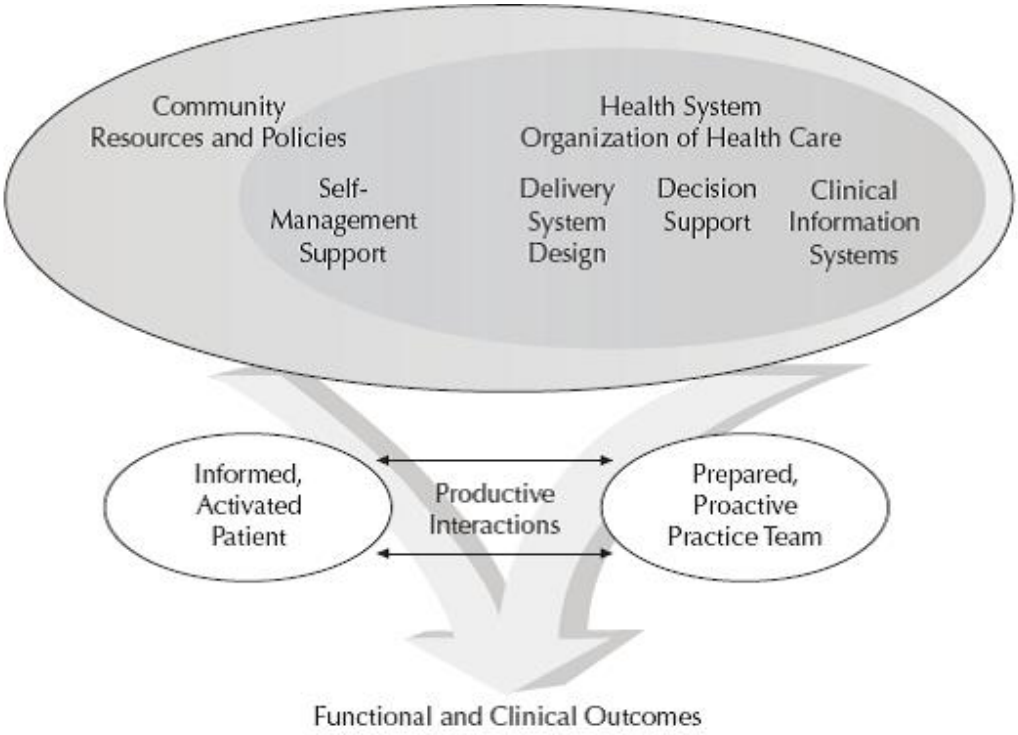


FIGURE 1 WAGNER ET AL.'S (2001) CHRONIC CARE MODEL (FROM GAMMON ET AL. 2015)

The CCM is evidence-based, population-based, and patient-centred (Glasgow et al. 2001). Compared to traditional provider-led healthcare, the CCM can be construed as a radical departure due to its democratic approach, depicting parity and partnerships, rather than hierarchical relationships between the formal (professional-led and hospital-based) and informal (community-based) healthcare systems, patients and professionals, and functional and clinical outcomes.

2.1.1 An introduction to telehealth

A recent addition to the CCM's practical implementation is the introduction of technology-based (e.g. telehealth) solutions to improve the quality of chronic disease patient monitoring for early detection of change in symptoms and prevention of exacerbations. Telehealth is the application of information and communication technology to deliver healthcare remotely (Koch 2004). Within health policy it is evident that the use of telehealth services plays a key role in strategic plans to inform and activate patients as well as providing a space for productive interactions at a distance. Policymakers from WHO (Sloninsky and Mechael, 2008; WHO, 2010) to the Department of Health (DH) (2012; 2013), to the current Health Minister, Jeremy Hunt (Gornall, 2012, DH, 2012b), consistently identify the role of telehealth services as a priority to underpin the CCM. According to

these sources, telehealth is a way to increase cost effectiveness, quality and equitable access to healthcare in developing and developed economies.

The dominant policy discourse about patient use of telehealth services concerns the assumed relationship between telehealth and patient empowerment. Firstly, it is argued that patient participation in their own healthcare can reduce demand for healthcare, while also improving the quality of the healthcare that is accessed because it is more targeted to the wants and needs of patients (Coulter 2012b). Secondly, patient participation and telehealth potentially change who, where and how healthcare delivery takes place, effectively transforming healthcare services (Oudshoorn 2011). Each dimension of change has significant implications on adapting practice. Thirdly, telehealth is portrayed as important because it can increase patient access to information about his or her own physical condition through increased monitoring which can lead a person to change their behaviour (Suter et al. 2011). Fourthly, although the mechanism of increased telemonitoring primarily serves to increase professional oversight of patients in order to prevent exacerbations requiring hospitalisation, it is argued that patient access to information about their own condition potentially allows them to make more discretionary and appropriate use of healthcare services (Suter et al. 2011; Alpay et al. 2010). Fifthly, the implication of access to information and the promotion of salient learning to increase relevant knowledge and skills to change behaviours (Lorig et al. 2001; Suter et al. 2011) is conceptually entangled with the rationalist logic. 'Rationality is distinguished by its formal and instrumental character, its abstraction from concrete situations, and its focus on means (the efficiency of doing a task) rather than ends (the 'rightness' of the task itself)' (Sayer, 2011 in Greenhalgh et al. 2013, p. 3).

2.1.2 How does telehealth work?

Although there are multiple forms of telehealth, this study is concerned with patient experience using clinical equipment to monitor their symptoms (e.g. blood pressure and heart rate monitor, finger-tip mounted pulse oximeter, weighing scale) and communicate their readings together with responses to a set of questions via a proprietary telehealth box or portal, which has been installed and tested by engineers in their homes by prior arrangement. Their readings are electronically transmitted from the portal to a remote server where it is stored and forwarded on-demand. Telehealth workers and clinicians login to a telehealth system to access the latest information about patients. The data submitted by patients is automatically analysed by a computer algorithm, which provides computer-aided decision support to the clinicians or non-clinicians. This support is the visualisation of the latest data against historical trends for detectable instances of conditions that breach 'normal' parameters. The normal range is set by patients' usual carers who are also clinical referrers onto the system (e.g. Community Matron, District Nurse, GP, specialist nurse). In the event of a patient breach, the severity is colour-coded using red, amber, green visualisation. The telehealth support worker protocol is to respond to the alarm by contacting the telehealth user by

telephone, to ask if they are okay, to request a retest if necessary, and to offer patients the option to be put in contact with their usual carers. The novelty of telehealth as a service is that: patients or their carers handle clinical equipment in a non-clinical setting, they have access to the visual display of their results, the symptom analysis is computer-aided, and the first human service response to changes in patient conditions is provided by an intermediary service employing telephone support workers that have low to no clinical training.

2.1.3 Changing the structure of healthcare service relationships

Advocates of telehealth suggest that it empowers patients to change healthcare services. This entails shifting the acknowledged roles and responsibilities that have long been embedded in the traditional division of labour in healthcare (Weinstein et al. 2013). These delineate relationships between medical experts, and are the foundation of the doctor-patient relationship (Parsons 1957; Freidson 1961, 1970; Dent 2006; Rogers et al. 2009, 2011). This relationship is normally set in clinical environments, however, judging by chronic disease care policies like the *NHS and Social Care Model for improving care for people with long term conditions* (DH 2005), the aim is to keep patients out of hospital by shifting the provision of care to primary care and patient homes. Further changes to the structure of healthcare service include aims (a) to decentralise power in the NHS from hospital-based services by increasing the plurality of provision through contracting more community-based organisations, and (b) to devolve power and accountability to frontline staff in local communities (DH 1999, 2000). These changes are based on the assumption that changing to local commissioning and provision will better reflect local needs, and also add familiarity and convenience to patients while reducing travel costs.

Devolution of power from clinicians to patients is also implied in chronic disease care and telehealth literatures. For example, telehealth is championed in *Policy: Improving quality of life for people with long term conditions* (DH 2013), which cites evidence for the introduction of assistive technologies and remote monitoring services helping to keep patients out of hospital and supporting them to become empowered through increasing their knowledge and skills for better self-management (Steventon et al. 2012). It is suggested that the provision of technologically-mediated clinical information to patients encourages them to take ownership of their condition, and share responsibility with healthcare workers to deliver innovative services. Usually telehealth services are introduced as part of a multichannel portfolio of services, e.g. traditional face-to-face interactions in the clinic and at home, telephone consultations, as well as technology-enabled patient monitoring incorporating a component of self-service delivery, used at home, on the move, and in their own time, in order to deliver healthcare services that better meet the daily demands of good chronic disease management (Steventon et al. 2012).

Therefore, telehealth is linked to a widely acknowledged view that improvement to healthcare entails a shift from a paternalistic understanding of what patients need (Wagner et al. 1998; Epping-Jordan et al. 2004; Gubb & Smith 2010) to one that is responsive to patient needs (Coulter 2012) and respects patient autonomy (O'Neill 2002). However, understanding whether telehealth helps to meet patient needs is complex and it is important to review the limitations of various methodological approaches that have been used to identify what matters to patients.

The following section reviews the self-management literature to investigate the notion of patient empowerment in healthcare services.

2.2 Patient self-management

There is no gold standard definition for patient self-management but it is generally defined as the knowledge, skills and self-efficacy to respond appropriately to changes in the illness experience, including knowing when and how to call for help (Barlow et al. 2002). This section discusses two schools of thought in the self-management literature. The previous section explained that in order for the CCM ((from Gammon et al. 2015)) to work in practice, patients must be transformed from passive recipients into 'informed, activated patients' (Hibbard et al. 2007) proactively self-managing their conditions. This opinion is largely based on early studies of patient self-management education provided by trained lay experts, like Stanford University's Chronic Disease Self-Management (CDSM) Program. Evidence suggests that CDSM interventions are effective at improving health outcomes by making patients more engaged in their self-care (Lorig et al. 1993; 1999). This literature takes a social-psychological approach to encouraging social change at the individual level by observing the improvement in health outcomes as a result of increasing patients' knowledge, skills and self-efficacy. Based on a socio-cognitive theory of behaviour change (Bandura 2004) this social psychology-based school of thought makes assumptions about the ability of individuals to exert transformational change in the realm of social interactions. This is based on an agentic theoretical perspective rooted in the exercise of perceived personal and collective efficacy, through adaptation at the individual and collective levels (Bandura 2002). Related to empowerment as pertaining to personal, social and political dimensions, these references to human agency 'may be understood as the capacity to exercise creative control over individual-level thoughts and actions' and relates to assumptions that humans in modern democratic society 'routinely exercise agency within the domain of their personal choices and in the social and political realm' (McGettigan in Givens 2008, p.44).

This portrayal of social change through the exercise of individual agency was roundly criticised by scholars in the UK who suggested that powerful structural influences in the healthcare context were observed to diminish the effectiveness of individual patient agency. This view was based on evaluations of the UK version of the CDSM Program, called the Expert Patient Programmes (run

by the NHS under licence from Stanford University), and other similar structured self-management education programmes. The authors argue that proposed benefits from self-management initiatives need to account for the context of a chronically ill person's recursive healthcare utilisation, creating dependency upon complex relationships in healthcare contexts that are characterised by powerful, structurally-embedded interests (Gately et al. 2007). They found short-term increases in patient self-management behaviours to be unsustainable because requisite change from healthcare providers has not occurred to maintain them (Rogers et al. 2008; Rogers et al. 2009a; Kennedy et al. 2005; Rogers et al. 2009b). Longitudinal studies suggest that 12 to 18 months after the self-management education intervention a patient may individually be willing to develop their self-efficacy beliefs as enacted in planned self-care practices, but are dissuaded from doing so by their clinicians in practice. This is argued to be due to patient intentions to self-manage being eroded during successive healthcare service interactions that are not structured to encourage self-management. Therefore, the literature argues that individualist, psychology-based theories of social action are untenable because they do not adequately account for the role of context to shape individual behaviours (Ong et al. 2014).

In reviewing the work of UK self-management researchers, it is clear that self-management scholarship has moved on to studying different methods of individual (Kennedy et al. 2003) and social network engagement at the community (Vassilev et al. 2011; Rogers et al. 2014) and provider (GP) levels (Kennedy et al. 2010) in order to study the wider scope of contextual determinants that could contribute to the maintenance of self-management practices. It is also clear from this work that they have not abandoned the concept of patient agency, but assume that it is enabled and constrained by structural arrangements. Their work researching self-management with telehealth (A. Rogers et al. 2011; Sanders et al. 2012) highlights the need to understand the interaction between self-management and telehealth services in ways that can illuminate and specifically account for individual agency *and* structural social influences.

The key debates in the self-management literature can be summarised thus:

Self-management:

- Is necessary because of structural change moving away from paternalistic care
- Can lead to improved patient outcomes
- Conforms to the trend for increased individual responsibility and consumer choice which focuses on rationalist logic

Views of self-management can be divided into two schools of thought:

- Assumptions that structural change is constructed by individual agency
- Assumptions that patient agency is affected by powerful structural factors that constrain individual ability to act autonomously.

Table 2 organises the different views of patients and their agency in relation to service structures and conclusions about what is needed for structural change. The top row assumes patients have agency to structure their service interactions. The bottom row describes how patients are structured by paternalistic healthcare service interactions. It shows the different conceptualisations of patient agency reflected in the ability to choose autonomously.

TABLE 2 SCHOOLS OF THOUGHT IN SELF-MANAGEMENT LITERATURE (ORIGINAL WORK)

Schools of Thought	Active patient ontology	Passive patient ontology
Individualist focus (social-psychological approaches)	• High patient agency to knowledgeably and skilfully self-manage • Activated patients with access to the knowledge, skills and self-efficacy (capabilities) with ability to decide between and choose ensuing actions effectively • Rational choice consumer paradigm (utility maximisers) → *Individuals structure service interactions through changing their demands for information and participation in treatment decisions (bottom-up)*	• Limited patient agency due to lack of knowledge and skills to self-manage • Patients struggle to achieve positive health outcomes beyond those delivered by established healthcare service channels • Patients commit poor decision-making due to high information asymmetry leading to poor choices → *Structural changes require individual changes, i.e. through patient self-management education (intrinsic change)*
Collectivist or Structural focus (sociological approaches)	• Temporarily high patient agency, low awareness of high structural barriers that limit choice • Patients make low level and temporarily effective decisions through activation and perception of improved outcomes • Individual effects eroded by structures that maintain asymmetries of information and power framing good decisions as those chosen by clinicians → *Structural changes are required for maintenance of individual change, i.e. educating social networks that support patients (extrinsic change)*	• Constrained patient agency in service structures that 'force' them to choose • Illusion of choice: patients conform to institutionalised norms of the 'sick role' or resist/withdraw (although illness can make this choice suboptimal resulting in poor health outcomes because of lack of support) • Choice is lip-service, through practice of obtaining 'informed consent' • No actual choices because patients lack knowledge and skills to be making informed choices → *Structural changes require clinicians to agree to change them (top-down)*

2.2.1 Conclusion

The review of the self-management concept development and evidence highlights the debate surrounding the influence of patient agency and social structures to understand mechanisms for changing service interactions. The social-psychological approach to showing the effectiveness of patient agency in improved self-management has not been able to contend with evidence of the structural barriers identified by a sociological approach to understanding health, illness and institutionalised healthcare services. It is argued that the sociological approach is sensitive to the influence of social structures on individual action, generally suggesting that social structures by and

large determine the scope of social actions. These schools of thought suggest that the characteristics of social structures can explain extant attitudes, beliefs, practices, and routines rather than suggesting these are the results of voluntarist social action, or individual agency without reference to the context of that action. Sociological approaches are predominantly concerned with social structures and movements affecting the relationship between structure and agency. However, they tend to shy away from individual perspectives and this approach may lead to assumptions about homogeneous social systems, and ignoring minority views in order to identify prevailing discourses or social structures.

2.3 Telehealth literature

Having briefly discussed the appearance of telehealth in the policy literature, and the assumptions that connect it with the self-management concept, this section reports findings from the telehealth literature review.

Telehealth is the application of information technology to enable the remote delivery of healthcare (Koch 2004; 2006). The UK Department of Health defines telehealth as a service that 'uses equipment to monitor people's health in their own home … [monitoring] vital signs such as blood pressure, blood oxygen levels or weight'(DH 2009). Telehealth is alternatively referred to as telemedicine, telecare, eHealth, mHealth and health apps *inter alia*, and is used in the literature as an umbrella term that encompasses a variety of IT-based healthcare interventions as technologies develop. Its breadth helps to explain its status as a widely researched subject offering 'a vast and diffuse' literature, including equally diffuse systematic reviews (Veterans Administration 2010).

When this study began, a survey of the last 20 years showed the fast-growing field of telehealth research producing over 1,300 peer-reviewed publications (Wootton 2012). A more recent Google Scholar search for telehealth articles since 2015 identified over 6,500 results. Further evidence of a growing market for telehealth research is the launch of five specialist journals[1] and numerous special issues in highly respected journals across disciplinary subject areas interested in the dissemination of peer reviewed findings from international studies. This vast literature can be described as divided into: (a) positivist research engaged in establishing 'proofs of concept' for the implementation of innovative service designs in novel contexts, and (b) mixed method and interpretivist research into service provider perspectives, with a minority of exceptions. This research tended to focus on telehealth interventions according to questions of risk, efficacy, cost effectiveness and resource implications for organisations, including workforce management (May et al. 2005; Hendy et al. 2012).

[1] *Journal of Telemedicine and Telecare; Telemedicine and e-Health; Journal of Assistive Technologies; Journal of Smart Homecare Technology and Telehealth; International Journal of Telemedicine and Applications*

The consensus view in the literature is that telehealth use for providing remote patient monitoring services can be beneficial to patients and healthcare providers primarily due to telehealth's ability to 'shrink' the distance between patients and healthcare (Glueckauf & Ketterson 2004; Bensink et al. 2007). This conclusion is based on a mass of studies focused on testing telehealth interventions across a variety of health conditions and contexts where access to usual care is constrained due to geography. Physical distance is a problem when trying to serve low-density populations which tend to lack access to locally available expert services. Of course, the concept of distance can be a metaphor to include any barriers to accessing local services. For example, the need to overcome restricted mobility can present barriers in terms of high economic and non-economic costs to attend appointments in person. It appears telehealth studies often highlight the distinct advantages it offers to patients by making care more accessible through virtual services provision that reduce the need for face-to-face appointments for regular check-ups and simple health monitoring.

Despite the volume of evidence suggesting publication bias (Wootton 2012), the conclusion of a systematic review of 130 telehealth studies of varying quality shows the evidence to be contentious and unstable, with reviewers urging caution about the acceptance of telehealth as a 'success' without robust calculation of cost, including implications for workload and other resources involved in its implementation (Bensink et al. 2007). Scholars aver that 'the political imperative may override any rational judgement of success' (Wootton & Hebert 2001, p.3) hastening its rapid expansion and adoption into practice (Hebert et al. 2006) in North America and Europe. According to some, this statement foretold the events that would unfold in the UK where the government's interest in becoming a world leader in the field of telehealth (DH, 2013, DH, 2012b) was evident. The Whole System Demonstrator (WSD) project was allocated £3 million to conduct the world's largest telehealth randomised control trial (RCT) over three years in three English counties (DH, 2009). Briefly, the combined RCT findings related to patient experience suggests that: on an individual patient basis, telehealth is not cost-effective compared to usual care (Henderson et al. 2013), but the cost savings to the health system are implied, as it might be reducing emergency hospital admissions and mortality rates (Steventon et al. 2012). Furthermore, as it is not shown to be any worse than usual care (Cartwright et al. 2012), prospective telehealth users would need to be educated about how easy the equipment is to use, and to be reassured that additional monitoring does not aim to limit independence or reduce self-care efforts (Sanders et al. 2012). Shortly after publication of the highly contentious conclusions (McCartney 2012; Greenhalgh 2012), a concordat between the UK government and the telehealth industry was announced to reduce barriers to mainstreaming telehealth, and in November 2012 the government launched the *3millionlives* campaign to provide 100,000 NHS patients with telehealth services by 2017 through five regional pathfinder sites in England as the first roll-out of telehealth as a mainstream service (www.3millionlives.org.uk).

2.3.2 The market context of telehealth

It is relevant to contextualise telehealth service within a period of transition in the healthcare market due to economic austerity, where shrinking public services can be said to encourage reliance upon greater individual responsibility and notions of self-enterprise (Rose & Wickham 1993). Increased patient activity is also encouraged by framing our understanding of public services as co-produced by service users (Osborne 2010; Osborne & Strokosch 2013; Osborne et al. 2015). Telehealth is also contextualised by a rise in hybrid healthcare provision, evident from the increased uptake of technology-based self-service eHealth applications to self-manage conditions like overweight and diabetes. These services cater to demographic changes in ageing technology consumers with habits and preferences that play a role in increased risk of chronic disease (Sloninsky & Mechael 2008). Scholars suggest that increased technology use facilitates access to a wider market of alternatives with potential to shift dependence upon trusted providers of healthcare expertise to other sources (from trained doctors and nurses, to online and automated and remote pools of health experts, to patients themselves being increasingly considered 'lay experts') (Eysenbach et al. 2004; Armstrong & Powell 2009) creating a choice of routes to healthcare information provision prior to formal healthcare service interactions (Ingram et al. 2013). Therefore, availability of multichannel healthcare services within a single or orchestrated among several healthcare providers can be understood to structure patient demand, for example with health information-seeking practices using resources provided by independent and allied healthcare providers on the internet, creating a pre-service virtual staging area where patients can privately deliberate whether or not to seek a professional consultation for more information and guidance (Ingram et al. 2013). From this literature, it is suggested that multichannel services users are confronted with a selection of services which requires awareness of how they can meet their perceived needs as well as sufficient competence and confidence to use them.

2.3.3 Research on patient perspectives of telehealth

There are many assessments of telehealth interventions but it is widely acknowledged that very few study the patient perspective (Mair 2000). In the early days of telehealth primary users were understood to be healthcare organisations and their medical staff (Nicolini 2006; 2007; 2011; Mort et al. 2003). It wasn't until providing household telehealth equipment became more affordable that the emergence of user-centred telehealth studies focusing on patients were perceived as relevant. What these studies tend to reveal are differences between expected use and the actual use. Telehealth adoption is seen to involve shifting service roles, making patients diagnostic agents in domestic environments respatialized to address clinical issues (Oudshoorn 2012). Such sociology-based studies provide an interesting and informative level of engagement into broad structures of influence on patient behaviours although they tend to shy away from detailed studies of individuals. Critical views of telehealth-like services suggest they are not as helpful to people who are

chronically ill or otherwise disadvantaged through age and frailty, and require significant customisation, highlighting the problem of unrealistic assumptions held by designers and commissioners about what matters to these patients (Mort et al. 2009; Greenhalgh et al. 2013; Finch et al. 2008).

However, a contrary view is provided by a huge number of studies suggesting that patients are highly satisfied with telehealth generally. This is based on data gathered using patient satisfaction surveys (typically nested within an RCT) that have been confirmed as validated and follow psychology-based measurements of satisfaction and self-efficacy, or health econometric schools of thought that are derived from them. The use of survey-based instruments provides a highly limited understanding of patient experiences of the service, although they presume to represent the salient issues and ask respondents to weight their experience according to the descriptions of the scales provided. As evidence, they have been criticised as being insufficiently informative, with a systematic review of 93 patient satisfaction studies reporting levels of satisfaction consistently greater than 80 percent and frequently reporting 100 percent although they only measured 1 or 2 dimensions of satisfaction (Williams et al. 2002). One reason patient surveys are problematic is because they rarely involve patients in the design or conceptualisation of issues and vocabulary used (Williams et al. 2002), therefore, in-depth research to understand why levels of satisfaction with telehealth is consistently high is necessary.

A focused literature search found nine studies investigating patient perspectives of telehealth, which are summarised below (Table 3). This literature suggests that patients perceive telehealth to affect their behaviours by making them more engaged and self-disciplined about their self-care, and leads to better communications with and feeling assured by their real and virtual relationships with healthcare providers (Hopp & Hogan 2009; Fairbrother et al. 2014). Generally patients experience few problems with the technology that can't be addressed with early intervention to provide reassurance (Currell et al. 2010; Cook et al. 2016). Although telehealth involves taking on low level diagnostic work and monitoring tasks (Oudshoorn 2012; A. Rogers et al. 2011), patients were generally positive about what they understood as the purpose of telehealth to provide early indicators of illness for action (Ure et al. 2012). Others conclude that equipment was often unsuited to diverse needs and patients regularly adapt unsuitable technologies (Greenhalgh et al. 2013). Patient experience of telehealth depended on paradoxes of telehealth. These resulted in frequent moral dilemmas which made it difficult to predict whether telehealth enabled or hindered: self-care and independence, a sense of reassurance, and level of acceptance of increased 'work' involved (Brunton et al. 2015; A. Rogers et al. 2011).

TABLE 3 PATIENT-CENTRED TELEHEALTH LITERATURE (ORIGINAL WORK)

Author, date, method	Findings
Hopp & Hogan 2009 **3 focus groups with diabetes patients of VA hospital, thematic analysis of perceptions for outcomes model**	The results suggest mechanisms by which telehealth systems influence the health care system. Enhanced communication with health carers Enhanced, personalised relationship with care managers Enhanced self-discipline Increased promptness of clinical follow up
Currell et al. 2010 **Systematic review (7 trials) of telemedicine as alternative to face to face patient care**	No differences (detrimental effects or clinical benefits) between telehealth and face to face care although economic assessment was needed. Equipment was generally reliable and patients accepted it well. No detrimental effects from interventions, neither did they show unequivocal benefits, and findings did not constitute evidence of the safety of telemedicine All technological aspects of the interventions appear to have been reliable and to have been well accepted by patients
Oudshoorn 2011 **Sociology of science and technology book theorizing from findings from empirical studies of telehealth services in the Netherlands**	Patients engage in diagnostic and identity work if supported by social actors
Rogers et al. 2011 **Semi-structured interviews (n=31), observations, focus group, thematic analysis of work practices**	Telehealth provides advantages including avoidance of travel for acceptable substitute care Feeling reassured by the increased oversight from their healthcare providers through more regular monitoring of their condition than is otherwise feasible, e.g. through regular home visits and in-clinic appointments Low level use of clinical information rather than more sophisticated interpretation of vital signs for self-management decision-making expected in policy discourses Paradoxical increased dependency through extraordinary reliance upon repetitive monitoring and increased virtual surveillance by healthcare providers
Ure et al. 2012 **In-depth interviews and 1 focus group with Scottish COPD patients (n=20) and professionals (n=25) in pilot study**	Enables earlier recognition of exacerbations Facilitates access to clinical advice
Fairbrother et al. 2012 **Semi-structured interviews with Scottish COPD patients (n=38) and provider stakeholders (n=32) (pilot and six months) nested qualitative study, thematic analysis using framework approach**	Patients generally appreciated being 'watched over' which gave them confidence to manage their own conditions. Patients used tele-data to improve their understanding of COPD, determine their current state of health and influence decisions about their daily activities. Numerical data was particularly valued. Changes in readings validated their decisions to adjust treatment or seek timely professional advice, and eased access to clinical care. Patients valued the personalised care provided by telemonitoring staff familiar with their circumstances and state of health. Importance of relationship-based continuity of care emphasised by patients and providers
Sanders et al. 2012 **Semi-structured interviews, observations (n= 22), work shadows (n=8). Thematic analysis of barriers to participation among people who declined to participate in WSD**	Anxiety about ability to use equipment Resistant to expected disruptions in services Perceived threat to independence, identity and self-care practices from increased monitoring Less prominent were dislike of technology or privacy concerns
Greenhalgh et al. 2013 **Case studies (n=40) Ethnography, phenomenological analysis of elderly people's perspectives of telehealth**	Participants' diverse and unique needs presented them with occasions to manage their multiple, mutually reinforcing impairments subjectively and experientially, appropriating and/or adapting technologies to enhance their capacity to sense and act on their world. Pragmatically customised the newer technology in combination with legacy devices. Divergence between distinct telehealth user groups: service providers and service users. Patient users employ a different way of knowing that is concrete – as opposed to numerically abstract. Users regularly customise technologies to suit their needs.
Brunton et al. 2015 **Qualitative meta-synthesis of 7 studies studies of telehealth use for management of chronic obstructive pulmonary disease (COPD)**	Using a line of argument synthesis, they identified three over-arching themes described as a series of paradoxes that can impede or promote positive user experience. Patients experience moral dilemmas about whether to seek help and that this can either enable dependency on care providers or self-care, and that this distinction is a continuum in telehealth use. Telehealth is transforming interactions which can be experienced as increasing risk because it is perceived to impede clinical assessment or lead to a false sense of security. Paradoxically transformed interactions can also enable positive user experience because it is perceived to increase social connectedness and reassurance. The reconfiguration of 'work' practices can cause burden if it increases patient anxiety, increases healthcare provider workload or threatens professional identity. Paradoxically it is perceived as empowering when it increases patients' ability to self-care.
Cook et al. 2016 **Qualitative semi-structured interviews with users and non-users (n=40) studying factors influencing decision to adopt and engage with telehealth and telecare; framework method analysis**	Role of referrers of patients onto the service is influential in decisions to adopt Users need early reassurance in order to continue, especially for older users who appeared to have more negative feelings toward technology. Clear need for the equipment usability and functionality to be improved.

2.3.4 Why patient perspectives are understudied

The relative paucity of evidence from qualitative patient studies suggests this might be due to pragmatic reasons. As aforementioned, it is likely due to telehealth users only including patients and carers once household technology provision became affordable. Methodologically, the task of obtaining ethical approval for vulnerable patient studies and the logistics of collecting and analysing qualitative data are time consuming even for small sample sizes because the nature of the data creates logistical barriers to collecting and analysing large samples favoured in statistical probability analysis for generalisability to populations (Miles & Huberman 1994). There is a question about the variability of qualitative, anecdotal data which means it is difficult to control when making causal inferences which are expected from quantitative studies (Shadish et al. 2002).

It is also apparent that there are socio-political barriers to conducting patient-centred research, which may account for the publication bias favouring other research designs and non-patient-centred foci. This hypothesis is related to institutionalised biases in healthcare research cultures (Dopson et al. 2008). For example, in the Whole Systems Demonstrator (WSD) research protocol (Davies & Newman 2011) the chief investigators explain their rationale for implementing an RCT design to evaluate telehealth interventions at scale because they are widely accepted in the hierarchy of medical scientific evidence and considered the most scientifically robust due to the avoidance of bias (Figure 2).

Qualitative health research occupies the two lowest levels of the hierarchy, denigrated as merely 'anecdotal evidence' due to non-generalisability and producing findings that are notoriously difficult to apply in practice (Morse 2011). Relatedly, 76 senior academics recently sent an open letter roundly criticising the editorial policy of the highly cited *British Medical Journal's* decision to view qualitative research in healthcare as 'low priority', 'unlikely to be highly cited, 'lacking practical value' or 'not interesting our readers' (Greenhalgh et al. 2016).

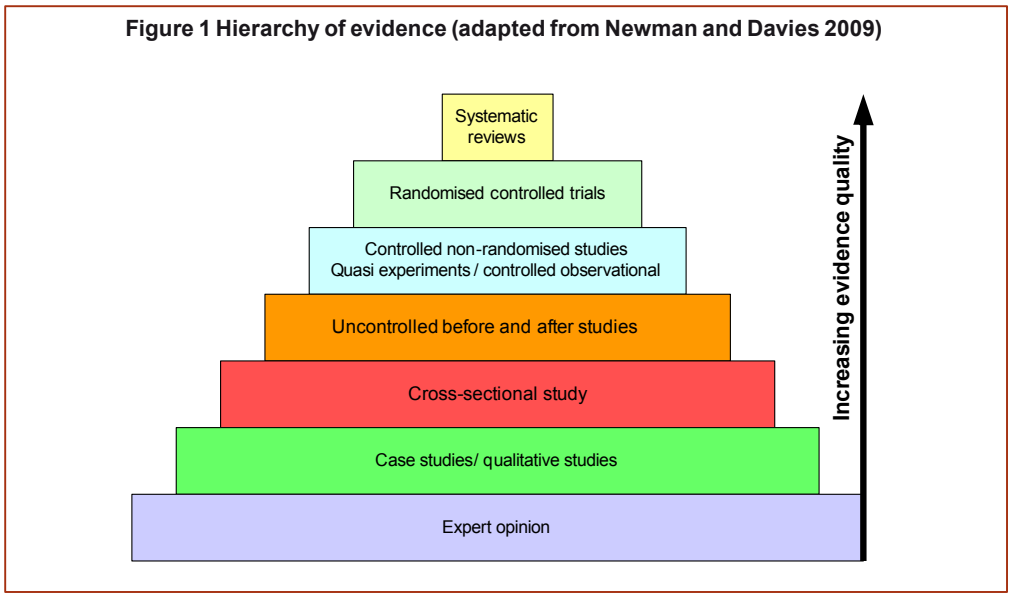


FIGURE 2 HIERARCHY OF EVIDENCE IN HEALTHCARE (Davies & Newman 2011, p.6)

The debate ensuing from the heated reception to the WSD evaluations (and withal the UK Government's responsive alacrity to draw upon its conclusions) stemmed from criticisms that they involve research designs that lack the reflexivity necessary to question the socio-political influences that underpin research designs, the construction of findings, and the interpretation of policy implications (Greenhalgh & Russell 2010; Greenhalgh 2012).

Greenhalgh et al.'s (2013) review of the telehealth literature speaks of the epistemological biases that inform the design, implementation, expectations and evaluation of telehealth interventions. The authors are critical of the basic assumption that there is value from telehealth efficiently meting out healthcare on the basis of rational clinical decisions made by clinicians viewing their biometric data on a remote computer screen. They also critique the assumption that people (telehealth users) employ an abstract, instrumental rationality to make self-management of illness decisions. In their ethnographic study they found that people use practical, concrete rationality, or *phronesis*, in everyday life. The second argument follows, that understanding the application of phronesis in patients' lives is more useful for identifying patient needs and tailoring designs to suit them. This argument highlights a problematic division between the telehealth worldview which only looks at/for the partial representation of people as abstract data (objective biometric indices), without reflexively considering the limitations of that partial view of the holistic, practical, subjective needs of telehealth users. In fact, their ethnographic study shows that the current suite of assistive technologies is so inappropriate that users regularly need to practise customising work, actively assembling ideas about what is needed to become practical *bricoleurs* in order to extract utility from technology.

Their findings resonate with literature on the paradoxes of technology consumption by Mick et al. (1998) and on the role of ideology in technology consumption experiences by Kozinets (2008). These two papers from the consumer research subfield of marketing suggest that there is a disconnect between how the consumption of technology presents as an idea borne of social norms which is experienced differently through its use. These ideas resonate with Greenhalgh et al.'s (2012) identification of four conflicting telehealth discourses (Modernist, Humanist, Political-economy, and Change management[2]) highlighting that telehealth's ontological status is still contested and ambiguous.

The telehealth literature, therefore, shows its symbolic importance in socio-political discourse, and alerts us to structural biases concerning the role of technology. It also clarifies the role of healthcare systems to determine what is important and what is valued, and how it persistently conceptualises this role without adequately considering the extent that it is appropriate to holistic and subjectively perceived patient needs. Finally, when Greenhalgh et al. make explicit their political motivation for choosing their research design as it aims 'to deliberately decentre technologies and place what matters to people at the centre of the research' (Greenhalgh et al. 2013, p. 87), they show how all research design is essentially politically motivated. They make a clear argument about *how* ways of knowing and what is accepted as valid knowledge is socially constructed. It also provides a commentary on how the validity of research findings is frequently judged according to its usefulness to the powerful decision-makers, arguably for establishing what is necessary to progress interests in existing social structures (Ferlie et al. 2005), rather than using it to criticise and question underpinning assumptions for social action and radical change.

These debates about the conduct and governance of telehealth research as a socio-political activity also suggest that the field of patient experience of telehealth research is fertile ground for the introduction of cognate epistemological approaches that can try to reconcile issues of how to validly represent patient perspectives, while also being mindful of the portability and usefulness of findings to influence managerial practice. The coherence of implications for practice is necessary to bolster the impact of qualitative research on policy.

2.3.5 Conclusion

The review of the telehealth policy background and literature identified telehealth's strategic role in the management of chronic disease care. The under-researched area of patient-centred telehealth

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2 The competing telehealth discourses are: (1) *Modernist* offering telehealth as a future solution in a technological utopia; (2) *Humanist* referencing uniqueness and moral worth of individuals and tailored to personal and family contexts, where technologies can solve and create problems; (3) *Political-economy* imagines powerful interests driving commodification of healthcare and diversion of public funds into private business; (4) *Change management* recognising the complicatedness of large-scale technology programmes, emphasising good project management and organisational processes) (Greenhalgh et al. 2012, p. 1).

studies was discussed in light of the vast literature. The review of qualitative patient-centred telehealth literature summarised in Table 3 identifies key themes related to: user attitudes to technology, user-machine interactions, and healthcare service relationships, especially in terms of moral dilemmas about deciding whether to get help, work, empowerment and subjectively perceived needs. Arguments for why this area is under researched are considered in terms of the shaping effects of socio-historical context on telehealth research.

Chapter 3 Conceptualising the research problem

This chapter begins by explaining the findings from a literature review of patient experience research highlighting a central paradox that it is provider-led rather than patient-centric. In order to address this inconsistency, various marketing perspectives are discussed in support of an alternative conceptual framework to study patient experience and patient value. It then explains the adoption of the S-DL as a theoretical perspective because it advocates attention to structure and agency to account for a person in context.

This is important because, as discussed in Chapter 2, chronic disease policy deals with the central role of self-management and telehealth, and different schools of thought advance competing theories about the critical determinants for making patient self-management sustainable. The first focuses on individual change, conceptualising a voluntarist notion of agentic patient ontology as a lever for changing interactions. We may consider this a patient-led proposition of social change. The second approach assumes a more passive patient ontology, where social change occurs through structural change. The focus of this second approach is considered provider-led rather than developing patient self-management skills *per se*, as it concerns changing environments that influence patients, i.e. clinicians' behaviours and patients' social networks, toward normalising patient self-management behaviours. Therefore, the second approach implies self-management might be a misnomer as it is less reflective of a voluntarist individual acting autonomously and more the result of structural determinism. This view suggests that collectively changing social behaviours influences individual behaviours.

These divergent theories about self-management suggest that empirical research is needed to clarify how telehealth factors either as a structural condition to which patients respond or if perhaps it is a personal resource to effectuate voluntary actions which is consistent with the ontology of an active patient self-managing. Further research needs to consider the patient-led/provider-led dichotomy in order to conceptualise how to study telehealth from the patient perspective. Although **Section 2.3.3 Research on patient perspectives of telehealth** shows studies have found interesting things about patient experience of telehealth (Table 3), it is argued that further work is needed to define what matters to patients in order to establish the patient perspective empirically.

This literature refers to 'technology use', 'acceptance', 'experience', 'patient experience' and 'patient perspective' interchangeably. In light of policy prioritising the collection of patient experience data for service quality improvement, the thesis considers patient experience of telehealth. Therefore, Section 3.1 discusses the theoretical underpinnings of the patient experience concept in clinical, survey, health economics and marketing approaches. Section 3.1.2 discusses the central paradox that the patient experience concept is provider-led rather than patient-centric. Section 3.1.3 discusses problematic use of patient experience data to identify patient value, and

how adopting the S-DL as a theoretical perspective can help to identify patient value in context. Sections 3.2 to 3.5 explain the conceptualisation of the research problem by defining patient experience from a marketing perspective.

3.1 Patient experience

Patient experience is acknowledged to be 'a complex, ambiguous concept that lacks a common or ubiquitous definition and also because there are multiple cross-cutting terms (e.g. satisfaction, engagement, perceptions, and preferences) in healthcare that make conceptual distinction (and therefore measurement) difficult' (LaVela & Gallan 2014, p.28). The Beryl Institute (n.d.), a community of practice dedicated to improving patient experience through sharing knowledge, defines patient experience as 'the sum of all interactions, shaped by an organisation's culture, that influence patient perceptions across the continuum of care.'

It is widely accepted that capturing patient perspectives of healthcare services is seen as a fundamental part of service quality improvement[3] (The Health Foundation 2013) with service users increasingly encouraged to report their experiences, especially incidents of poor practice endangering patients (e.g. HealthWatch UK, PatientOpinion.org). These policies assert that obtaining deep insights from descriptive research is as important to guide quality improvement as studies with generalizable findings (The Health Foundation 2013). Since 2004 a mass of patient experience data has been regularly collected by the NHS, but due to the ambiguity of the patient experience concept and the lack of a gold standard for its use (Coulter et al. 2014), the external validity of various measurements aiming to capture such a wide-ranging construct is still subject to debate. Scholars often refer to its face validity, believing there is intrinsic value to providing patients with opportunity to have a 'voice' to influence service quality (Doyle et al. 2013). Obtaining information about patient experience as necessary insight into what patients think is a first step toward strategically focusing the organisation to be 'customer-centric' in design and culture (Bate & Robert 2007).

Practical implications of regularly collecting 'real time' NHS patient experience data[4] (Coulter et al. 2014) for patients and families include being increasingly tasked with requests to share their

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[3] In April 2015, a policy initiative came into effect that requires the routine collection of patient experience data from all NHS patients in England (typically a variant of the Family and Friends test). After more than a decade of gathering patient experience data there is still no consensus on ways of analysing and interpreting the data to improve services (Coulter et al. 2014), leading some to suggest that a dedicated institutional resource is needed to make use of it, such as the Health Experiences Research Group at Oxford University.

[4] Regularly used national health and social care surveys carried out in England are: Care Quality Commission (CQC) national patient experience surveys – inpatients, outpatients, emergency departments, community mental health, and maternity; General Practice Patient Survey; National Cancer Patient Experience Survey; NHS Staff Survey; VOICES survey of bereaved people; Patient reported outcomes of selected surgical procedures; Adult Social Care Survey; Adult Social Care Carers Survey; CQC Social care user surveys – people who live in care homes (18-65 years old), older adults in care homes, and people who use domiciliary care services. (Source: Coulter et al. 2014, p. 2).

opinions in a structured feedback format. Although using patient experience surveys to change service delivery is argued to benefit patients, chronic disease patients may benefit more directly as they tend to be recurring service users, unlike an acute patient providing feedback after experiencing a singular episode of care. Predominately, the role of patient experience data is portrayed as a way to influence organisational culture. Recent studies using quantitative approaches show patient experience for patients whose life activities are limited by chronic disease report poorer experiences and more problems with hospital care (Hewitson et al. 2014). Although the majority of single chronic disease patients seem to have good experiences with primary care, patients with multiple chronic conditions report worse experiences with primary care because appointments are structured to deal with single health issues (Paddison et al. 2015). These studies suggest further research is needed to explain how patient experience relates to interactions with the organisational culture underpinning service design.

Organisational culture is reflected in the suggestion that there is value in seeing patient-provider interactions as part of building customer relationships (Needham 2012) often referred to as a 'therapeutic alliance' (Doyle et al. 2013) between patients and providers who are described as collaborating partners, jointly co-producing positive outcomes (Stacey 1976; 1984). The appearance of strategic marketing approaches in the patient experience literature further suggests that the focal relationship between patients and providers is framed as assisting organisational performance. Examples include aims to capture and maintain market share through establishing consumer loyalty.

> Measurement of patient experience is important because it provides an opportunity to improve care, enhance strategic decision making, meet patients' expectations, effectively manage and monitor health care performance, and document benchmarks for health care organizations. Measurement of patient experiences can also inform an organization on improvement of processes and clinical outcomes, utilization of resources, and enhancement of safety. Furthermore, organizations also want patients to return, to refer their friends and family, and to provide positive word-of-mouth (behavioural loyalty) about their health care experience (LaVela & Gallan 2014, p 29).

Therefore, the literature increasingly argues that obtaining 'customer insight' through analysis of patient experience data is useful for service improvement that is beneficial to organisations and patients through addressing a need to change organisational culture (Bate & Robert 2007). For example, in the CCM ((from Gammon et al. 2015)) new provider-patient relationships are mapped to show patient-provider partnerships producing 'improved clinical and functional outcomes'. In this model, clinical outcomes refer to established, population-based clinically evidenced outcomes. Functional outcomes are person-centred, and defined as maintaining the activities of daily life. Because functional outcomes for chronically ill patients are highly variable depending on the personal experience of the life-limiting illness as it progresses, it is necessary to establish a baseline

in order to measure effects of improvements although there is scant evidence that this is what is captured in patient experience data.

Thus far, the discussion reflects the literature's tendency to assume that using patient experience data is intrinsically valuable because it gives patients a voice. The literature focuses on its use to generate extrinsic value when applied to the task of improving organisational culture in order to create better patient experiences. Better patient experiences are also argued to improve organisational performance. The next section considers how these assumptions about use of patient experience for extrinsic value creation have resulted in a paradoxically provider-led patient experience concept.

3.1.1 Provider-led patient experience

The growing expectation that patients and families regularly provide structured feedback e.g. using questionnaires, was mentioned above. While it is argued that this method enables data collection to be minimally intrusive for participants, this is not always the case, as shown by a recent telehealth acceptance study:

> it remains possible that some of the patients in the sample responded to the questionnaire by referring to relatives or other caregivers. […] patients had difficulties in understanding the concepts of some items, in particular: "access to care" and "continuity of care" […] some patients had difficulties in answering using the Likert scale (Dario et al. 2016, p.9).

Scholars argue such questionnaires are biased by provider perspectives because they tend to be conceptualised and worded without patient input (Williams et al. 2002) which increases risk that the data is unreliable and increases risk to the construct validity (Shadish et al. 2002) of the patient experience it purports to reflect. Further evidence that use of structured data privileges provider perspectives is because it is widely acknowledged that using unstructured data is more resource intensive to collect and analyse although it might be relatively easier for patients to participate because they can ask for clarification and use their own language to express their opinions. Shorter and faster data collection procedures suit healthcare organisations affected by time and resource constraints that are currently preventing the regular collection and interpretation of structured patient experience data (Fitzpatrick et al. 2014). Structured patient experience data complements evidence-based healthcare built upon robust findings that are generalizable to populations and can be compared through meta-analysis in systematic reviews, which are recognised as the gold standard of clinical evidence (Greenhalgh 2014). These reasons may explain why most patient experience literature tends to use a largely quantitative approach (Nairn et al. 2004).

Most studies typically use survey instruments that have been subject to intensive development and refinement through repeated studies (Coulter et al. 2014; Fitzpatrick et al. 2014; Gallan & Shattell 2015; Browne et al. 2010). Patient satisfaction measurement is the most common approach,

employing a number of validated survey instruments to focus on single service experiences or treatment events rather than measuring patient experience of the whole patient journey. Despite limitations to survey instruments like patient satisfaction questionnaires to obtain patient perspectives, it is important to acknowledge that questionnaires are efficient data collection tools and are arguably better than not collecting any feedback at all. Even imperfect measurements help to ensure the sense that there is some provision of the intrinsic value that is assumed in including patient experience as a pillar of service quality (Doyle et al. 2013). As mentioned previously, intrinsic value of patient experience data refers to the generally accepted belief that patients should have the opportunity to voice their opinions and concerns, although there seems to be a significant gap in the literature exploring the nature of that intrinsic value.

An example of extrinsic value justified on utilitarian grounds is shown in the use of patient experience data for routine auditing of service performance for improvement. It is argued here that this has created quite a narrow framing of patient experience, based on the aggregate findings of multiple studies, rather than open to possibilities of extraordinary or alternative forms of experience.

> It is more common to use generic patient satisfaction surveys or reporting aspects of specific conditions or procedures using a measure of health status collected at different times allowing comparisons between patients. These instruments were initially used only in research but they have come to be used to routinely audit quality of healthcare services (Black & Jenkinson 2009: 2).

The utility of patient experience for auditing purposes, therefore, is conceptualised according to its utility to providers. By holding up a mirror to the service as it is understood and expected to function, patients serve the organisation rather than the service gaining access to more rounded insight into their needs, what matters to them, and whether the service meets those expectations. If we recall that the massive telehealth literature is focused on efficacy trials, and when studies report patient perspectives it is through the use of questionnaires related to acceptance and/or satisfaction in a nested study. Of these consistently high ratings (typically 80-100% satisfaction based on 2-3 dimensions of satisfaction or acceptance) (Williams et al. 2002), it is possible to suggest that the questions seek perfunctory confirmation of the extent that the service meets provider expectations based on the construal of language and measurement constructs that reflect provider thinking. According to the broad definitions of patient experience provided at the beginning of this section, it is clear that satisfaction and acceptance provide a partial view that reflects a primarily cognitive understanding of a multi-sensory experience. The expression of experience in structured formats arguably focuses more on the expression of convergence with the provider's cognitive framing of experience than it does on capturing the patient perspective. Therefore, the construct validity of patient experience as reflective of what patients really experience, rather than confirmation of

provider expectations of that experience and the extent that it is satisfactory or acceptable, is not established.

Although it is argued here that the patient experience concept still requires theoretical development before it can be shown to provide construct validity to assert that there is intrinsic value to patients from its use, the literature is striding forward to evidence the extrinsic value of using patient experience data to improve provider value. For example, a widely cited article (233 citations on Google) by Doyle et al. (2013) reports findings from a systematic review of 55 studies for evidence of association between **patient experience**, **clinical safety** and **clinical effectiveness.** Their meta-analysis shows a consistent positive association between the three measures across a wide range of disease areas, study designs, settings, population groups and outcome measures. The authors conclude that patient experience is positively associated with

- self-rated and objectively measured health outcomes;
- adherence to recommended medication and treatments;
- preventative care such as use of screening services and immunisations;
- healthcare resource use such as hospitalisation and primary care visits;
- technical quality-of-care delivery and adverse events (Doyle et al. 2013, p.1).

Their review therefore suggests that patient experience data is trustworthy based on triangulation with objective measures that have been validated and accepted by the healthcare organisational culture. In other words, the review finds that patients' views can be trusted to reflect objective measures of the same experiences. Therefore, the value of patient experience, which is assumed to be intrinsically valuable to patients themselves, is expressly aligned with the clinically-evidenced core values of the healthcare provider. Moreover, this conclusion underscores the assumption that the individual view that patients have about services reinforces the population-based view that providers have of how services should be delivered to patients.

Firstly, for any research focusing on patient perspectives, the significance of this study highlighting the extent that patient experience data is argued to be clinically valid or trustworthy should not be underestimated, especially because the field of healthcare research respects a hierarchy of evidence that privileges 'scientific objectivity' and denigrates the value of 'expert opinion', much less patient opinion, as 'merely anecdotal' (Morse 2011).

Secondly, their findings suggest there is a degree of convergence between patient and professional perspectives of the same service experience. On one hand, we may see this as confirming the mutual aims of the 'therapeutic alliance' between patients and professionals working together to co-produce patient benefit. This assumption of fundamental affinity between provider and patient value (Swick et al. 2006) is described by the professional model of healthcare. However, the

prioritisation of patient interest in the professional model has been challenged in the sociology of the professions literature and in practice due to conflicting interests such as income generation through providing treatment (Freidson 1970b; Illich 1975; Brennan et al. 2003) and professional culture valuing population-based evidence of treatment effectiveness rather than reports of efficacy based on individual cases (May, Rapley, et al. 2006). Other challenges to the assumption of convergence between patient and provider perspectives of value come from recent studies showing their perspectives of the same service 'experience' (the process and outcomes) are dissimilar (Hartzler & Pratt 2011; Berry & Bendapudi 2007; Entwistle et al. 2012; Ryan et al. 2014). Therefore, although Doyle et al.'s (2013) review tends to blur differences between patient experience and provider perspectives of the components of service quality (safety and effectiveness), the literature suggests there may be conflict related to the growing acceptance of patient experience data's external validity and the limited construct validity of patient experience data reflecting patient perspectives.

3.1.2 Patient experience and an object-oriented goods logic of healthcare services

Having discussed the growing acceptance of structured patient experience data using quantitative approaches for healthcare service improvement, and the limitations of questionnaires which are argued to result in provider-led rather than patient-centred constructs being measured, this section argues that the paradox of patient experience as provider-led may be due to problems with the ontological definition of patients in healthcare services. This section argues that the provider-led bias stems from the 'wrong' underpinning mid-level theory conceptualising healthcare services as object-oriented rather than intersubjective.

With reference to a marketing perspective, assuming healthcare services are object-oriented (Mol 2003) is reflective of a goods logic (Vargo & Lusch 2004) which results in the patient experience being understood as something that is inherently provider-led. In order to manage this paradox and make patient experience more patient-centric, this section argues that healthcare services as an ideal type would be better framed as fundamentally intersubjective, an orientation consistent with a S-DL (Löbler 2011). Intersubjective orientation is suited to concepts of humane and empathic care sought by patients in their healthcare service interactions (Doyle et al. 2013). To illustrate the difference between patient experience conceptualised using object-oriented and intersubjective healthcare relationships, two patient experience studies are compared. The objectivist-orientation is illustrated by the aforementioned systematic review by Doyle et al. (2013) published in the *British Medical Journal*. The intersubjective orientation draws on an interdisciplinary article by Gallan et al. (2013) published in the inaugural issue of a new *Patient Experience Journal*, which uses a psychology-based marketing approach to evaluate and measure patient experience by applying assumptions from customer experience literature.

A simple definition of patient experience is *patient satisfaction with the humanity*[5] *and effectiveness of their care* (Black & Jenkinson 2009). Doyle et al. (2013) explain that humanity and effectiveness have relational and functional dimensions. They clarify that relational refers to the interpersonal aspects of care. Examples include clinicians' capability to empathise, respect patient preferences, engage in collaborative decision-making, and provide the information necessary for patients to self-care. The relational also refers to patients' expectations that professionals will prioritise their interests above other considerations, as well as expecting them to be honest and transparent if something goes wrong. Functional aspects relate to patients' basic expectations about how their care is delivered. This includes attention to their physical needs, the timeliness of the care provided, ensuring that the environment is clean and safe, and that professionals provide continuity of care through effective coordination.

Doyle et al. describes a consensus view that patient experience is useful for measuring how well healthcare meets patients'

> expectation of humane, empathic care [which involves] clear information, empathic, two-way communication and respect for patients' beliefs and concerns [which] could lead to patients being more informed and involved in decision-making and create an environment where patients are more willing to disclose information (Doyle et al. 2013, p.2).

The authors' proposition ('could lead to…') articulates the belief that a necessary condition for patients becoming 'more informed and involved' as a precursor to greater participation in collaborative decision-making (Coulter et al. 2015) is the requirement that clinicians improve their 'empathic, two-way communication' skills and that they understand the importance of treating patients respectfully and humanely as subjects with beliefs and concerns rather than as inhumanely-treated objects. This passage suggests that normative responsibility for improving patient experience rests with clinicians to create a conducive therapeutic environment that meets their expectations. Their argument therefore implies that the right 'environment' encourages patients to disclose diagnostically relevant information more efficiently and effectively. The structure of the interaction, therefore, is something to which patients are perceived to respond.

It is argued here that this line of argument is inherently paradoxical because it suggests patient experience is the result of professional agency rather than patient agency. Agency (discussed in Section 4.3.4) is simply defined here as the ability to act autonomously. This can be demonstrated by comparing Doyle et al.'s conceptualisation of *how patients experience services and how experiences influence changes in patient behaviours*, with another patient experience study which

[5] Humanity relates to basic human rights and is explicitly applied to current healthcare guidance: 'Human rights are not an 'add-on', they are an inherent part of care' (Department of Health 2008, p.6) and affirms the 'FREDA' values of Fairness, Respect, Equality, Dignity and Autonomy (Ryan et al. 2014, p.200).

integrates a marketing approach, namely Gallan et al. (2013), which tested a patient-centric psychology-based theoretical model using data from 190 'medical clinic customers' in the US.

Gallan et al.'s study shows a relationship between positive patient affect (positivity) as an antecedent condition for participation during service encounters with highly uncertain outcomes to produce positive healthcare service experience assessments (service quality and satisfaction). Their model conceptualises the patient experience as *the patient as an individual participating in service encounters in order to co-create positive experiences*. Their approach can be seen as patient-centric because their variance model of causality assumes the ability of a patient to feel their subjective emotions, reflect on them, and participate in ensuing action to co-create a patient experience outcome. The patient (or medical clinic customer) in this service marketing study is assumed to be agentic and able to instigate social action through the exercise of individual volition (in the market context). It is possible to suggest that the framing of the service user as a 'customer' brings with it certain ontological assumptions about consumer choice and agentic market interactions.

In Doyle et al. the authors vacillate in their argument between describing patients as subjects and objects. They initially assign the patient the status of social participant who has a valid understanding of their situation (amounting to 'beliefs and concerns') from their viewpoint as a participant. The intersubjective orientation of the clinician-patient relationship centres on the 'humane and empathic' care they advocate. These terms assert the humanity of the patient as a subject possessing such 'beliefs and concerns' that can be recognised and understood empathically by the clinician, who is also a subject, thus suggesting an interaction between subjects.

They switch from ascribing to agency to patients with capability to interact as subjects to describing patients as objects in a subject-object relationship. This is implied in their endowment of agency to clinicians empowered to influence the interaction, creating an environment with *structural capabilities* to trigger changes in patients' reactions. As the following excerpt shows, a list of changes in patient behaviours that are argued to result from clinicians changing the environment of service interactions are constructed as provider benefits as they relate to duties and responsibilities of clinicians to get their patients to do as they are told for treatment efficacy and organisational effectiveness.

> Patients could have more 'ownership' of clinical decisions, entering a 'therapeutic alliance' with clinicians. This could support improved and more timely diagnosis, clinical decisions and advice and lead to fewer unnecessary referrals or diagnostic tests. Increased *patient agency* can encourage greater participation in personal care, compliance with medication, adherence to recommended treatment and monitoring of prescriptions and dose. Patients can be informed about what to expect from treatment and be motivated to report adverse events or complications and keep a list of their medical histories, allergies and current medications (Doyle et al., 2013, p. 2, emphasis added).

The framing of patients as either passive and reactive (Doyle et al.) or active and agentic (Gallan et al.) helps to shed light on the paradox of framing the patient as subjects yet disempowered in the creation of their own experience. In Doyle et al. patients are viewed as reactors rather than actors. Subjectivity is advocated and then withdrawn from the patient ontology. Subjectivity refers to the ontological and epistemological position that assumes 'society is understood from the standpoint of the participant in action' (Morgan, 1980, p. 608 in Löbler 2011, p.57). Although suggesting scope for patient agency, the authors aver that its articulation is broadly to react and respond to structural shifts. Hence patient agency is 'colonised' to accomplish provider aims, therefore, patient experience is subsumed by the provider perspective, as shown in Doyle et al.'s list of normative expectations for patient actions (e.g. complying, adhering, reporting, disclosing). It upholds rather than challenges the paternalistic healthcare paradigm (Robinson & Thomson 2001). Therefore, although Doyle et al. suggest that clinicians should make healthcare interactions humane, empathic, and intersubjective, the outcomes of change remain provider-led and are narrowly framed by object-oriented relationships.

Although their inconsistent treatment of patient agency is critiqued here, it is thanks to Doyle et al.'s explanation of relational and functional aspects of patient experience that the importance of patient subjectivity came to the fore in the conceptualisation of the critical role of patient agency in patient experience for this thesis. By contrasting Doyle et al.'s sociology-based framing of patients as less agentic and more structurally determined, with the Gallan et al.'s social psychology-based framing of patients agentically experiencing service interactions, we can see that patient-centred experiential accounts of interactions relate to patients' beliefs and concerns rather than those of providers. Therefore, in the identification of patient desire for humane and empathic service interactions, it is argued that what matters to patients can be seen as reflecting a turn toward intersubjectivity in patient-provider relationships.

This turn poses a challenge to current organisational culture, which are fundamentally subject-object orientated. This draws on theories developed in sociology of health and illness literature that describe clinicians as subjects treating patients as objectified worksites and inputs to biomedical processes, which involve interacting with material bodies rather than holistic patients (Mol 2002; 2003). This essentially dehumanised patient concept (explored in more depth below) befits an object-oriented relationship between service users and providers (Löbler 2011). This objectivist-orientation is ingrained and sustained by biomedical (Engel 1977) research cultures (Ferlie et al. 2012). These subject-object relationships are characterised by an imbalance in the distribution of agency that sustains a paternalistic approach to healthcare (Freidson 1961; Freidson 1970a; Freidson 1970b; McKinlay 1977; McKinlay 1993; Scott 2008; McDonald et al. 2013) depicting a relatively disempowered patient (Schon 1991).

It is argued here that the assumption of patient agency as relatively absent in the healthcare service relationship reflects a misconception of healthcare services. According to the marketing literature defining services as a service-for-service exchange (Maglio & Spohrer 2007), services are simultaneously produced and consumed by providers and service users, and this assumes, therefore, that either party potentially exerts change in the encounter (Akaka & Vargo 2015). The marketing construct of service endows both provider and patient with potential for agency in the service context.

Because Doyle et al. do not articulate the role of patients doing something as participating actors about their dissatisfactions and grievances when their humanity is not respected, other than to react in this way (i.e. dissatisfied and aggrieved) if clinicians fail to respect their humanity, this highlights an interpretation of patient agency according to a single dimension, which is the ability to act in a way that is facilitated by existing social structures. However, agency is the ability to act independently (Barker 2005). The freedom to act autonomously therefore implies the freedom to act otherwise. In this way, Doyle et al.'s formulation poorly conceptualises patient agency and suggests that patient experience is structurally determined by such mechanisms of the healthcare service interaction and that experiences have a linear causal relationship instigated by provider actions alone. Conceptualising healthcare services as object-oriented results in a blindness to the contextualisation of the interaction experience from the holistic patient perspective because it is not structured to accommodate the potential exertion of patient agency.

3.1.3 A service perspective of patient experience

In order to deal with the critique of Doyle et al., taking a service research perspective enables the patient experience concept to consider a holistic and agentic patient subject. Service theories explain that when service interactions fail to meet their expectations of humane treatment and dignity, there is scope for patient agency in co-creating the service recovery process (Michel 2001) in order to address an adverse event or service failure (Dong et al. 2007). This is a more patient-centric nuance that is different to suggesting that without clinicians improving their practice to avoid service failures, patients may yet be recalcitrant (e.g. remain non-compliant, non-adherent, non-owning, ill-informed, possess unrealistic expectations and lack motivation), contributing to negative patient experiences.

Comparing the two papers applying different theoretical perspectives and research methodologies to conceptualise patient experience illustrates the important role of disciplinary research cultures in maintaining (Ferlie et al. 2005) rather than questioning assumptions. These assumptions relate to *how patients are conceptualised as social actors and what determines their experiences* can be seen to differ according to a healthcare or marketing perspective. It is suggested here that the framing of patients (what they are and what they do) is a consequence of different understandings about the

nature of services. Essentially Doyle et al.'s paper makes assumptions about clinicians as central actors in social change, who transform the raw material of the passive patient, by adding value, i.e. producing health outcomes through diagnosis and treatment. The metaphor of patients as raw materials, draws upon Mol's (2003) description of the biomedical encounter objectifying the patient body as parts, e.g. organs, cells, disease, rather than holistically viewing the person in context. It follows that the ideal types of healthcare interactions described by Doyle et al. portrays clinicians as subjects with agency to produce the patient experience where the patient's role is to respond to environmental cues (i.e. interventions) leading to positive health outcomes. Patient experience is thus co-produced according to a goods logic (Vargo & Lusch 2004).

Co-production is a form of customer involvement during service production that emphasises a firm-centric view (Chathoth et al. 2013) focusing on value-added processes pertaining to the firm's value creation activities (Vargo & Lusch 2004; 2004b) with customers viewed as partial employees (Verhoef et al. 2009), rather than for their propensities toward prosumption (Toffler 1980). The concept of prosumption (a portmanteau of production and consumption) was welcomed by marketing scholars because it removes the artificial separation between these phases, which is argued to prevent consumers from being seen as creative actors in the value creating process of consumption experiences rather than a passive responder (Eiglier & Langeard 1975; Firat & Venkatesh 1995; Xie et al. 2007). Early marketing perspectives that presumed consumers to be relatively passive in their ability to resist manipulation by marketing strategies, were challenged by consumer researchers studying how consumers collectively exhibit agency to construct markets (Peñaloza & Venkatesh 2006).

The challenge to a provider-led view of services by marketing scholars suggests that healthcare consumers have a more active role in the service interaction than the co-production model informed by a goods-logic. The advantage of a perspectival shift away from provider-led co-production is that doing so endows patients with an active role in simultaneously producing and consuming services. As a consequence, a marketing perspective enables patients to be conceptualised as actors who are necessary in addressing failures and recovery (Grönroos 2000), including seeking alternatives through exit or withdrawal. The existence of alternatives suggests that there are service contexts external to the co-productive doctor-patient relationship that influence the interactions, therefore, not only must the understanding of the service relationship extend beyond the doctor-patient dyad, the dyad should be conceptualised as having distributed agency in a balanced service relationship (Gummesson 2008) thus according the patient with agency beyond reacting.

In summary, the literature highlights a paradox of patient experience as provider-led whereby patient experience is the result of provider agency rather than the product of patient agency. This was explained to result from a goods-logic of healthcare services, which rather than endowing the

patient with subjectivity as a social actor agentically constructing their experiences in ways to reflect a holistic rather than partial patient in context, relates to patients in object-oriented relationships that only empower clinicians as subjects that construct the environments determining patient experiences. The difference between object-oriented and intersubjective approaches to healthcare interactions was discussed, leading to the suggestion that a marketing perspective could allow a patient-centric conceptualisation of patient experience that respects patient agency to be constructed.

3.1.4 Against provider-led definitions of patient experience and value

This section develops the conceptual link between value generation and consumption experience mentioned above by discussing mainstream approaches to identifying patient perspectives of value from patient experience data. The healthcare literature frequently links the two constructs of experience and value, which is argued to be a problematic extension of provider-led conceptualisations for patient-centred constructs.

A growing body of research aims to identify what patients value through analysis of patient experience data (Entwistle et al. 2012). These frequently involve the use of structured patient data in quantitative approaches using health economy methods. In telehealth and self-management studies, patient value is usually determined using these types of quantitative valuations focusing upon structure and process-type attributes of healthcare delivery. Therefore, patient perspectives of value tend to be narrowly defined measurements of 'acceptability, effectiveness and cost effectiveness' using qualitative patient reports of estimated cost savings related to transport and time (Rogers et al. 2011) and questionnaires to assess economic and non-economic costs compared to attending face-to-face appointments (Cartwright et al. 2012). This includes health econometric measures, such as quality adjusted life years (Henderson et al. 2013), and cost effectiveness compared to standard care, which is a measure determined from the provider's perspective of costs against objective patient outcomes.

Such studies are primarily informed by reports of provider perspectives about what health services and staff are like or do, and consequently what they ask patients to do (Entwistle et al. 2012). For example, the calculation of patient value is tightly aligned with the service as it frequently considers aspects of service provision such as: treatment location, travelling time to appointment, travel costs, waiting times, continuity of care, length of consultation, privacy, and many others. That these commonly cited attributes do not consider patient perspectives is evident from how the attributes are worded, and how they are assumed to consider the kinds of impact that healthcare delivery has on patients within a wider lifeworld context (Rogers 2011).

> Few studies have attempted to value directly the kinds of personally experienced aspects of wellbeing or quality of life that healthcare delivery can impact on. Ambiguities in wording can

> sometimes support an interpretation that attributes do reflect patients' perspectives (Ryan et al. 2014, p.198).

Rather than addressing the ambiguity, health econometric studies are criticised for taking for granted that provider and patient perspectives of service experience are similar. This assumption is shown to be unsound in recent conceptual maps (Entwistle et al. 2012; Ryan et al. 2014) evidencing clear differences between provider and patient views of the same interactions. These studies map divergence of perceptions between: (a) the official and unofficial ways that healthcare staff perceive patients' experiences; and (b) between those and the patients' own perceptions. They suggest that there are different levels of provider-led understandings which bias the conceptualisation of patient experience, leading to extrinsically derived approaches to the identification of 'patient value' that bear little relation to patient views. This assertion underlines the importance of studying patients' subjective experiences of healthcare service interactions using wider contextual frames in order to calculate value. The authors suggest

> the complexities of the real world … [make it] difficult to pinpoint the value of features of healthcare as delivered because the wellbeing or quality of life 'achievements' that these might contribute to are also shaped by patients' individual attributes and wider contextual issues (Ryan et al. 2014, p.195).

By showing divergent views of the same interactions, Ryan et al.'s work suggests that patient perspectives are necessary to identify patient value from service experiences because healthcare interactions occur between actors with different opinions and underlying value systems, that include their own assessment and evaluation processes (see also Helkkula et al. 2013). Therefore, appropriate framing of patient value needs to consider individual level personal attributes and their interaction with personal contexts in order to understand the impacts of service experiences on personal circumstances.

Framing patient value that is contextualised to the patient lifeworld rather than narrowly to the service context itself is argued to provide more insight into how and why patients value healthcare, which is different to confirming that cost effective access to healthcare services (more or less as they are) automatically provides value. Yet this assumption drives the use of patient experience data within standardised service improvement practices, that focus on the incremental improvement of services rather than providing guides for transformative redesign. An example of incremental improvement is the use of patient feedback in routine performance auditing (Black & Jenkinson 2009), which treat patients as partial employees in a micro- and meso-level quality assurance process. Not only is this incremental improvement meant to improve existing practices, whose ability to produce patient value is uncertain, this kind of confirmatory patient feedback is being used at the macro level to affect the wider market of available providers. This is because the use of patient experience data to enable healthcare organisations to highlight the extent that they are

market oriented is evident through its appearance in public and organisational policy related to macro level reform, e.g. using patient experience measurement in order to incentivise and sanction professional practice when managing contracts and reimbursement in the wider healthcare provider market (Browne et al. 2010).

It is paradoxical, however, that arguments for making healthcare organisations more market oriented through patient feedback is arguably more focused on an internal B2B market, i.e. intra-organisational quasi-competitive commissioning priorities. As reimbursement refers to economic value to healthcare organisations, the use of patient feedback is another way of prioritising provider-led perspectives. Of course, fundamentally the ability to have access to continuity of care from sustainable healthcare organisations is assumed to be a necessary condition for the emergence of patient value, but influencing commissioning decisions in such an indirect way affects patients at a population level rather than more timely improvements to respond to individual need. It is reasonable to argue, therefore, that current conceptualisation and operationalisation of patient experience data and value assessments need to reconsider their taken for granted assumption that provider value is commensurate with the value that emerges from B2C relationships. Without this, healthcare providers are not adequately investigating what it means to become more market oriented in response to the heterogeneous market of individual patient need. One remedial step is to reconsider extant concepts of patient experience to provide insight into what subjective value looks like according to individual patient need given their personal circumstances.

Studies using alternatives to health econometric approaches have conceptualised the patient experience and value connection using service process analysis. What these approaches share in common is a greater emphasis on the role of the patient as an autonomous social actor. A growing literature by service quality researchers provides insight into the process and relational aspects of the service experience (Berry & Bendapudi 2007; Sofaer & Firminger 2005). The literature is informed by different schools of thought including psychological (LaVela & Gallan 2014; Gallan & Shattell 2015) and social psychological (Doyle et al. 2013; Ryan et al. 2014) approaches to studying patient experience through studying the role of individual patients and their service interactions. A third stream is based on the customer experience literature, translating frameworks of experience-based design to the co-design of healthcare improvement which focuses on the sensory clues and considers all of the touchpoints of the user experience, not only for functionality and safety, but also considering the aesthetics of the experience. These scholars suggest that the user experience should strategically inform both the organisational design and the culture (Bate & Robert 2007; Berry & Bendapudi 2007; Berry et al. 2002). A common problem with the different methodological approaches discussed is an attempt to disentangle confusion between patient perceptions and patient satisfaction, especially with questionnaire data. This points to the difficulty

in determining the extent that systematic variations in patient perceptions should be attributed to differences in expectations or actual experiences (Sofaer & Firminger 2005).

A fourth group of scholars working on patient experience studies attempts to understand it from the perspective of value, but rather than undertaking a quantitative, economic approach, it focuses on processes of interaction and can be explained as ascribing to a more sociological understanding of individual action within a service context. These works apply an intentionally abstract theoretical framework: the S-DL (Vargo & Lusch 2004; 2008), a system-level approach to the study of linked production and consumption processes that constitute patient value co-creation (Osei-Frimpong et al. 2015; McColl-Kennedy et al. 2012; Nordgren 2009; Nordgren 2008; Hardyman et al. 2014; Merz et al. 2013; Reijonsaari 2013; Janamian et al. 2016; Helkkula et al. 2013). Rather than simply applying its foundational principles to identify instances of theoretically-grounded value, this stream of research acknowledges the need for further empirical research to specify the extent that the theory accurately describes what occurs in practice. The approach takes for granted that theoretically-grounded methodologies for defining value according to a set of social actors (e.g. providers) could be empirically contested, or falsified, by the contextual conditions of the service ecosystem that ultimately influence the phenomenological value that emerges (Akaka, Vargo, et al. 2013; Akaka & Vargo 2015). It is argued here that this framework offers an important perspectival difference that challenges the dominant economic perspective of provider value presuming to dictate the framing of patient value. S-DL's central focus considers the service interactions that are salient to value co-creation processes. Rather than engaging only in experience definitions, this area of scholarship suggests that it is more fruitful to consider the outcomes that ensue from interactions, and how those outcomes are valued by the key actors. Its greatest potential contribution to the area of patient experience research is its framing of value not only as emerging during the interaction, but also that which relates to later stages of the consumption experience. The following chapter will explain the elements of this approach in more detail.

3.1.5 Conclusion

It is reasonable to argue that the assumptions about disempowered or passive patients from the healthcare literature persist in the conceptualisation of patient experience as mostly affected by structural factors determined by clinicians' modes of interaction. Based on the literature, there is an extent that patient behaviours and experiences can be said to adhere to structurally determinist explanations that are sympathetic to the depiction of patients as disempowered. Yet, paradoxically, the patient experience concept is frequently linked to notions of patient agency although a clear account of the role of patients in processing how and why patient experience matters is currently lacking. It is also unclear how patient experience relates to patients' role in changing the relationship with clinicians which could lead to improvement of perceived service quality along relational and functional domains. A further paradox implicit in the patient experience concept is

the clear tension between a normative move toward intersubjective relationships with agentic patients, and cultural-cognitive resistance to change from professional dominance in service interactions. Such change would require a shift from institutionalised subject-object-oriented healthcare relationships where the interaction dynamic is between agentic clinicians and relatively passive patients. Despite attempts to consider the patient perspective in higher order terms of human rights and humanity requiring empathy to guide all social interactions, patient perspectives are not easily understood or accepted without being counterbalanced by more easily assimilated objective determinants of healthcare interactions: clinical safety and clinical effectiveness.

The thesis argues that maintaining an object-oriented understanding of patient experience is inappropriate because it is not a consistently patient-led construct. This is because object-oriented patient experience is conceptualised according to a relatively passive patient responding to what clinicians do to them. The portrayal of what patients do as reactive responders in co-production processes is compared to a goods-logic model of healthcare. An alternative to an object-oriented conceptualisation of healthcare is an intersubjective service relationship (Löbler 2012). The difference is discussed through comparison with literature that assumes a dichotomy between a more agentic understanding of how experience comes to be or assuming that it is structurally determined. This section contrasts patient experience from healthcare and marketing perspectives, advancing the latter for its ability to more consistently consider experience and agency from patient perspectives. An explanation of a marketing approach to defining healthcare services is then explained as enabling a more holistic patient-centric service experience conceptualisation.

The use of patient experience to underpin the identification of patient value using various methodological approaches was reviewed. The difficulties discerning between satisfaction with actual experiences or expectations were highlighted and arguments against assuming that provider value is commensurate with patient value was discussed, particularly considering the use of patient experience data as feedback to sustain current practices through incremental service quality improvement processes rather than to inform transformative redesign. The current use of patient feedback to make healthcare provision appear to be market-oriented is also challenged because it is not a direct route to ensuring services respond to individual patient need in a timely way that is suited to personal circumstances.

Through exploring in depth the patient experience concept, defining and explaining its relational and functional dimensions from the literature and arguing that its subsequent operationalisation in the healthcare literature is problematic because of theoretical inconsistencies around the role of patient agency in patient experience, gaps in current research are identified. Mainstream conceptualisation of patient experience is based on survey data using narrowly framed questionnaires. This conceptualisation is argued to lack insight into the patient-led drivers that

inform subjective agency and underpin patient experience. Further limitations emerge from its conceptualisation as part of firm-centric co-production processes, rather than framing patient experience in terms of co-creation, a process that revolves around consumer benefit emerging during the service interaction as well as later stages of the consumption process. This means that current definitions of patient experience are considered in the narrow context of touchpoints of interaction (with some reference to previously held personal beliefs and expectations) rather than the wider context of conditions and consequences that occur before, during and after the interaction. Although some definitions of patient experience suggest a holistic framing that accounts for all points of interaction in a patient journey, their operationalisation in the literature is much less clearly articulated beyond conceptual maps showing what it is not (i.e. not provider-led). The advantages of scholarship framing patient experience using a marketing approach are advanced to more consistently focus on patient perspectives of service relationships, and what about interactions is relevant to patient value contextualised to personal circumstances.

3.2 Service marketing

This section introduces the development of service research before explaining the relevance of findings from the sub-field of SST to telehealth studies.

After critiquing provider-led conceptualisations of patient experience and suggesting that a marketing perspective is well-equipped to counteract some of the disciplinary assumptions that diminish potential for patient agency within provider-patient interactions, this section introduces the perspective of service marketing and identifies why it is an important approach for the study of telehealth from the patient perspective. Section 3.3 then explains the conceptualisation of telehealth as a potentially transformative SST. It provides a conceptual background for studying the relationship between telehealth users and service providers in a multi-interface, multichannel service ecosystem. Sections 3.4 and 3.5 explain how patient-centric conceptualisations of patient experience and patient value can be studied through the application of the S-DL perspective.

Telehealth scholars acknowledge the dearth of studies from the patient perspective and few studies have engaged further with telehealth as a potentially transformative service since Oudshoorn's (2011) book, which considers the multi-faceted effects of a Dutch service on healthcare providers, and studies the impacts of shifting spatial geographies as a result of technologizing the patient home. Her work notes telehealth's transformative ability to change the gendered nature of work at home, and considers ontological shifts within patients and what they do in response to changed socio-technical relationships and personal responsibilities. Although the book does not engage with current debates around the use of patient experience measures to judge service quality or the use of patient experience to estimate patient value, recent developments in service research theory can

usefully address both user experience and value, while also developing upon the findings of Oudshoorn's sociological study of service transformation.

In the past, services were usually defined by a list of attributes that differentiate them from products (Shostack 1977), i.e. services are heterogeneous, intangible, perishable, and simultaneously produced and consumed (Parasuraman et al. 1985). Service science has since moved on to define its own approaches, tools and strategies (Berry & Parasuraman 1993). Within this marketing subfield, it has been widely accepted that customers play a role in favourable service delivery experiences (Lovelock & Young 1978; Normann & Ramirez 1993; Bitner et al. 1997; Bendapudi & Leone 2003; Prahalad & Ramaswamy 2000; Grönroos 2006; Xie et al. 2007) which accounts for the rise of the consumer's engagement in hybrid concepts describing simultaneous production and consumption processes: e.g. *prosumption* (Toffler 1980), *servuction* (Eiglier & Langeard 1975); customer participation (Dabholkar 1990); consumer creativity (Burroughs & Mick 2004); co-production (Prahalad & Ramaswamy 2004) and co-creation (Vargo & Lusch 2004). Bitner et al. (1997) charts the chronology of the development of customer participation in the service literature and classifies types of customer participation based on the level of participation and according to customer roles as a productive resource; a contributor to quality, satisfaction and value; and a potential competitor. Service scholars consider healthcare as a service requiring high levels of participation, and agree that patients are involved in co-creating the service because they have critical production roles for the fulfilment of the service as intended: 'Unless the customer does something (e.g. studies, exercises, eats the right foods), the service provider cannot effectively deliver the service outcome' (Bitner et al. 1997, p.195). They suggest that not all customers will be interested in co-producing services but they may be more interested in ensuring they derive the outcomes they desire. Enjoyment can be a factor in participation, and there is a tendency for customers to blame themselves, holding themselves at least partially responsible for service failures.

The growing importance of services to economic and social well-being has been a topic of research since the 1970s when it was noted that the contribution of services to economic productivity in the United States surpassed that of the manufacturing sector (Kotler & Levy 1969; Kotler 1972). Recently estimated to contribute nearly 80 percent of US GDP and a growing percentage of GDP around the world (Bitner et al. 2008), proceeding decades of scholarship have concentrated on advancing the science of services to improve productivity. This began with a retrospective study of services around the exchange paradigm, resulting in explanatory frameworks that first served to view the contribution of markets for both goods and services, 'but also any valuable resource (e.g. time, energy, feelings, places, ideas, symbols or information)' as following principles of exchange (Achrol & Kotler 2011, p.35). Scholars worked to understand the distinctiveness of services from

the production and sale of goods as value generating activities, where the aim was not only to guide improvements for service organisations but to improve all firms' competitiveness (Grönroos 2000). By shifting the focus from particular firm activities to firm-wide activities, and thence to viewing the customer's interests as centrally important, the marketing worldview is tied much more closely to the normative principle that satisfying the customer is the key to all firm activities.

However, marketing scholarship has been actively highlighting that there are layers of stakeholder interests in society (Freeman 1994) that can be construed as having conflicting interests over longer timespans that also normatively require satisfying (Grönroos & Gummerus 2014; Heinonen et al. 2013; Cova et al. 2011). This is particularly the case in light of a shift that occurred in management thinking in the early 2000s, as firm and customer interactions began to be understood as equivalently – or in some literature more – central to the firm's functioning than the research and development department (Prahalad & Ramaswamy 2000; 2002; 2004a; 2004b). A wish to optimise this relationship led to the conceptualisation of customers as 'partial employees', serving as company resources (Baron & Harris 2008) for the generation of firm value through competitiveness. Several scholars trace the co-creation concept as intrinsic to all forms of capitalist and non-capitalist economies (Cova et al. 2011) although Prahalad and Ramaswamy are understood to have given birth to the area of research known as value co-creation. This is the production of value that takes place through collaborative firm-customer interactions. The operationalisation of value co-creation in recent marketing and management discourses, however, are distinctive for their aim to reconfigure

> the production of use and exchange value – previously considered internal to, as well as the sole purvey and 'competitive advantage' of, the firm – as increasingly dependent upon the active participation of formerly passive(ied) consumers (Lagace 2004 in Cova, Dalli, and Zwick 2011, p. 232).

Therefore, current marketing scholars highlight the hyper normative importance of putting the customer to work in the dyadic firm-customer relationship as the next frontier in competitive effectiveness (Bendapudi & Leone 2003; Vargo & Lusch 2004), while also acknowledging the role of wider networks of actors and resources in which both are embedded, and which affect those firm-customer relationships (Akaka, Schau, et al. 2013; Vargo et al. 2015). What is clear within most mainstream thought about the concept of customer value co-creation is the assumption that it benefits customers (e.g. more relevant, faster, cheaper services) and firms (e.g. better productivity) (Claycomb et al. 2001).

This broader view of marketing has enabled scholars to conduct research into the relationship between citizens, customers and business – withal the multiple aspects of how firms influence customer interests, and *vice versa*, at different levels, i.e. their subphenomena (consumer experiences and sensory systems), phenomena (marketing networks), and superphenomena

(sustainability and development) (Achrol & Kotler 2011, p.35). These different domains foster different theoretical approaches to understanding what has come to be understood by various general theories about marketing phenomena that assumes their interconnectedness at a holistic, rather than reductionist level.

As service marketing scholars studied value-generating market interactions between firms and customers, they developed versions of explanatory frameworks to account for all effective modes of industrial productivity as fundamentally conforming to a resource-based theory of competition (Hunt & Morgan 1995) and a service logic (Grönroos 2000). The service logic emphasises a series of strategic shifts in the way firm operations are conceptualised: from value-added to value co-creation; products to experiences; value delivery to value propositions; and exchange of operand (e.g. tangible, economic) to operant (e.g. intangible knowledge, skills) resources as fundamental (Vargo & Lusch 2006; Lusch & Vargo 2006; Vargo 2008). This is because value generation through service-for-service interactions entail the proficient deployment of resources for integration between actors in an ecosystem (Hibbert et al. 2012).

Although the ambition to develop grand or general unifying theories of value generation following a S-DL (Vargo & Lusch 2004) as the normative explanation for all market interactions may yet be contested as adequately explaining what occurs in practice (Winklhofer et al. 2007), there is an equally all-encompassing theoretical perspective that might be more intuitively acceptable. This is that most people in contemporary globalised contexts are constantly being subject to, surrounded by and form part of a nexus of service environments all of the time (whether they are aware of them or not) (see Bitner et al. 2008). Evidence of constant innovation in service designs, moreover, are suggested to bring with them the possibility to establish novel ways for people to interact in order to satisfy formerly unknown and heretofore unrealisable demands via access to services (Ng 2007). In many ways, a service-dominant understanding of the way we live now is both compelling and relevant as a way of engaging with the study of social interactions, particularly as they relate to the provision and consumption of services.

3.3 Self-service technologies

An emergent specialist area of service research focuses on the study of technology-based self-services as potentially creating disruption in the demand and expectation for innovative multi-interface service designs. In light of the ambiguous ontological status of telehealth due to conflicting and competing discourses described in Section 2.3, it is reasonable to argue that some latitude in its conceptualisation and study in order to synthesise previous knowledge and undertake its theoretical refinement is both relevant and necessary. Therefore, this section considers telehealth as a self-service technology (Dabholkar 1999).

The following section provides a concise review of concepts and understandings from the SST literature which is instrumental for conceptualising telehealth as a service that is contextually embedded within the wider healthcare service experience. Insights from this literature contribute to a theoretically-grounded conceptual framework for the study of patient experience of telehealth.

The increasing use of technology to mediate interactions between firms and customers was described by Parasuraman (2000) to herald a new conceptual model of services marketing. The 'pyramid model' (Figure 3) highlights the new path of interactions between customers, company and employees. One form of mediating technology is the use of semi-automated technology by customers to interact in a particular way with services, which has resulted in the growth of multi-interface, multi-channel services which creates a more complex service blueprint for providers that use them (Patricio et al. 2008). By extension, the consequent complexity is equally pertinent to service users.

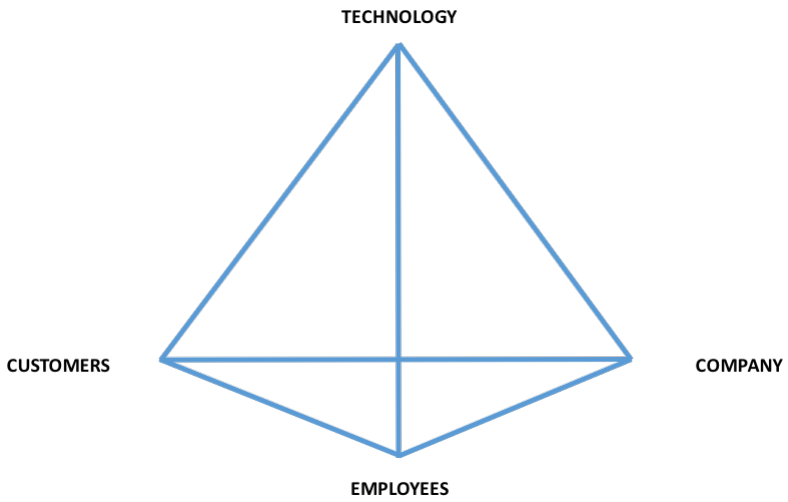


FIGURE 3 THE PYRAMID MODEL OF SERVICES MARKETING (Parasuraman 2000)

Early literature on SST (Dabholkar 1994, 1996, 1999) explains some effects of service providers introducing self-service technologies, (e.g. banking cashpoints, retail self-checkout, transport self-

check-in, library book self-scanning). From a provider perspective, SSTs are frequently used to contain costs of service personnel by breaking down complex services into simpler, discrete semi-automated tasks. They are structured to introduce constraints to services (and service user interactions) by making users interact with a more narrowly scoped service via 'easy to use' equipment, replacing a proportion of the interpersonal with a technological interface.

The normative managerial argument for their use is that they enable the whole service to respond in a much more customer-centric way. This is because the way the service responds is driven by its reaction to the service user request for service attention, although this response requires that customer needs are presented in a way that is specific and framed to be actionable by the service provider. Introducing service constraints focuses the service interaction with customers, which can lead to efficiencies that make handling volumes of customer demands possible with fewer staff.

The service provider gets to streamline the customer demand by filtering out extraneous requests and irrelevant 'noise'. What results is a form of service delivery that is designed to respond to narrowly scoped forms of customer needs, and allows the strategic organisation of necessary resources to intelligently serve that demand in the most efficient way possible. Because these efficiencies can lower costs for the service provider, they can translate into lower prices for customers. Therefore, research into SST generally suggests that this kind of service is meant to offer advantages to both providers and users (Dabholkar 1996). The self-service user gets added convenience, recognised to be a driver of intention to use and adoption (Dabholkar & Bagozzi 2002), once they have figured out how to use the new technology-based service interface and have changed their expectations about what good service interactions entail in the given situation.

The effectiveness of the SST depends on its design, which must consider the aims of the service provider but also the needs of the technology and the customers.

> The infusion of technology into services has created many opportunities for developing new offerings, but to take full advantage of these capabilities, technology and customer perspectives must be completely integrated into service design and management (Curran, Meuter, and Suprenant 2003; Meuter et al. 2000). […] software engineers must understand customer needs to better design technology solutions (Patricio et al. 2008, p.319).

There is congruency, therefore, between findings in the telehealth and SST literature that research needs to better understand customer need and translate that knowledge to the design community.

Literature from service scholars studying consumers' motivation to use and behaviours related to SST suggests that the technological attributes of the equipment (reliability), consumer differences (demographics, speed, ease of use, enjoyment, effort) and situational influences (convenience, control, privacy, interpersonal interaction, having a right to be served) drive preference to use or avoidance behaviours (Dabholkar et al. 2003). The reference to 'situational influences' includes the

option to use interpersonal services and interacting with employees as an alternative to SST. When Reinders et al. (2008) studied the 'forced use' of SST, or situations when consumers have no other option for service delivery because SST has replaced traditional full-service, they found that forcing consumers to use SST leads to negative attitudes toward the SST and service provider. It is also found to lead indirectly to adverse effects on behavioural intentions. Furthermore, they suggest 'that offering interaction with an employee as a fall-back option offsets the negative consequences of forced use' (Reinders et al. 2008, p. 107). Finally, they found that having prior experience with SST in general leads to more positive attitudes to SST when offered, which can offset the negative effects of forced use to an extent.

Therefore, it is suggested that a combination of SST and full-service channels might be the best option for positive customer experience. Patricio et al. (2008) suggest that the use of SST and full-service options within a multi-interface service experience should allocate service activities to the interfaces that are best suited to provide the desired experience, defining both channel specialization and integration blueprints. Such a blueprint should leverage what is best about the unique capabilities of each type of service interface, as well as serve as a guide for customers to engage in whichever interface better enhances the overall customer experience. The services should not necessarily replicate exactly what the other offers. In fact, when Ostrom et al. (2014, p.54) studied customer encounters with SST, they found that 'customers were clearly most satisfied when they received unique benefits from SST that they perceived were not available from traditional interpersonal service-delivery alternatives'.

In order to develop the knowledge about SSTs, Ostrom et al. (2014, p. 54) suggests that research applying interpersonal service aspects that are understood to influence customer satisfaction are needed in SST studies. Examples cited include service recovery, the importance of customization ('flexibility', 'adaptability', and 'bending the rules') and spontaneous delight ('special extras') as primary sources of customer satisfaction (Bitner et al. 1990).

Service recovery is defined as the actions taken by an organisation in response to a service failure (Grönroos 1990) and it is understood that the firm's response can either reinforce a customer bond or transform a minor glitch into a major incident leading to disenchantment (Dong et al. 2007). Gronroos (1990) describes the two dimensions of service recovery as outcome and process. Outcome is the technical dimension and refers to what is done (e.g. recompense) to rectify, amend and restore losses incurred after the failure. Process is the functional dimension concerned with how it is done. Both influence customer perception. In order to update the service recovery concept in light of the importance of customer participation in value co-creation, it is important to see it in terms of customer co-created service failure and recovery (Dong et al. 2007). In relation to SSTs, scholars recognise that customer reactions to and attributions for SST failures include blaming

situations, processes and technology design, as well as customer-driven factors, such as acknowledging mistakes made (Meuter et al. 2000). Further research into the role of service recovery in the context of SSTs is still needed (Ostrom et al. 2014).

> For instance, what is the role of service recovery in the context of SSTs […] and what characteristics should an effective SST-recovery system have? What roles do/can customer education and learning play in preventing SST failures and satisfactorily recovering from those that occur? Are there steps that retailers can proactively take to minimize potential customer confusion, frustration and resistance to change? (Verhoef et al. 2009: 36).

Verhoef et al. therefore extend the specificity of the SST research agenda to not only consider service recovery in the context of SST but within the holistic customer experience, otherwise SST research will only provide an inadequately 'piecemeal' account of customer experience. For example,

> in addition to the direct effects that SSTs may have on customers' experience, there may be secondary effects through potential changes in employee demeanour and behaviour. […] Moreover, the choice between SST- and employee-based service systems is characterized by potential conflicts from both cost and customer-experience perspectives. (Verhoef et al. 2009: 36-7).

The review of the SST literature is salient for a patient-centred telehealth study for several reasons. Firstly, the SST perspective enables an overview of telehealth as a technology-based service that avoids the provider-dominant framing from the patient experience healthcare literature because it is poised to consider of central importance the user attributes as requirements for the service to work, and how it relates to perceived unique benefits emerging that are differentiated from expectations from a full-service or other channel experience. Users are understood to integrate their own personal resources (e.g. preferences, experience, intention, ways of calculating value) that interact with a physical touchpoint representing provider assumptions about what can be stripped away to reveal the critical elements of the service they provide. In other words, it can 'test' assumptions about similarity between what patients and providers value.

Because an SST user's interactions with the service are literally bounded by the design of the human-machine interface in ways that users may not be aware of or understand (e.g. technical or strategic designs that enable or constrain their use), adopting an SST perspective addresses the critique of patient-centred telehealth and self-management studies grounded in social psychology models which are argued to be too voluntarist and involve rationalist or predominantly cognitive processes in their assumptions regarding self-determined social identity or self-categorisation theories (Champniss et al. 2016), without accounting for structural mechanisms of behavioural control and influence about which they may be unaware. Similarly, an overly deterministic approach to understanding the user experience and value that emerges from SST, as a structured service interaction that is designed deliberately to introduce service constraints and thereby limits

scope of process outcomes, is also more nuanced by the literature showing provider identified benefits and actual user benefits may diverge due to potentially conflicting goals for use, such as value from avoidance of service interaction rather than fostering loyalty with the service provider. Conflicts in perceived benefits of use may signal divergent value systems. They may also signal social structural mechanisms that do not conform to broad brush sociological assumptions about the way structures influence individual behaviours.

As an SST, telehealth can be understood to generate value for providers and users although the dimensions of emergent value may not be in alignment and may reflect potentially divergent value systems. By reviewing the literature on the customer experience of SST, we see the importance of equipment attributes as well as consumer and situational factors as drivers for preference to use or avoidance (see also Mick et al. 1998). The literature considers different aspects of the relationship between SST and full-service channels within a multi-interface, multi-channel service, suggesting there may be strong preferences for one over the other as they contextualise the options against each other, and that forced SST use may bring negative responses, therefore the availability of a choice to combine the two may be the best blueprint for positive consumer experience. As a relatively recent area of service research, the literature suggests widening and deepening our understanding of the role of SST in consumer experience in relation to other conceptual frameworks, particularly in service failure, service recovery and the perceived side effects of SST on employee-based service interactions.

3.4 Customer experience

This section briefly reviews the customer experience literature. Scholarship on this approach to explain consumer behaviour contributes to the development of a patient-centred patient experience construct. Customer experience is often linked with SST, as 'scholarly research on the impact of such systems on customers' experiences is still at a nascent stage and much of that research to date has focused on determinants of customers' intentions to adopt and use SSTs…' (Verhoef et al. 2009, p.36). Customer experience aims to identify what a customer thinks about a company, typically using survey data, targeted studies, observational, and 'voice of customer' research in order to 'create fulfillable expectations and better experiences with products and services' that are attuned to customers' needs (Meyer & Schwager 2007, p.4-5). According to the Marketing Science Institute (2016), despite the perception of its importance and large amounts of scholarship on it, the theoretical and substantive knowledge about customer experience remains quite limited. This is due to its complex nature, presenting managers with an overwhelming set of issues and challenges relating to customer experience, and insufficient empirically-based guidance to inform management best practice.

There are two branches of scholarship advancing customer experience as a framework for explaining consumer behaviour as alternatives or complements to rational choice theories (Homans (1961) in Scott 2000). One experiential perspective comes from a psychological school – identifying the stimulus and individual level response, and then exploring multi-dimensional factors (Verhoef et al. 2009). So in combining psychological components and relating them to service components, together they inform a psychological account of individual experiences. These epistemological frameworks have been extended by Verhoef et al. (2009) in order to consider the effects of SSTs within multi-interface services (Patricio et al. 2008) on customer experience.

> The customer experience originates from a set of interactions between a customer and a product, a company, or part of its organization, which provoke a reaction. This experience is strictly personal and implies the customer's involvement at different levels (rational, emotional, sensorial, physical and spiritual). Its evaluation depends on the comparison between a customer's expectations and the stimuli coming from the interaction with the company and its offering in correspondence of the different moments of contact or touch-points (Gentile et al. 2007, p.397).

Related to this school is the social-psychological approach, which includes self-determination (Ryan & Deci 2000), social identity (Tajfel & Turner 1986), and self-concept and self-categorization (Hogg & Turner 1985) theories which attempt to explain consumer experiences and behaviours as influenced by the interplay of intrinsic and extrinsic motivations and potentially related to social group membership (Champniss et al. 2016). These individualist approaches assume a level of consumer awareness about their individual position in the midst of social factors, and seek to elicit information about their decision-making processes.

The second branch of customer experience scholarship is known collectively as applying Consumer Culture Theory approaches. These studies focus on the interaction between agentic individuals and cultural contexts. The aims of this anthropology-based sociological scholarly project are to decentre economic and psychological explanations for consumer behaviour (Arnould & Thompson 2015) by highlighting how consumption experiences are influenced by socio-cultural factors. Individual accounts of experience are theorised interpretively as signs of wider cultural and collectively experienced phenomena. Therefore, by conceptualising consumers as actors situated within cultural contexts, they assume a constructivist ontology, where actors construct contextually meaningful value (Venkatesh & Peñaloza 2014) from their enactments as a result of their interactions with the cultural contexts of consumption that precede them and of which they are an active constituent part (Schouten & McAlexander 1995; Schouten et al. 2007). Therefore, their definition of customer experience extends the scope of consumption beyond the act itself to consider antecedent and post-interaction consumption experiences as dimensions (Belk 1988; Belk 2010).

Both schools have applied theory to explain consumer experience in ways that are managerially insightful but differ in their account of the ontology of customer experience in relation to context as a social actor. As with patient experience, customer experience is wide-ranging, ambiguous and difficult to manage.

> [Companies] must gain an understanding of the customer's journey – from the expectations they have before the experience occurs to the assessments they are likely to make when it's over. Using that knowledge, companies can orchestrate an integrated series of 'clues' that collectively meet or exceed people's emotional needs and expectations. *The internalized meaning and value the clues take on can create a deep-seated preference for a particular experience* – and thus for one company's product or service over another's (Berry et al. 2002, p.85, my emphasis).

With either approach, the concept of customer experience is comprised of internal and subjective responses that customers have 'to any direct or indirect contact with a company. Direct contact generally occurs in the course of purchase, use, and service and is usually initiated by the customer. Indirect contact most often involves unplanned encounters with representatives of a company's products, service or brands and takes the form of word-of-mouth recommendations or criticisms, advertising, news reports, reviews, and so forth' (Meyer and Schwager 2007, p. 118 in Verhoef et al. 2009, p.32). Customer experience is a holistic construct involving 'the customer's cognitive, affective, emotional, social and physical responses to the retailer. This experience is created not only by those elements which the retailer can control (e.g. service interface, retail atmosphere, assortment, price), but also by elements that are outside of the retailer's control (e.g. influence of others, purpose of shopping).' (Verhoef et al. 2009, p.85). Notably, despite the influence of multiple environmental factors, within an experiential perspective, consumers are understood to possess agency as actors and producers of their consumption experiences, rather than passively reacting to stimuli (Carù & Cova 2003).

The social psychological approaches are discounted because they are not equipped to consider structure and agency. However, applying CCT's concept of experience enables a more consistent treatment of patient experiences as the result of constructivist interactions, or agency. This approach invites further scrutiny of detailed micro level interactions at the level of a person in context, as opposed to moving immediately toward scalar understandings of collective experience which assume that interactions are effectively managed behaviours, i.e. predicated upon stimuli in service designs, clinician prompting, environmental cues. The experiential account in CCT delves beyond the individual level to suggest individual enactments matter to social fabrication. In adopting a structuration lens (Giddens 1984) CCT scholars argue that consumer agency is not only implicit in interpreting cultural signals (see Graeber's (2001) anthropological account of meaning making and the emergence of contextualised value) at the individual level toward the construction of individual value but also can be theorised to the meso and macro level to explain the construction of emergent

markets that serve changing demand signals as a result of consumption activities (Venkatesh & Peñaloza 2014).

Customer value, therefore, is argued to be contextualised to culture (Akaka, Schau, et al. 2013) at many levels of analysis. Within this understanding, services are a component of cultural interactions, where their role is to provide clues that customers then pick up on and use. Clues are emitted by things ('mechanics') and people ('humanics') and are just as important as those clues that are related to functionality, which customer experience scholars believe are interpreted by the logical circuitry of the brain. Other clues relate to emotions and the sensory attributes of the good or service and the service environment. Furthering the argument against an economic model to explain consumer behaviour, scholars from the experiential perspective suggest that, 'Customer value can't be reduced to functionality versus price. Instead, it is composed of both the functional and the emotional benefits customers receive minus the financial and the nonfinancial burdens they bear' (Berry et al. 2002, p.86). Therefore, one benefit of considering the customer experience concept is that the focal consuming actor is laden with many levels of experience, action, and choice based on preference, and value is subjective according to the consumer's interactions with a wider cultural context of consumption. In other words, customer experience is a concept that assumes consumers have agency which is affected by more complexity than that described by rational choice economic models.

Straightforward application of customer experience as a conceptual framework in empirical studies is challenging for several reasons. According to Palmer (2010), critics of customer experience suggest that it is frequently linked to the measurement of 'quality and satisfaction [which] have been criticised for bias towards cognitive rather than affective outcomes, although it has been acknowledged by some (e.g. Rust and Oliver, 1994) that customer satisfaction is a cognitive or affective reaction to a single or prolonged set of service encounters. Satisfaction, therefore, is alternatively defined by Getty and Thompson (1994) as 'a summary psychological state experienced by the consumer when confirmed or disconfirmed expectations exist with respect to a specific service transaction or experience' (Palmer 2010, p.199). These debates show that the link between customer experience and satisfaction is slippery due to lack of consensus about underlying constructs. Another challenge is defining the focal phenomenon of interest, as Palmer (2010, p.199 my emph.) argues that

> amidst the debate about the delimitation between service quality and satisfaction constructs is the question of *what constitutes an 'event' or series of events that are the focus for measurement*. The satisfaction literature has acknowledged the cumulative effects of exposure to sequences of service processes and outcomes, but delimiting a customer experience poses further conceptual and measurement problems.

In this research, the issue of whether to focus upon an event or cumulatively at a series of events to analyse all customer touch points is relevant. As discussed in Section 3.1, research based on patient experience questionnaires are often criticised for this ambiguity. In healthcare, where there are so many touch points that may bear relatively scant structural relationship (e.g. diagnosis of gastric flu preventing scheduled eye treatment) to each other apart from the individual experience – and where the 'customer' may be unconsciously engaging in many different touch points – and also where dissatisfaction with a 'negative service' potentially means more complex things (such as whether they agree with biomedical diagnosis and treatments and to what degree, etc.) the ability to discern which events are responsible for what customer experience is very difficult to define and evaluate.

Such methodological issues are further complicated by the empirical context of chronic illness service experiences. So, although these 'experiential components' are known to be affected by chronic illness, specifically that they are hampered or stressed by 'life-limiting' illness effects (Lorig et al. 1993), there is insufficient customer experience scholarship on vulnerable, marginalised and disadvantaged consumers (Rosenbaum et al. 2015) upon which to build and generalise toward novel theoretical perspectives (Rogers 2011). Healthcare poses a challenge to marketing perspectives, as Berry and Bendapudi (2007) state, patients are unlike other consumers because they are ill which introduces instability and unpredictability as well as a highly subjective individual experience.

Therefore, in translating a marketing approach to healthcare, it is necessary to occupy a middle ground. For example, Gentile et al.'s (2007, p.398) customer experience concept comes from a managerial perspective, and privileges the company with power to 'strategically market in ways that stimulate the senses and the affective system through the generation of moods, feelings, emotions [as well as a] cognitive component concerned with thinking and conscious mental processes,' they also suggest that 'an offering may engage customers in using their creativity or in situations of problem solving.' Drawing on this customer experience concept, it is reasonable to argue that patient experience is neither wholly constructed by patients nor clinicians during interactions, and that it is a co-created experience. However, when Gentile et al. (2007, p.398) suggest that the experience components of marketing strategies are intentional and purposive to trigger certain experiences, we must apply caution because 'normal' responses to the healthcare provider can be affected unpredictably due to illness and keenly experienced by the service user (Mol 2008). Therefore, applying the normative conceptualisation of the customer experience concept to the healthcare context requires adaptation to account for this difference to the focal actors' endowments and the socio-historically structured interactions of the healthcare service which constrain agency.

> As a verb, experience describes a process of learning, leading to learned response, but as a noun emphasises novelty and the lack of predictable, learned response. By incorporating emotions and perceptual distortion over time, customer experience overcomes many problems associated with static, partial measures of service quality [Customer experience has a] *multi-dimensional, situation-specific nature* […] The unique nature of customer experience, which is specific to a customer, at a specific time and location, in the context of a specific event, limits its managerial usefulness for planning and control purposes.' (Palmer 2010: 196, my emph.)

The nature of customer experience, therefore, contains many paradoxes. Although understanding the managerial implications from customer experience research is essential for healthcare providers to understand the multi-dimensional, situation-specific nature of patient experience in order to offer patient-centred services, it is also acknowledged that insights from patient experience may be difficult to integrate into management strategies and practice.

In response, the next section discusses an alternative theoretical framework, the S-DL, which is argued to be a more appropriate framework for reconciling problems that are inherent in trying to integrate patient experience insight into management strategies. This is because it focuses on a resource-based view of processes and outcomes of interactions.

3.5 Service-dominant logic

Having conceptualised telehealth as an SST, and discussed the advantages and limitations of the customer experience concept, this section explains why the theoretical lens offered by a S-DL is an appropriate alternative. This section will explain its critical development and its treatment of the structure and agency dialectic.

3.5.1 Service marketing for firm-value

In light of the importance of services to economic productivity, there was a need to conceptualise how services create firm value. In the 2000s, services were viewed initially as strategic opportunities for enhancing firms' profit-making ability and competitive advantage (Zeithaml and Bitner, 2003). Service marketing theorists took their lead from strategic management literature on the optimisation of ingoing firm resources for value generation and competitive advantage (Hunt & Madhavaram 2006). The resource-based view (RBV) of competitive advantage (Barney 1991)[6] focuses on the management of incoming resources. The RBV suggests a firm's performance

[6] The RBV can be traced to Zimmermann (1951) and Penrose (1959) who first viewed the shifting role of incoming resources to firm performance. Further resource-based theory was developed by Lippman and Rumelt (1982), Rumelt (1984), Wernerfelt (1984), Dierickx and Cool (1989) and Barney (1991, 1992). The centrality of resources to firm performance was also developed in Resource-advantage (R-A) theory (Hunt & Morgan 1997) a general theory of competition describing the process of competition. R-A and the RBV both focus on operant resource allocation and optimisation for sustainable competitive advantage (CA), e.g. through management of endogenous resources like IT and HR competences (POWELL, T. C. 1997. Information technology as competitive advantage: the role of human, business, and technology resources. *Strategic Management Journal,* 18**,** 375-405, HUNT, S. D. & MADHAVARAM, S. 2006. The service-dominant logic of marketing: theoretical foundations, pedagogy, and resource-advantage theory. *In:* LUSCH, R. F. & VARGO, S. L. (eds.) *The service-dominant logic of marketing: dialog, debate and directions*. Armonk, NY: M E Sharp.).

depended not only on the management of tangible, inert, physical goods (or operand resources); it also involved the successful exploitation of intangible, endogenous operant resources (Vargo and Lusch, 2004), such as the firm's 'complex bundles of skills and accumulated knowledge' (Day, 1994, p. 38). Prahalad and Ramaswamy (2000) recognised the role of exogenous customers on firm performance, suggesting that proactive customer involvement in firm processes could be considered an important firm resource. Therefore, firms should co-opt customer involvement for co-production of tailored products and services. Thus, a firm's strategic value creation process should optimise customer involvement. These key works are recognised as highlighting the importance of intangible resources embodied in human resources and capabilities, within and outwith firms.

From these perspectives developed two mainstream service marketing conceptual frameworks. The first was a service logic (SL) capitalising on marketing research between 1977-2004, especially from France and Nordic countries, that challenged a goods-based logic (Gronroos, 2006). The Nordic school of scholars suggested that competitive firms focus their operations on strategic market orientation (Grönroos 1989) because they cannot fulfil services without customers' participation in the creation of outputs of value. They distinguished services from products on the basis of their process nature, where customers participate in open service processes as co-producers, highlighting the need to understand the 'black box' of consumption and interaction, or value creation processes (Gronroos, 2006). The SL was a managerial strategy that attempted to move the marketing perspective from an organisational function to a transformative organisation-wide attitude (Grönroos & Gummerus 2014) in order to more clearly direct firm strategy.

By contrast, scholars from the North American school are credited with the conceptual development of a related framework: the S-DL (Vargo & Lusch 2004), whose later iterations worked to remove the divide between producers and consumers by viewing them both among a network of generic service ecosystem of actors (Akaka, Schau, et al. 2013).

S-DL aims to provide the foundations of a general theory of markets and marketing (Storbacka et al. 2016) based on systematic value co-creation and service-for-service exchange (Akaka et al. 2015). This perspective led to an alternative explanation of market interactions that was distinct from that embodied in goods manufacturing logic of value generation (Vargo & Lusch 2004; Vargo & Lusch 2004b). Service is the application of competencies for the benefit of others – the basis of all exchange (Vargo & Lusch 2004; Vargo & Lusch 2008). It takes a more inclusive view of stakeholders as social and economic 'actors' who exchange service and integrate (primarily intangible and dynamic) resources (knowledge, skills) in efforts to create value for themselves and for others (co-create value) they call beneficiaries (Vargo & Lusch 2016).

Whereas the SL is managerially oriented, suggesting that all firms should follow a service logic for competitive advantage, by highlighting operational 'spheres' of firm-customer interaction as

providing differentiable managerial foci (Grönroos & Voima 2013), the S-DL aims to advance a 'service perspective on an aggregate, societally oriented level' (Grönroos & Gummerus 2014, p.207). Although initially couched as a response to goods-centred marketing conceptualisations that historically define services as unproductive activity and 'not goods', the attention given to S-DL helped services emerge from a subgenre to the most influential marketing approach (Gummerus, 2013). The adoption of a service orientation, or S-DL, enables all firms to approach customers as service firms. The S-DL says that goods facilitate services, which are defined as

> the application of specialised competences (operant resources – knowledge and skills), through deeds, processes and performances for the benefit of another entity or the entity itself (Vargo and Lusch, 2006b, p. 43).

This definition is developed from an evolving list of foundational premises and axioms (Table 4) central to the S-DL approach to business and marketing (Vargo & Lusch 2004a, 2006b, 2008, 2016). Vargo and Lusch (2004a) worked up the concept of services positively, eventually redefining all economically productive firm activity as service-related (FP5), designating the subordinate position of goods as appliances that facilitate service (FP3), and elaborating a normative approach for all marketing as ideally informed by a S-DL (Vargo and Lusch, 2006b). In order to derive optimal firm performance, they assert that it is necessary to reposition the scope of firms' economically productive activity beyond the idea of value-added manufacturing and economic transaction (or value-in-exchange) (FP7), and acknowledge that firm value is realised only when their customers realise value from their offer (or value proposition) (FP7). Therefore, the firm should be responsive to the value co-creation process that their customers contribute as it is inherent to the realisation of firm value (FP6). For sustainable competitive advantage, firms should focus on establishing that customer relationship (FP8).

TABLE 4 EVOLUTION OF THE FOUNDATIONAL PREMISES AND AXIOMS OF SERVICE-DOMINANT LOGIC (ADAPTED FROM VARGO AND LUSCH 2016)

Foundational Premises of Service-Dominant Logic (* denotes axiom status)	
FP1*	The application of specialized skill(s) and knowledge is the fundamental unit of exchange (2004). Service is the fundamental basis of exchange (2008).
FP2	Indirect exchange masks the fundamental basis of exchange.
FP3	Goods are a distribution mechanism for service provision.
FP4	Knowledge is the fundamental source of competitive advantage (2004). Operant resources, especially know-how, are the fundamental source of 'competitive advantage' (2008) [changed to 'strategic benefit' (2016)].
FP5	All economies are service economies (2004).
FP6*	The customer is always the co-producer (2004). The customer is always a co-creator of value (2008). *There is no value until an offering is used – experience and perception are essential to value determination*. Value is cocreated by multiple actors, always including the beneficiary (2016).
FP7	The enterprise can only make value propositions (2004, 2008). *Since value is always determined by the customer (value-in-use), it cannot be embedded through manufacturing (value-in-exchange)*. Actors cannot deliver value but can participate in the creation and offering of value propositions (2016).
FP8	A service-centred view is inherently customer oriented and relational (2004, 2008). *Operant resources being used for the benefit of the customer places the customer inherently in the centre of value creation and implies relationship*. A service-centred view is inherently beneficiary oriented and relational (2016).
FP9*	All social and economic actors are resource integrators (2008).
FP10*	Value is always uniquely and phenomenologically determined by the beneficiary (2008).
FP11*	Value cocreation is coordinated through actor-generated institutions and institutional arrangements (2016).

3.5.2 Consumer-value perspective

S-DL emphasises the consumer role and draws on the concept of the consumption experience as a result of consumer resource integration processes (Baron & Harris 2008). The role of consumers as 'interpretive agents rather than passive dupes' (Arnould & Thompson 2005, p.875) suggests that the value they co-create is subjective, and relates to personal projects and life goals (Arnould et al. 2006). Subjective consumer value may be at odds with firm value (Helkkula et al. 2013) and scholars have conceptualised this potential disconnect as value co-destruction (Echeverri & Skålén 2011), although the non-alignment of consumer and provider value systems may be overcome through perspectival adjustment *en route* to greater strategic market orientation (Skålén, Pace, et al. 2015), or through recognition that competing values may be specific to a dynamic interaction context (Skålén, Aal, et al. 2015).

S-DL scholarship has attempted to absorb all of these nuances, despite early iterations of S-DL presenting as a predominantly firm-based perspective, depicting any value realised as beneficial to both firms and customers in value co-creative processes (FP10), and highlighting the need for firms to consider themselves and customers in 'balanced centricity' (Gummesson 2008). Although providers and consumers were a focal dyad, critics suggested there was a questionable imbalance if S-DL described a normative expectation that the customer role includes an obligation to co-produce service processes in order to co-create value (Cova & Dalli 2009; Cova et al. 2011). This

was interpreted as still being firm-led co-production (Schembri 2006). Lusch and Vargo proceeded to adapt the concept of marketing informed by RBV to mean

> the process in society and organizations that facilitates voluntary exchange through collaborative relationships [and creates] *reciprocal value* through the application of complementary resources (2006, p. xvii-xviii, my emph.).

'Reciprocal value' draws upon concepts of mutually beneficial value co-creative relationships also developed in relationship marketing (Alqahtani, 2011), and customer participation research (Dong et al., 2008). Although the concept of reciprocal value is not new, the S-DL claims a contribution to marketing theory by perspectival shifts: from tangible to intangible resources, from the producer to the consumer, and from the thing exchanged to the process of exchange (Lusch and Vargo, 2006). Further clarification was needed, however, as Vargo and Lusch (2016) acknowledge that greatest controversy relates to FP6 which is reflected in the evolution of the language from an earlier firm-centric co-production by customers to value co-creation by actors. Vargo and Lusch suggest conflict regarding the implications of FP6 is down to the interpretation that the meaning of value co-creation is 'normative' rather than 'positive' (i.e. descriptive). They clarify three points: 'the beneficiary is always a party to its own value creation' where the beneficiary is an actor that can be the firm or customer. Firm-led co-production is optional for actors, and the assertion that value co-creation always occurs is a positive description of the process reflecting the interdependency between actors on a massive scale but with the referent beneficiary in the centre, in specialised human systems where

> value is not completely individually, or even dyadically, created but, rather it is created through the integration of resources, provided by many sources, including a full range of market-facing, private and public actors. In short, co-creation of value is the purpose of exchange and, thus, foundational to markets and marketing (Vargo and Lusch 2016, p. 9).

The critical conversation has led its creators to constantly evolve the S-DL, with its current manifestation as an abstract, system-level understanding of generic actors, resources, institutions, networks (i.e. service ecosystems), and processes of value co-creation (Figure 4).

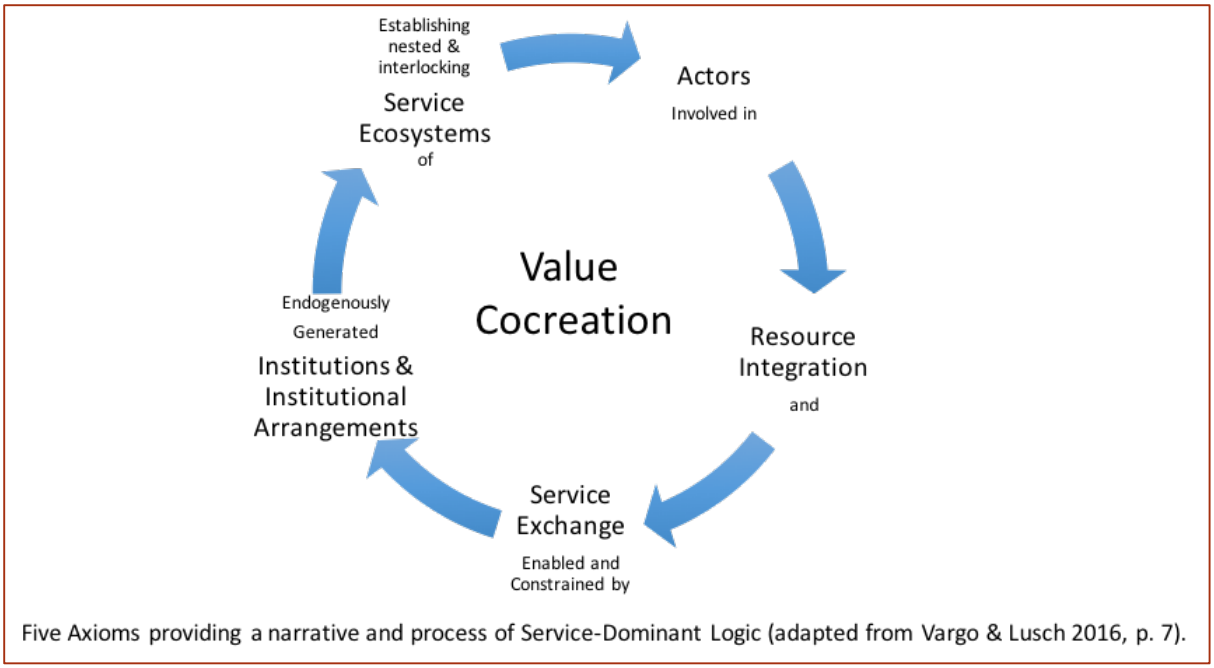


FIGURE 4 FIVE AXIOMS OF SERVICE-DOMINANT LOGIC (ADAPTED FROM VARGO & LUSCH 2016, P.7).

Value co-creation, therefore, is understood to be a process that enables a range of cumulatively coordinated activities among multiple actors to interact in ways that relate to institutional arrangements, and by the same token, the value that emerges must itself be understood as related to that institutional context. Scholars advancing a CCT approach (Arnould & Thompson 2005) to researching consumer behaviour have aligned their work as complementary to S-DL, showing that the RBV can be applied to cultural resources (Arnould et al. 2006) resulting in refinement of the concept of value that emerges from co-creation, as value-in-cultural-context (Akaka, Schau, et al. 2013). CCT scholars continue to develop perspectives on consumer engagement with institutional concepts, from the anthropological tradition, as cultural contexts, and commonly refer to these cumulatively coordinated activities of value generation as meaning-making processes (Graeber 2001; Venkatesh and Penaloza 2014). These scholars explain that consumption experiences are evaluated and value is determined (Peñaloza & Mish 2011) because they are simultaneously individual and phenomenological experiences that are embedded in stratifications of cultural meaning (Askegaard and Linnett 2011; Karababa and Kjeldgaard 2013).

3.5.3 Ethics and S-DL

By paying heed to the agentic power of the individual consumer as centrally important (i.e. they integrate resources in order to interact in value co-creation processes), advocates claim that S-DL is more ethical (Abela and Murphy, 2008) because it is an improvement on firm-centric goods-logic marketing – which locates value generation processes within firms' manufacturing and R&D phases

(e.g. value added to raw materials). Its advocates argue that market-oriented firms following the S-DL approach are normatively more inclusive of the interests of external stakeholders as beneficiaries since it acknowledges the importance of good quality relationships with customers, and relationships are recognised to transcend a purely transactional and time-limited customer interface. As a normative approach to marketing (Winklhofer et al. 2007), S-DL advocates that firms take customers' preferences and perceptions of value to the heart of firm processes and competitive strategies, making the market truly reflective of and responsive to customer wants and desires (Bastiat, 1860).

However, many critics highlight the uneven distribution of benefits accrued from value co-creation processes, asking how it is ethical to ask customers to work (i.e. co-produce) as well as pay? Doing so leads to risk of double exploitation. The first form of exploitation is as unpaid labour. The second results in increased customer vulnerability to lock-in leading to exploitation through premium pricing and high switching costs (Prahalad & Ramaswamy 2004). This is because co-production with specific firms to customise service effectively decreases the market of available alternatives (Cova and Dalli, 2009, Cova et al., 2011). However, there is evidence from crowd-sourced innovation, particularly in software development, that there are benefits to customer value co-creation felt by customers (Blazevic and Lievens, 2008), although wider social effects from firms' exploitation of unpaid labour continue to be a concern (Kleeman et al., 2008).

Another concern is the FP7-paradox, which limits a firm's contribution to offering value propositions only. This could absolve firms of responsibility for ensuring downstream value creation from their products and services. Gronroos (2006, 2012) argues that the Nordic School's SL more consistently encapsulates a firm's duty to ensure value is created for customers, which is above and beyond the S-DL's normative notion that firms are only responsible for making promises through value propositions (Vargo and Lusch 2004, 2008). Although the latest evolution of S-DL does not address this directly, Vargo and Lusch's (2016) newest FP11, regarding the role of institutions and institutional arrangements to enable and constrain conditions of value co-creation, relates to this issue. A firm's intentions to ensure customers co-create value may be impossible due to wider socio-political institutional arrangements creating characteristics of service ecosystems that may make it difficult for firms (or generic actors) to ensure such value is co-created for other generic beneficiaries.

With reference to their earlier work, however, Lusch and Vargo (2006) referred to service interactions as 'endogenous environments' or potential operant resources. The thesis understands this to be the case because they provide a context of micro-institutional affordances (van Dijk et al. 2011) where resistance can be exploited as opportunities by actors in ways that enable subjective value to be produced despite wider institutional constraints within the exogenous environment

(including the political, economic, social, technical and legal environments that are largely uncontrollable marketing constraints) (Baron & Harris 2008).

This body of work highlights how consumer resource integration can form part of new institutional formation or transformation of existing institutions. Although scholarship linking consumer experience and S-DL generally refer to Giddens' structuration theory as a way to introduce a practice perspective to understand cultural value-based market formation (Peñaloza & Mish 2011; Akaka, Schau, et al. 2013), Chapter 4 of this thesis will argue the case for applying a realist perspective of morphogenetic transformation to deliver a more specific and granular investigation of consumer resource integration for value co-creation within highly structured endogenous and exogenous healthcare services environments.

3.5.4 Value definitions

Although the prominence of the firm-perspective is present in both S-DL and SL streams, the service logic more consistently makes explicit appeals to ensuring that value creation from the customer perspective occurs. The debate itself has brought the need for research to define what that value entails and how it is created to the fore (Woodruff and Flint, 2006). According to S-DL, value is uniquely and phenomenologically determined by the beneficiary (FP10) and it is understood that beneficiaries, or actors, interacting in a service ecosystem during value co-creation may be co-creating differently determined forms of value at the same time (Helkkula et al. 2013). The concept of customer value in terms of utility to consumers (*value in use*) predates Adam Smith's (1904) instrumental conceptualisation of *value in exchange* to denote exchange of tangible outputs with embedded utility, or value-added (exchange value) (Lusch and Vargo, 2006). Recent service marketing literature advocates a return to view of *value in use* (potential or actual usefulness perceived by the consumer: *ibid*) although latterly, this has, when zooming out (Leroy et al. 2013), been shown to have a close link to the structures wherein that individual value-in-use resides and experience is evaluated collectively (Helkkula et al. 2013). This collective, social or cultural dimension to evaluation of experience has been defined using *value in context* (Chandler and Vargo, 2011), *value in social context* (Edvardsson, Skålén, et al. 2011), and *value-in-cultural-context* (Akaka et al. 2015) constructs, each of which elaborates a framework for understanding the manifold contextual forces that enmesh to inform value determinations.

In these value concepts, both structure and agency are accounted for. They assume consumers are actively involved in realising value from the value propositions offered by firms, through the integration and use of personal and network resources (Arnould, 2008, Arnould et al., 2006). Because the relative contributions required of firm and customer in each instance are dynamic (Gronroos and Ravald, 2009), the process of value co-creation is highly influenced by customers' subjective, personal experience (Prahalad and Ramaswamy, 2000, 2002, 2004) and the influence

of context at individual and structural levels exerting influence on customer behaviours. S-DL and CCT scholarship use structuration theory (Giddens 1984) to explain the ontology of value from iterative interactions between structures and consumers as agents (Chandler & Vargo 2011; Arnould & Thompson 2005).

A framework of competing value from the study of public healthcare systems in Finland was developed by Helkkula et al. (2013) to depict the intersection of differently determined value according to calculated (e.g. organisational or public health econometrics) or subjectively experienced value, and how these two categories are prioritised according to favoured evaluation measures (preferred and non-preferred). These four domains distil the depth perspective of macro, meso and micro level interactions to show how value co-creation is contingent on the framing of value as either calculated, or subjectively experienced and evaluated, and that these also have an impact on each other -- presumably because the healthcare service organisation is a learning and adaptive system. Figure 5 depicts the intersection of non-aligned value determination systems affecting each other, to show how value is subject to trade-offs as changes in calculated priorities or subjective experience are introduced and observed empirically to shift the value emerging from one domain to another. The authors suggest that NW and SE quadrants are areas for managers to focus on encouraging value co-creation.

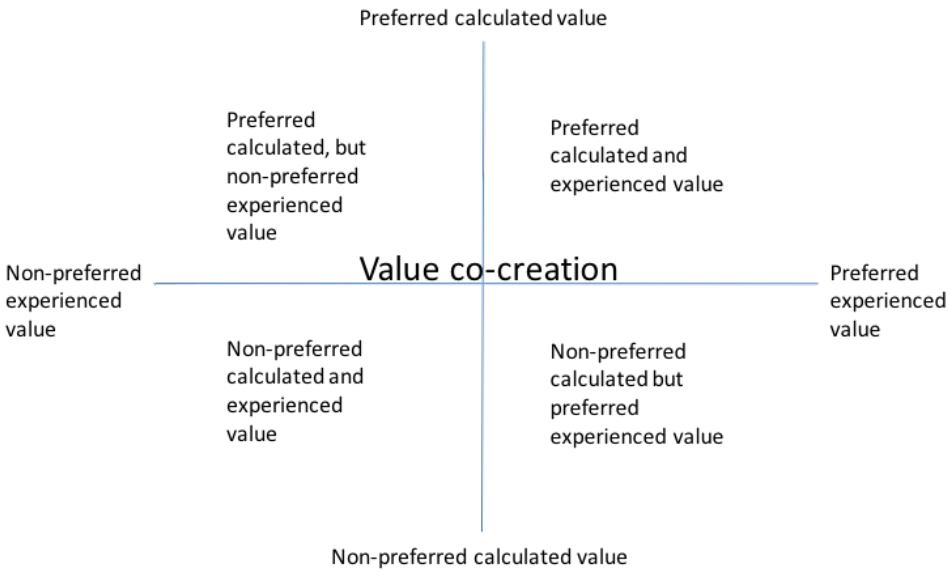


FIGURE 5 VALUE CO-CREATION ALIGNMENT FRAMEWORK (ADAPTED FROM HELKKULA ET AL. 2013, P. 6)

In summary, the literature shows that it is widely accepted to integrate S-DL and CCT theoretical approaches because they share many philosophical and theoretical underpinnings. For the purposes of this research, they are able to contend with the analysis of telehealth service experience in a way

that accords with dynamic and potentially competing value systems. The literature provides a conceptual framework for patient agency in subjective value determination, while also recognising that value may be differently determined by other actors in the service ecosystem. These actors may be part of the endogenous environment or the exogenous environment, although distinguishing between the two may be difficult. It is reasonable to argue that these conceptual frameworks are well equipped to consider healthcare consumer roles which are transitioning from the traditionally passive 'sick role' (Parsons 1951) toward a more consumerist approach to healthcare (Lupton et al. 1991; Lupton 1997; Sulkunen 2009). Meanwhile, significant system level change is suggested by healthcare policy and implementation of novel technology-based service channels that introduce and must contend with pre-existing forms of value related to the biomedical research culture (Engel 1978) or another organisationally framed concept of value.

3.5.5 Mapping the consumer's value co-creation process

This section describes how studying patient experience of telehealth can be approached using a consumer value co-creation perspective. Whereas extant approaches tend to blur the differences between provider and patient value, adopting this approach can clarify the process of creating patient value and explain how it is determined by the patient in context. We begin by explaining how patients are understood to participate in the emergence of subjective value and then describe the underpinning consumption process as requiring the consumer to integrate resources in order to derive value from a service's value proposition.

Marketing scholarship has established our understanding that the role of the consumer in realising service delivery is inherent in the characteristic inseparability of production and consumption. The consumer's individual traits and attributes also appear in the variability of service design, making service experiences highly subjective (Prahalad and Ramaswamy, 2004). The role of the consumer was developed in research on customer participation, which is concerned with mobilising customers to undertake altered roles within the transaction process. Customer participation is 'the degree to which the customer is involved in producing and delivering the service' (Dabholkar, 1990, p. 484). According to Dong et al. (2008) customer participation research evolved first from considering why and how customer participation in firm activities can result in economic benefits for the firm.

Research then considered how customers could be managed and socialized to act as 'partial employees' of the firm in co-production processes, and how this results in increased customer satisfaction. These perspectives implicitly led to firm-dominance, normatively capturing consumers as resources within their co-production processes. Co-production is defined as a form of customer involvement that is much more central to service production as it emphasises a firm-centric view (Chathoth et al. 2013) focusing on value-added processes pertaining to the firm's value creation activities in the form of scripted roles absorbed by customers (Normann & Ramirez 1993). The

value of telehealth services according to extant literature that studies organisational and professional perspectives can be conceptualised in terms of patients co-producing a value-adding (Holbrook 1994) innovation from the firm perspective in that value from telehealth focuses on its potential contribution of value to the health service in terms of materials, labour and service configurations for healthcare service efficiency. This perspective tends to overestimate how well managers (i.e. professional and organisational telehealth users) understand the ways in which customers (i.e. patients as service users) view the offering relative to their needs and use situations (Woodruff & Flint 2006).

Developments in service marketing theory enlarge the importance of the customer value-creative process to firms' strategic decisions about resource optimisation for sustainable competitive advantage (Hunt and Madhavaram, 2006) but also to consideration of what the consumer does with services in their own life spheres in terms of value creation and value outcomes (Gummerus, 2013). This is evident in a third stream which considered the motivations for customers to participate in co-creating services as somehow distinct from the firm's view of value creation, suggesting 'we know very little about the process of value creation when it starts, what it includes and when it ends" (Grönroos 2011, p.282). Scholars began describing a process that is 'driven by value-in-use but mediated and monitored by value-in-exchange' (Vargo & Lusch 2008, p.150) which suggests value-in-use is consumer value, and value-in-exchange is firm value in which the consumer also participates as a value determinant. The literature acknowledges that 'it is unclear how actors other than firms participate in value co-creation processes' (Akaka & Chandler 2011, p.250).

> What kind of activities and process elements constitute the value co-creation process? What kinds of resources do the seller and the buyer contribute to value co-creation? (Aarikka-Stenroos & Jaakkola 2010).

These distinctions between buyer and seller perspectives of value and value determination processes outline a research agenda focusing on the need to identify the interests of consumers (see also Heinonen et al. 2010; Heinonen et al. 2013) to explain how consumers co-create their own subjective value, in which firms are assumed to participate as value determinants during various stages of the consumption process (Grönroos & Voima 2013) in ways that are perceived to be relevant to consumers, which refers to a firm's market orientation (Grönroos 1989).

3.5.5.1 Maintaining co-production and co-creation as distinct processes

As previously explained, different patient and provider perspectives can be assumed to apply different determinants of value, leading to dissimilar value definitions. In healthcare services, customer or patient value is assumed to be a component of provider value, although this assumption is disentangled within the literature review.

Although we can assume there is some overlap because a fit and healthy healthcare service is also of benefit to patients, the thesis argues it is analytically useful to separate provider and patient value in order to clearly conceptualise the patient perspective. One way of doing this is to distinguish between provider and patient value according to whether the interactions that underpin the telehealth service conform to the definition of co-production or co-creation. These terms are often used interchangeably (Payne et al. 2008) and they both revolve around the understanding that customers participate in the production and consumption phases in order to derive benefit or value (Etgar 2006; Etgar 2007; Vargo 2008; Akaka, Schau, et al. 2013). However, co-production in this thesis is explicitly used to nuance the service interaction in a way that suggests provider value ontologically frames the process and output, and dictates the extent that they are perceived to be valuable or not. Co-creation, therefore, is used to highlight a distinctive form of patient participation in the service because it is subjectively judged according to the patient's ontological framing of the service experience and its outcome. This means a positive service outcome must be recognised by a patient to be subjectively valuable.

The importance of the relevant actor's perspective is described in the refinement of the value construct as value-in-context (Chandler & Vargo 2011) which aims to sufficiently conceptualise individual practices and service interactions within the context of relevance to the focal actor, which is the patient perspective in this thesis. Value-in-context acknowledges the social construction of patient value in relation to the healthcare services, and the structuration of co-creation processes through institutions (Edvardsson et al. 2011), including the social construction of technology as an operant resource through its use (which will be explained in Section 3.5.6) in service ecosystems (Akaka & Vargo 2013). These suggest that patient value is informed by a cultural perspective of value (Akaka, Schau, et al. 2013) that plays a part in the patient's own subjective determinations of value.

3.5.5.2 Customer resource integration

Resource integration is one of the five axioms of the value co-creation process described by a S-DL perspective (Figure 4). S-DL's theoretical grounding in resource-based theories of competitive advantage, mean scholars conceptualise consumption in terms of resource integration (Arnould et al. 2006). As the S-DL's contribution was to view the customer endogenously within a focal dyadic relationship critical for firm value generation, the aim was to clarify the contributions of firms and customers to the emergence of value. Further refinements described how both resources and value determinations are derived from a customer's personal contexts which both enable and constrain the process and outcomes which relate to how a customer accesses necessary resources for integration to support the co-creation of value (Arnould et al. 2006; Hibbert et al. 2012).

Although the designation of customers and firms (and their resources) were eventually replaced by purposely abstract and implicitly democratic terms such as generic actors and beneficiaries (Vargo & Lusch 2016), the literature encourages researchers to identify specifications for particular actors in particular contexts in order to establish boundary conditions for the validity of S-DL as a mid-level theory of value generation. Empirical research is needed to provide an understanding of value co-creation in context, and thence the context of context (Askegaard & Linnet 2011) 'to consider any actor (human or non-human) within a close context of co-creation practices and a broader context of history and place (understanding the geographic context) of relationships between an organisation, its stakeholders and any other elements at stake in the co-creation process.' (Leroy et al. n.d., p.9).

In order to explain customer resource integration, Arnould et al. (2006) provide a unifying conceptual framework based on social structuration theory (Giddens, 1984) which describes the close interaction of operant and operand resources and how they shape consumers' goals and life projects (Sewell, 1992, Swidler, 1986). It describes a process of resource integration by customers where they can view the firm, marketplace and culture as resources to draw upon for support. This is described as engagement through authoritative and allocative acts to deploy salient resources for the achievement of life goals and projects. The firm's and consumers' own personal and network knowledge (FP1 and FP4) and relationships (FP 6-10) converge in order to

> co-create value through patterns of experiences and meanings embedded in the cultural life-worlds of consumers […] through the deployment of consumer operant resources, consumers engage brands and organizations to co-create value in interactive and sometimes unanticipated ways (Arnould et al., 2006, p. 100).

As Arnould et al.'s consumer resource integration framework (Figure 6) maps the physical operant resources alongside other key social and cultural operant resources, it is applicable to the shifting operant resources accessible to chronic disease patients and shows a conceptualisation of the value-creative resources at the disposal of consumers in order to explain how they interact with firm resources agentically rather than passively.

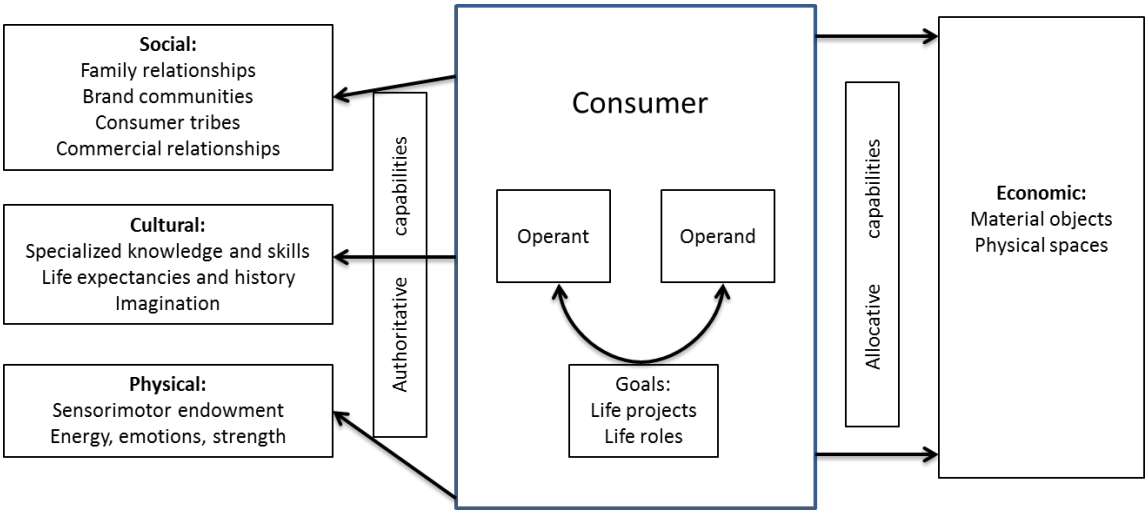


FIGURE 6 THE CONSUMER'S OPERANT AND OPERAND RESOURCES (ADAPTED FROM ARNOULD, PRICE & MALSHE, 2006, P. 92)

On the right side of the map are depicted the consumer's accessible, usually tangible, operand resources, that are typically economic. Consumers possess partial or full allocative capabilities over these objects or spaces in order to carry out behavioural performances relating to their life projects and social roles. These allocative capabilities affect their exchange behaviour and relationship with firms. Consumers' use of their operand resources influence the manner in which they capitalise on the operant resources of firms, i.e. accessing what knowledge, skills and techniques they cannot (or choose not to) source elsewhere. They suggest that operand resources are used by consumers to achieve their goals. Although from the firm perspective, the customer is primarily an operant resource, from the customer perspective the firm is one of a constellation of operant resources available. The left side shows the configuration of operant resources by type that constitute consumers' life projects, social roles and goals, including a changing inventory of social, cultural and physical resources that they can mobilise. These influence how they will deploy firms' operand resources in value creation. According to Arnould et al. physical operant resources are least explored in the literature, which suggests that consumer research is needed to explore the effects of lower than average physical resources, such as limited physical or mental endowment or the effects of illness or disability, on customers' life project, goal strategies and value co-creative processes. This feeds into their critique that research into consumer motives typically relies on cognitivist theories of planned behaviour and goal striving, whereas examination of the interplay between life projects, narratives and roles and consumers' operant and operand resources may be more insightful.

Each of the operant resource types are argued to link to cultural schemas that create an enduring social fabric or context through performative reproduction or enactment of socially generalized

procedures (Giddens, 1984). Such virtual resources include attitudes, beliefs, routines, conventions, traditions, recipes, or habits of speech and gesture. Consumers' social operant resources are networks of social relationships with co-consumers over which they assert authoritative capabilities. In the health domain this can relate to an intuitive understanding of the need to enact the sick role, or the right to refuse treatment and seek alternative opinions authoritatively. Cultural resources can include choosing to follow officially sanctioned knowledge of how to navigate the healthcare services organisation (e.g. calling NHS Direct for advice before booking a GP appointment), or deploying unsanctioned knowledge (e.g. how to use A&E and other acute care services to get treatment and how to get it most efficiently) (Holohan et al. 1976 in Stacey, 1991).

In the telehealth context, cultural resources are key. In provider-led co-production, value is determined through telehealth use as patients act as the firm's endogenous resources, in that they perform tasks at home on behalf of professionals. Taking a consumer perspective enables patient use of telehealth to be viewed exogenously and autonomously, where patients may capitalise on the provider's operand resources (telehealth devices and services) and operant resources (accessible professional knowledge) to co-create value of mutual benefit. This benefit may be of a form that is not officially sanctioned (e.g. strategic non-compliance) but which results in other perceived forms of value (e.g. wellbeing, sense of being in control, satisfaction, less healthcare utilisation). Strategic non-compliance is 'the thoughtful and selective application of medical advice rather than blind adherence to it' (Campbell et al., 2003, p. 680). This suggests patients reference their highly individual experience of illness and quality of life in the calculation of trade-offs involved when considering whether to comply with the treatment, hence they exert authoritative capability over which resources to deploy for well-being. This relates to the use of experiential determinants of value from service interactions (Helkkula et al. 2013).

3.5.6 Technology as an operant resource in service (eco)systems

It is necessary to consider how Arnould et al.'s framework applies to the integration of technology as a material artefact (operand) which embodies and requires the integration of social, cultural and physical (operant) resources in the construction of socio-technical (eco)systems.

Recent S-DL literature has focused on the role and scope of technology in value co-creation processes. Akaka and Vargo (2013) consider two frameworks for their conceptualisation of technology as an operant resource, which they integrate with the S-DL. The first is by Orlikowski (1992) which explains the role of technology in organisations. Her framework considers the dual nature of technology: as an objective material artefact and as a socially constructed product that has the ability to change the structure of interactions between 'organisational agents'. Her 'structurational model of technology' extends Giddens' (1984) theory of structuration, which omits to consider technology. Orlikowski suggests that technology influences and is influenced by

institutions (social norms) as well as the actions, or practices, of social and economic actors (Giddens 1984).

Akaka and Vargo (2013) argue that the scope of technology defined by Orlikowski's model is overly focused on 'material artefacts,' or 'outcome or human actions,' both of which lean toward the category of operand resources in the S-DL framework, and they suggest this limits the understanding of contributory processes that occur in the service ecosystem by which value is co-created and innovation occurs (Arthur 2009). Arthur's explanation of technology's influence on structures, emphasises the dynamic mutability of technologies that deviate from much of the original design intention as a result of usage processes. He suggests technological innovation does not reside in the design stage, but is driven by the purposeful application of knowledge and skills that reflect influential institutional norms, and this helps to explain the use and proliferation of innovative value that is more than the initial purposes of technology design. His perspective, therefore, suggests that defining technology according to the materiality of the technological artefact itself is too narrow. It is possible to see how conceptualising technology as an artefact also references a goods logic, where technology's value is conceived as a provider value-added product, rather than encapsulating the view that products facilitate value co-creation in later consumption stages.

By integrating Arthur's stronger emphasis of technology as socially constructed in the consumption phase, with Orlikowski's framework, Akaka and Vargo argue that technology is an operant resource. Whereas Orlikowski aims to separate outcomes from actions in order to serve her analytical purposes of understanding agency in organisational change through technological implementation, Akaka and Vargo similarly work toward elaborating a conceptualisation of technology that meshes with the ecosystem view of knowledge as a resource which is assembled through simultaneous production and consumption of technology toward value co-creation. This perspective requires a broader view of who contributes necessary knowledge resources. They suggest that knowledge as an operant resource resides in social institutions within a multi-level network of beneficiaries that both construct and are constructed by those institutions. Technology is seen to contribute to value co-creation 'by enabling the sharing of information within and across service systems' (Akaka & Vargo 2013, p.368). Thus, they explain that S-DL's emphasis on operant resources necessarily extends the scope of technology beyond the *output* of human action, toward the definition of technology as a collection of *practices and processes*, as well as symbols (Spohrer and Maglio 2010), that are drawn upon to serve a human purpose (Arthur 2009).

Movement from a dyadic view of providers and consumers to a network of beneficiaries in S-DL underpins its development as a service ecosystems approach (Vargo & Lusch 2011). Therefore, S-DL 'emphasises the dynamic qualities of technology and how it can contribute to value co-creation

at multiple levels – micro, meso and macro – of interaction (Chandler & Vargo 2011). Service ecosystems are defined as 'relatively self-contained self-adjusting systems of resource integrating actors connected by shared institutional logics and mutual value creation through service exchange' (Vargo and Lusch 2011b in Akaka and Vargo 2013, p. 368).

What is implicit in this literature is the treatment of institutions as influencing interactions through a pattern of accepted practices and processes of meaning-making and value generation. For this research, the appearance of social structures as institutionalised symbolic systems clearly applies. Examples of symbols in the healthcare context that are interpreted for value creation include the use of vital signs, which are symbols laden with meaning for clinicians who are expected to use them in evidence-based treatment decision-making processes.

3.6 Conclusion

The integrated review of relevant literatures identifies several gaps addressed by this research.

In order to consider the implications of chronic disease policy on the care provided to chronic disease patients, research needs to investigate the relationship between patients and clinicians as it is redrawn around the principle that self-management is good and necessary for co-production of clinical and functional outcomes. Different schools of thought around self-management and how it can be maintained suggest that assumptions about the role of patient agency and service structures need further investigation. These issues apply to telehealth, which is argued to enable patients to self-manage, although the effects on patient experience and existing provider relationships as a result of introducing a novel technology-based self-service structure are understudied.

The telehealth and patient experience literatures are shown to be provider-led and needing research into patient perspectives to investigate the construct validity of many of the assumptions relating to patient value. The patient experience literature highlights the influence of research cultures on the conceptualisation and use of patient experience, and drawing on sociological literature, it is possible to suggest this is due to a tendency to sustain the subject-object relationality that is common to a biomedical approach to healthcare. Subject-object relationships maintain information asymmetries, with clinical actors holding all the power in an imbalanced dyadic relationship that is focused on the generation of provider value. The thesis argues that in order for the issues and concerns of patients to be adequately conceptualised, a conceptual shift toward intersubjective relationships is necessary. Intersubjectivity requires that the notion of patient agency is understood to be more than reactive, but subjective, where the patient is an influential social actor. Subjectivity entails a holistic concept of the patient, to replace the partial, object-oriented passive patient entirely contextualised by its provider relationship. The patient-subject is a person in context of which experience of healthcare services is a part. The notion that subjective and clinical value are different explains the

irreducibility of the separate outcomes (clinical *and* functional) identified in the Chronic Care Model ((from Gammon et al. 2015)).

By considering social-psychology and CCT-based customer experience concepts, it is possible to see how patient experience could follow a patient-as-subject conceptualisation, whereby patient experience is understood as an agentic and person-centred response to a mass of multi-sensory elements extending into culturally embedded influences of which they may be unaware. This concept of experience supports the argument that elements of patient experience are outside of the control of providers, and therefore the ontology of patient experience cannot be confined to a provider-led understanding, whereby patients experience the interactions and outcomes that are structured by their clinicians, i.e. reacting to their behaviours and information provision, which erroneously assumes only clinicians have agency to influence patient experience.

Researchers in telehealth and SST call for more detail from the patient/service user perspective, in terms of specific equipment, process, situational and consumer dimensions, but also in terms of understanding the co-production of process and functional outcomes relating to service failure and service recovery. These may be indicators of value that is not normally realisable through full-service options, which might explain the high levels of patient satisfaction with telehealth reported in the literature. The SST literature also calls for research that considers the role of SST within the holistic patient/customer experience.

Although the customer experience perspective is insightful, the practical limitations of using customer experience as an epistemological framework for this research are due to psychological processes being difficult to observe. Because the customer experience approach does not explicitly account for the importance of resource implications in the customer experience, it is argued that this approach may be ascribing too much homogeneity in user resources as inputs to SST use. This may be due to the presumption that SST are easy to use and have low resource implications, as well as focusing overly on the majority of adequately-resourced consumers. Although the current study involves chronically ill service users, the generalisability of its findings to theories are also applicable to other contexts where cognitive capabilities are highly relevant due to complex technological developments and in light of demographic changes increasing the incidence and prevalence of ageing and chronically ill consumers. It is helpful if the analysis of the phenomenon of patient use of telehealth for self-management of chronic disease needs is able to account for variability in the resources that the user brings to the SST and other service interactions.

Therefore, the thesis argues that S-DL's value co-creation focus on access to resources by a patient in context is most appropriate. S-DL's system perspective allows for the study of interactions between a person's context (lifeworld) with other actors in the service ecosystem, and offers a purposely abstract and flexible analytical framework to consider the patient perspective as

simultaneously central but contiguous or co-present with service system resources, with potential for viewing interactions as instigated by patient concerns. S-DL's unit of analysis is process-oriented and interaction focused, both of which are more easily investigated through interview and observation than internal cognitive responses to intrinsic and extrinsic stimuli. S-DL's multiple generic actors may also be construed as structures and resources (machines, people, social networks, institutions and socio-technical institutional arrangements comprising a service ecosystem) depending on their dynamic integration by patients who conscript them to the resource integration process when required to respond to patient need to co-create subjective value.

Chapter 4 Methodology

4.1 Introduction

The purpose of this chapter is to situate the thesis within an epistemological tradition in social science and draws upon literature to integrate critical realism with service research to explain the basis of the integrated conceptual framework and research questions for the thesis. The chapter begins by explaining the choice of a critical realist perspective to provide philosophical depth to the study of patient value co-creation processes before describing the key ontological principles of critical realism and its epistemological development to enable social science research. This chapter follows the convention of using a first-person perspective in order to serve the purposes of reflexivity and argument.

4.2 Choosing a methodology

Research methodology is the beliefs and principles that guide research and inform its practices. It respects rules that specify how investigations should be approached, focusing on consistency between ontology and epistemology in order to arrive at a method through which the truth or valid knowledge of social reality can be argued (Taylor et al. 2015). Research paradigms for naturalistic management research generally follow a positivist (objectivist) or interpretivist (subjectivist) approach, and currently there is no consensus over which approach to take (Tranfield & Starkey 1998, in Peters et al. 2013). However, within the field of healthcare research, there is a pronounced bias against qualitative studies (Kushner 2016) partly because they are denigrated as merely anecdotal, cannot be easily generalized to populations, and their findings are difficult for practitioners to integrate in practice (Morse 2011). Moreover, in a field in which the medical profession dominates, there are institutional preferences for quantitative over qualitative studies, exemplified in the criteria for 'gold standard' evidence identified in Cochrane reviews.

In order to select between potential methodologies, typically researchers decide on the approach that is consistent with a focus on structures, actions, behaviours, systems, and/or processes (objectivist) or focusing on how people give meaning to, interact with, and construct their world (subjectivist) (Cunliffe 2011). The choice and the treatment depends on researchers being mindful of the fundamental basis of their chosen paradigm(s), and proceeding with integrity according to the ontological perspective (Peters et al. 2013). I selected a hybrid approach and was drawn by the concept of the stratified ontology to critical realism as a methodology.

My review of the literature identified the debate between schools of thought (Table 2) informing our knowledge of the phenomena of self-management and telehealth. Psychological views describe individuals responding to environments; social-psychological views describe patients as social actors assumed to have power to change social relationships; and sociological views describe patients as constrained or otherwise determined by the influential social structures in which they

are embedded. The contradictory research findings are constructed and delimited by their research methodologies, leading to open debate between them rather than providing a unifying explanation of plausible effects of telehealth on self-management.

In order to find a path through the above debates, I turn to the stratified ontology that forms the basis of critical realism (see 4.3 An introduction to critical realism). Stratified ontology refers to the realist proposition that reality is separable into three domains: the empirical, the actual and the real (see 4.3.1 Ontic depth). The implication of the stratified ontology is that scientific knowledge belongs to the realm of the actual and is not an explanation of causality that refers to the real. The real is made up of intransitive objects that have structure and influence that are felt as observable tendencies, but are otherwise invisible (unobservable).

Scientific knowledge that pertains to the actual is labelled transitive; its fallibility applies to the scope of all epistemological approaches, which are necessarily fallible and open ended (Section 4.3.2). This realist proposition fundamentally assumes that dissimilar epistemologies share the possibility of offering partial or probabilistic truth claims that may be descriptively insightful, but without presuming they provide adequate theories sufficient for explaining the causal mechanics of reality, which is always imperfectly apprehensible. Hence, because critical realism accepts that divergent views can be altered as a result of research accessing additional information, overturning our knowledge based on previous assumptions about what is understood to be real (e.g. Popper's (1962) scientific falsification and Kuhn's (1996) scientific paradigm shifts), critical realism takes this distance perspective in order that it can consistently integrate otherwise opposing positivist and interpretivist ontologies. This hinges upon critical realism's stratified ontology and its stance regarding the multiplicity of views of reality as transitive knowledge.

Here I reflexively draw upon critical realism's assertion that that multiple forms of transitive knowledge may be plausible yet limited as a consequence of the metatheory that informs the research. It became clear through the iterative research process that the research design's methodological stance constructs and has a bearing on which observations and interpretations are held to be relevant and 'true' reflections of the experiences of the sampled participants. The quality of evidence depends on the framing of the unit of analysis, and it became clear that confinement to one level of analysis (e.g. theorising about value generation from micro level user-machine interactions), rather than integrating several levels (e.g. considering interactions between value generation at the micro level SST-based *and* meso level of multichannel full-services), would lead to very different findings and interpretations of what is probabilistically true about the phenomenon of telehealth experience in the open system being studied.

Therefore, choosing a holist, objectivist stance, or a purely individualist, subjectivist stance (Cunliffe 2011) would not be adequate to describe the multiple realities emerging in the data and

also described by Mol (2003) in her medical ethnography. Furthermore, by committing to the same either/or approaches that I critique (in Section 2.3 Telehealth literature) for being overly committed to a narrow perspective, such an either/or choice would fall at the first hurdle in my attempt to develop knowledge that relates to all of the findings in the literature although they are derived from different methodological approaches. Therefore, I argue that the research aims are best served by a hybrid approach that is capable of considering both objectivist and subjectivist dimensions of social research.

Hybridity suits a critical realist perspective, which considers possible that co-existing and contradictory truth claims from previous studies have the potential to be partially and probabilistically true, rather than wholly true. It is able to treat all knowledge and truth claims equitably as transitive knowledge, which includes all forms of scientific knowledge constructed under the assumptions of different methodologies, which are universally understood to be fallible in their attempts to describe reality (the real), which is imperfectly and probabilistically apprehensible. The real is distinct from yet co-exists with the researchable external reality of human experiences as a result of sensory perceptions (the empirical), which may be misleading yet are assumed to be representative of a reality (the actual) that results from an imperfect understanding of causality yet explains ontological and epistemological beliefs. Knowledge of the actual is understood to describe the observable tendencies of otherwise invisible intransitive mechanisms of the real. Therefore, although from other philosophical standpoints, objectivist and subjectivist findings often provide philosophically contradictory explanations of similar phenomena, maintaining the tension between them suggests that they are dealing with different levels of fallible knowledge claims. The realist stance accepts that probabilistically both may provide partial evidence of observable tendencies of the real.

Drawing on Berger and Luckmann (1966), the combination of socially constructed knowledge which becomes taken for granted as reality, can influence beliefs and behaviours and become the basis for social action, even when they are proved to be unsound. In this way, both objectivist and subjectivist approaches to establishing truth claims about telehealth use are empirically real for me as a researcher. As the literature review attests, their truth claims play a role in conceptually structuring the substantive domain of this research topic. Thus their various findings are experienced as empirically and actually real and thereby require logical refutation in order to highlight their limitations toward justification of alternative approaches (immanent critique) and evidence the extent that the ideas and the theories that frame them may be only partially true, if not mistaken (scientific falsification). From the literature review, I concluded there was one choice for a scientifically robust methodology: critical realism. Not only was this appropriate to address the current state of competing knowledge claims, but it also supports the decision to dedicate this research opportunity to studying different perspectives of a well-studied topic (telehealth).

To these considerations can be added that the researcher's choice is realistically constrained by the proposed contribution to the state of scientific knowledge, i.e. whether the topic according to the literature requires an exploratory study or a theory testing approach. Therefore, a fundamental condition for establishing an appropriate methodological approach ideally needed to offer a stratified ontology, acknowledging that clinical research cultures have tended to mistrust patient experience as reflective of valid 'truth' and treated as merely anecdotal. Realist approaches however, can treat accounts of patient experience as real, despite their inability to account for the invisible aspects of service structures and social structures that influence their experiences. Service structures and social structures are simultaneously real because realism holds that knowledge of those realities is separate from their existing (Peters et al. 2013).

Researching telehealth from the under-studied patient perspective therefore involved justification of the validity of perspectival shifts to improve knowledge. This conviction was maintained in the process of drafting a new approach, and to consider the implications of adopting a realist methodology on the research design. Together these elements of the research design provide a clear statement of the purpose and intention motivating this work: to contribute new knowledge across all three domains. A three-dimensional model of the research process (Figure 7) depicts the organisation of this study, with telehealth acting as the substantive domain that provides 'specific empirically observable phenomena, problems, or settings; a conceptual domain associated with abstract ideas and theories about the nature of the world; and a methodological domain associated with the procedures used to relate ideas from the conceptual domain to the 'real world' of the substantive domain' (Brinberg and McGrath 1985 in Langley et al. 2003, p.197).

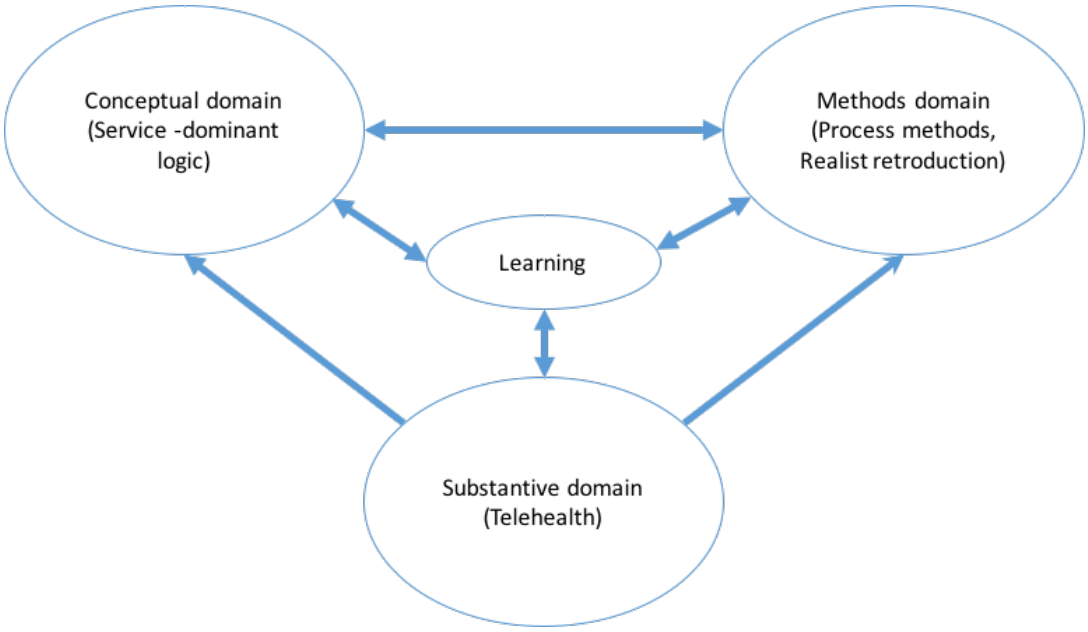


FIGURE 7 A THREE-DIMENSIONAL MODEL OF THE RESEARCH PROCESS (ADAPTED FROM BRINBERG & MCGRATH 1985 IN LANGLEY ET AL. 2003, P.197)

4.2.1 Discounting alternatives

In order to justify my choice of critical realism, I explain my reasons for discounting certain alternatives. Objectivist approaches, like Comte's (1968) positivism, assume that reality is a concrete given. It is 'external to, imposes itself on, and determines individual behaviour. It treats knowledge as similarly 'real' with observable and measurable regularities, laws and patterns' (Cunliffe 2011, p.649). By focusing on the social structures we see as real, without analysing the invisible interactions that reproduce or transform them seems naïve, especially in an era of climate change that more consciously attributes negative causal effects to habitual discounting of long-term invisible interactions with our environment.

Critical realism is often criticised by its detractors for its ambitions toward philosophical abstraction and because it attempts to refute science on the basis of its fallibility (Bhaskar 1998c). It does this by criticising positivistic science for its pretense of confining itself to the empirical domain of what is observable and measurable. Realists refer to the work of influential scholars of scientific knowledge that have reflected on the social construction of observability and measurability as metric development, whereby scientific knowledge is acknowledged to be frequently overtaken by technological innovation, eventually leading small shifts cumulatively to overturn accepted paradigms (Kuhn 1996). Kuhn's theory of scientific revolutions explains how important social understanding is to the acceptance of ideas as observable fact. Objections to the role of scientific conjecture (Popper 1962) about conceptualising the immeasurable and the influence of invisible social interactions can be upheld by their contradictory use in the fields of theoretical physics and pure maths. Finally evidence of the role of social interactions as influencing the practice of hard sciences further serves to refute claims to purely positivist (empiricist) scientific endeavour (Latour 1987) and suggests that alternative methodologies to positivist approaches are more valid for establishing what is real in a less artificially bounded construction.

Subjectivist approaches, like social constructionism (Berger & Luckmann 1966), social constructivism (Harré & Bhaskar 2001) and phenomenology (Schütz & Luckmann 1973), assume reality is the product of the human mind, that humans are relatively autonomous actors and creatively give meanings to their surroundings. They believe that knowledge is personal and experiential and see rules and principles as generated through social interaction, whereby actors autonomously construct their own environment. Autonomy is understood to be influenced by socially constructed reality that comes to be taken for granted, and therefore sets the basis for social action. Therefore, both concepts -- taken for granted reality and social action -- may be understood to reflect both an individual's autonomy to construct reality and a collective reality. They interact and potentially influence the shape and outcome of social action at various levels. We may think of these as the influence of socially constructed preconceptions, pre-interpretations or heuristics,

which, when challenged, may occasion new individual interpretations of experience, thereby modifying previous understandings of causality. These interpretive theories clearly link epistemology and the ontology of reality by highlighting the importance of social action in socially constructed reality. Examples of this reality include institutional structures like laws and norms. Critical realism claims affinity to these interpretivist approaches but takes issue with their tendency toward methodological individualism resulting in upward conflation of structure into agency (Archer 1998a), which is discussed in a later section (4.3.4 Agency).

I find the phenomenological account of a self-constructed lifeworld (Schütz & Luckmann 1973) ontology compelling because it privileges unique perspectives as empowered to construct realities, and is inclusive of those disadvantaged voices at the margins of society, treating them theoretically as equally valid as those more powerful. Such a democratic understanding supports this thesis' implicit claim that studying patient perspectives is as important as studying provider perspectives. However, to consider the thoughts of the actors as more real than the conditions that helped construct their marginality seems to compromise away the opportunity to examine why their status as social actors embedded in contexts emerged as it did. Conflation of structure and agency makes this process difficult to analyse. Furthermore, by undertaking to examine the potential for causality in the relationship between the interactions of actors and environments, it is possible to theorise about how change in the conditions necessary for different outcomes to emerge can be fostered and managed, i.e. through service (re)design.

4.3 An introduction to critical realism

Critical realism is a philosophy of science, a social theory, and a methodology primarily developed by Roy Bhaskar (1944 - 2014) and Margaret Archer (b. 1943), that considers social reality from a realist perspective. Its development stemmed from a programme of immanent critique of the ontological and epistemological assumptions of two scientific traditions: empirical realism (or positivism), and transcendental idealism or hermeneutics (including later poststructuralism and postmodernism). Although critical realism shares certain methodological aspects in common with social constructivism, it has radically different philosophical underpinnings (Olsen 2009, p.2), especially as regards the belief that relationships have causal powers (beyond language) to exert change in the social order (Peters et al. 2013). It has far less in common with empiricism, which makes reference only to experience (the empirical). Empiricism is problematic specifically because realists believe events exceed what is experienced (i.e. is observable), and because of this belief, the necessity for a 'larger conceptual map of reality' that encapsulates 'the domain of real structures and other generative mechanisms' (Olsen 2009, p.6) is elaborated by Bhaskar (1978).

4.3.1 Ontic depth

Critical realism assumes the existence of a reality that exists although our knowledge of it is socially constructed and fallible. It suggests that some theories are more plausible in approximating reality than others, and that there are rational ways of assessing knowledge claims. This relates to the critical realist methodologies of ontic depth and retroduction to explain social phenomena.

According to critical realism a stratified ontology exists that is comprised of the real, the actual and the empirical (seeFigure 8). Each domain is relatively autonomous from the other two. The **real** consists of structures and objects (physical and social) with capacities for behaviour called mechanisms. These mechanisms have the potential to trigger events in the domain of the actual. These events may (or may not) be observed in the empirical domain (Bygstad & Munkvold 2011) but their imperceptibility does not preclude the existence of an associated causal mechanism. The domain of the **empirical** is made up of human sensory experiences and perceptions. The **actual** refers to events occurring in the world, where

> perception can sometimes be misleading or unreliable. […] The real is not the same as the empirical. The empirical gives us an avenue of access to the real, but only when the former is guided by theory. That is, for the realist, the goal of science is the theoretical identification of things and their causal powers (Warner 1993, p. 312 in Olsen 2009, p.6).

In the application of critical realism to research, then, the aim is to theorise from the empirical toward understanding the causal mechanisms that are caused by the structures and objects of the real domain. We can think of the actual, then as a relegated domain of transitive knowledge products of empirical science, which fallibility and failure to approximate the real is criticised by Bhaskar (1998) for ontological inconsistency.

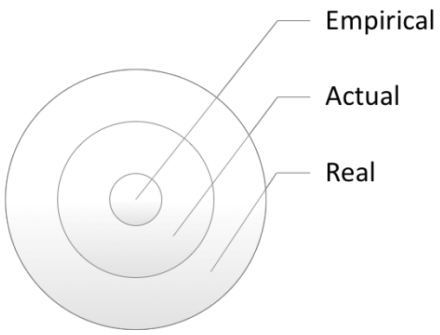


FIGURE 8 CRITICAL REALISM'S STRATIFIED ONTOLOGY

The work of critical realists to establish their concept of ontic depth pertains to their likewise criticism of methodological individualists (whose approach is seen as too simplistic and empiricist)

and post-modernists (whose resistance to the possibility of the existence of structures is similarly called to task) (Archer 2000).

Through carefully defining structures and causality as real but difficult to observe, 'realists argue that it is possible to carry out many post-structuralist research practices without becoming committed to an excessively relativist or totally constructivist ontology' (Olsen 2009, p.3). Through ontic depth, realists can recognise as valid the role that concepts play, while also recognising other real agents (people, courts, lawyers, mediators) as sources of action. 'Realists also appreciate the role that structural locations play in creating standpoints from which people and other agents begin to act' (Olsen 2009, p.4).

4.3.2 Intransitive Objects, Transitive Products, Transfactual Powers and Emergence

As a critical philosophy of science, critical realism defends its ontic depth through a critique of epistemology. Critical realism distinguishes between the objects of knowledge which science seeks to understand (intransitive) and the knowledge products of science (transitive) which are fallible. By this distinction, Archer et al. (1998) argue against the 'reification of fallible social products of science'. Intransitive objects pre-exist and operate prior to and independently of their discovery and subsequent incorporation into transitive products of science (Archer et al. 1998, p. xii). These intransitive objects have associated causal powers that function independently of a particular sequence or patterns of events, which is defined as transfactuality. They posit the transfactual nature of intransitive objects to counter 'the fallacy of *actualism*' (Archer et al. 1998, p. xii) in which the domain of the real is reduced to the domain of the actual because there is a denial of the existence of mechanisms that realists acknowledge to be real but are unactualised or unobserved.

Identifying and analysing otherwise unobservable or unactualised transfactual powers must be done through looking to their tendencies. Tendencies are 'powers or liabilities of a thing which may be exercised without being manifest in any particular outcome' (Bhaskar 2008a, p. 14) where powers refer to an object's internal structure (explained further below) and ability to act under the appropriate conditions. Powers like mechanisms can act transfactually, i.e. they can be exercised but unactualised, or actualised but unrecognised (Fleetwood 2009, p. 364).

4.3.3 Structure

The concept of social structure depends on the sociological approach and commonly refers to (1) patterns of aggregate behaviour that are stable over time; (2) lawlike regularities that govern the behaviour of social facts; (3) systems of human relationships among social positions; (4) collective rules and resources that structure behaviour (Porpora 1998, p.340). The realist approach favours the third definition, arguing that the first definition is methodologically individualist, the second is structurally deterministic, the fourth is closely associated with Giddens' ideas of structuration

(1979, 1984), (Porpora 1998) which critical realism argues against (elaborated below). Using Porpora's example of a table, an entity with causal properties (i.e. tendencies, forces, and capabilities) that are a function of its internal structure, is causally capable of exerting an upward force sufficient to counteract gravity for objects placed upon it. By extension, humans 'with our own more complex internal structure are causally capable of intervening in the world in a purposive way' (Outhwaite 1987, p. 22 in Porpora 1998, p. 343).

> The causal effects of the structure on individuals are manifested in certain structured interests, resources, powers, constraints and predicaments that are built into each position by the web of relationships. These comprise the material circumstances in which people must act and which motivate them to act in certain ways. As they do so, they alter the relationships that bind them in both intended and unintended ways (Porpora 1998, p. 344).

As an entity, social structure is a nexus of connections between people who causally affect and are affected by them. The causal effects of structures are designated as structural emergent properties, which are relational and irreducible to the powers of the individuals that comprise them (Elder-Vass 2007).

Careful to avoid essentialism with regard to the reification of structure (Sayer 1997), realists describe the structures ascribed to the domain of the real as not deterministic, rather they have the capacity to enable and constrain events (Archer 1995). Bhaskar developed a view of the relationship between agency and structure in his Transformational Model of Social Action, which was elaborated further in Archer's (1995) morphogenetic model. They both agree with Giddens'(1984) structuration theory, in assuming that social action and structure are mutually constituted. However, their divergence from structuration relates to the inter-temporal conceptualisation of the nature of structures (Peters et al. 2013), whereby critical realism insists that social structure exists independently of current human activity. This implies that although social structure may exist only through human activity, it is not reducible to such activity (Archer 1998a). Examples include the effects of past human activities, like environmental pollution, or the introduction of human rights, that continue to be felt today as enablers and constraints. This distinction clearly resonates with the study of healthcare service user interaction, which addresses not only user experiences, but also must duly consider large, durable technical systems and socio-technical structures (Kallinikos 2004 in Bygstad & Munkvold 2011) of the biomedical approach to healthcare services.

4.3.4 Agency

Agency is the capacity of individuals to act independently and to make their own free choices (Barker 2005). The freedom to act autonomously therefore implies the freedom to act otherwise. In critical realism, the treatment of agency is very bound to structure, however it is equitable in its conceptualisation of who holds creative power and when.

Bhaskar (1998a, p.411) takes for granted that humans have 'the capacity for intentional agency and for the reflexive awareness and organisation of such agency and by a thoroughly social existence'. However, the structure/agency debate describes the operation of social constraints on agency. Benton (1998, p.305) clarifies that there is a distinction between 'powers of agents possessed in virtue of their intrinsic natures, and powers of agents possessed in virtue of their relational properties' rather than suggesting that all agents are 'autonomous possessors of causal powers' affecting the real as opposed to the empirical. There is no agency without context, as context provides the 'conditional effects of structure upon action in terms of the former supplying *reasons* for different courses of action' (Archer 1998b, p.372) and in all cases, the context needs to be specified.

The role of agency is clearly elaborated in Archer's (1995) realist model of structure and agency, or morphogenetic approach, where she describes structures as existing before the development of agency and influencing actors in the present. Actors reproduce or transform pre-existing structures through their interactions. Structures are not deterministic but they 'strongly condition what type of Social Actor the vast majority can and do become' (Archer 2000, p.285). She argues that

> structural properties shape the situations that agents face involuntarily and have generative powers of constraint and enablement over individuals' subjectively defined concerns; and therefore, social practices are produced from agents' reflexive deliberations, which determine their projects by reference to their objective social circumstances (Archer 2003b, p.135; 2007a, p.17 in Caetano 2015, p.3).

She explains that structures do affect life-chances through the endowment of initial interests, and by providing the leverage for different courses of action to operate in the pursuit of those interests. Agency is dependent on her concept of reflexivity as an emergent personal property that mediates between structure and agency. She defines

> reflexivity as an internal dialogue, a condition of existence in society which activates the causal powers of structures and allows individuals to project their actions based on the articulation between personal concerns and the conditions that make it possible to accomplish them. (Caetano 2015, p.3)

Reflexivity is affected by culture but agency is not reducible to social norms. Archer (1988) defines culture as systems of thought, belief, and ideology within which actors are embedded. Culture affects actors as they undergo a process of reflexive internal conversation in a 'constellation of concerns' regarding the natural, practical and social orders of reality. Reflexive internal conversations are argued to be precursors to courses of action. These internal conversations are the primary medium by which the social world is mediated in action, and agency is the ability of individuals to choose among various courses of action that are available to them (Archer 2007 in Caetano 2015). 'Although reflexivity is common to all individuals, different people exercise it

differently' (Caetano 2015, p.3). Her typology of four modes of reflexivity (Archer 2007, 2012 in Caetano 2015, p.3) is detailed in Table 5.

TABLE 5 ARCHER'S (2003, SAIC) FOUR MODES OF REFLEXIVITY (CAETANO 2015, P. 3)

Communicative reflexivity	Stemming from internal conversations requiring confirmation from others before resulting in specific courses of action
Autonomous reflexivity	Self-contained inner dialogues that lead directly to action without the need for validation by other individuals
Meta-reflexivity	Refers to the reflexive critique that subjects direct at their own internal conversations, which intensifies personal stress and social disorientation
Fractured reflexivity	Exercised by individuals whose inner dialogues do not allow them to deal properly with social circumstances

In the morphogenetic approach the influence of structure as relationships (connections between people in social structures) as interactions relates to the ability of reflexivity (underpinning agency) to lead to actions that influence social order as generative mechanisms in two ways: through morphogenesis (transforming) or morphostasis (reproducing). In specifying that some social actions are morphostatic, Archer (2000) is differentiating between two kinds of agency and how they are analytically useful. Morphostatic agency is illuminating because it explains to researchers how an open system can remain relatively constant over time in certain respects. So although morphostatic agency may seem less impactful than the transformative form of morphogenetic agency, this is, arguably, not the case.

Applied critical realism is therefore an interpretivist approach. It is applied to the study of meaning (hermeneutics) using analysis of narratives, texts, meanings and social norms about discourse by analysing the reality of textually-grounded objects via the analysis of the social outcomes that appear to be caused by them (Outhwaite 1987 in Olsen 2009). Social objects, like narratives that explain a service experience, can be observed to be 'real' causal mechanisms without needing to be recognisably 'universal, material, easily observable, permanent or globally existing' in order for them to be identified as 'objects which *for a caused event or for a specific observer at a point in time* are causal and very important' (Olsen 2009, p.11). The study of 'how a narrative works, how it has its effects and what it means to different observers is helpful in exploring how that narrative is part of real structures and institutions' (Outhwaite 1987 in Olsen 2009, p.11).

According to the critical realist perspective, structure enables and constrains action, and human action reproduces or transforms structure, 'although this is not usually the intention of the activity'

(Bygstad & Munkvold 2011). Critical realists use temporality to understand the generative mechanisms that shape social systems. Temporality is not an option but a necessity for understanding this process, and without problematizing the relationship between structure and agency as operating on different timescales, their 'mutual constitution […] hinders the analysis of their interplay' (Caetano 2015, p.2). Archer's (1995) morphogenetic approach outlines a cycle of three sequential phases to explain the analytical dualism that treats structure and agency as separable. This is theoretically necessary for 'unravelling and explaining the processes involved in the structuring of society and the specific forms of re-structuring to take place over time' (Archer 1998b, p.376) . (T1) structural conditioning precedes (T2) social interaction, which in turn precedes (T3) structural elaboration (morphogenesis) or reproduction (morphostasis).

In elaborating the morphogenetic approach, Archer's intention is to offer working tools to identify and unpack historically significant events according to the dual analysis of structure and agency in a search for causality. As an analytical framework, it is non-discriminatory, allowing for the integration of objectivist and subjectivist approaches (multiple interpretations of the real that share in common being fallible) in order to provide insight necessary for the process of retroduction (explained below) and identification of causal generative mechanisms through application of the morphogenetic approach. Through its application, researchers are expected to contribute 'to the conceptualisation of the structural conditioning, the specification of how structural influences are transmitted (as reasons not hydraulics) to particular agents in determinate positions and situations (the who, the when and the where), and on the strategic combinations which result in morphogenesis rather than morphostasis (which outcome)' (Archer 1998b, p.379).

4.3.5 Alternatives for studying agency

There are, of course, many alternative epistemological frameworks for the study of agency including rational choice theory (Homans (1961) in Scott 2000), whereby all social phenomena are attributed to self-interested individuals guided by their rational calculations. Rational choice theory is generally criticised for an overemphasis on cognitive processes, individual action and the invisibility of the role of social norms in decisions, as well as the influence of other social structures. For example, methodologically individualist theories like rational choice have been criticised for their inability to explain actions for collective interests, although some responses have been to suggest that these are part of self-interest. Theories such as symbolic interactionism as developed by George Herbert Mead's account of the social origins of reflexive consciousness have been criticised by Archer for being radically anti-subjectivist (Dépelteau 2008). Frequently cited in social-psychology and CCT consumer research, both symbolic interactionism and phenomenology are integral to theories about the ontology of the consumer subject. Among CCT scholars social life is conceived as the active accomplishment of purposive, knowledgeable actors (Peñaloza & Price 1993). Although scholars have worked to construct the ontology of the consumer as agentic in

structurating social reality, from within consumer-centred research a challenge has been issued to move on to providing a theoretically robust explanation of the social-structural context of agency theorisations (Askegaard & Linnet 2011). This may account for the popularity of Giddens' (1979) theory of structuration in both S-DL and CCT literatures in order to explain the interaction of structure and agency. Giddens (1979, p.62) suggests that constraints and opportunities created by social structures inform action by '*patterning of interaction* and the *continuity of interaction* in time'.

> 'Action' or agency, as I use it, thus does not refer to a series of discrete acts combined together, but to a continuous flow of conduct. We may define action … as involving a 'stream of actual or contemplated causal interventions of corporeal beings in the ongoing process of events-in-the-world' (Giddens 1979, p.55).

Because Giddens (1979, p.49) introduces temporality as a framework (e.g. 'continuous flow' and 'ongoing process') in such a way that makes it difficult to extricate action or agency from the context in which it is 'embroiled in both those conditions and consequences', according to Archer, Giddens' structuration introduces the problem of 'conflation', where agency is conflated into structure. Hence the problem of their inseparability, or what Bhaskar and Archer called conflation of the social; this is because analytical precision requires that structure and agency be treated separately on their own terms, hence their argument for 'analytical dualism' which purposely treats structure as extrinsic and individual reflection necessary for agency as intrinsic (Dépelteau 2008). Therefore, whereas Giddens' concept of 'structuration' compellingly describes social structures as constructions borne of repetitive practices, and therefore, social actors simply enact processes that reinforce social structures, Archer argues that this is an inadequate account of 'agents' if the schema describes human individuals as doing nothing more than enacting the imperatives of social norms and structures. Giddens, however, does suggest that social change is the result of powerful individuals making these happen, and therefore, agency is relatively scarce in the construction of social reality. Archer considers this to be an example of methodological holism. Like its opposite, examples of methodological individualism, which purport to study agency without giving adequate consideration of the force of context upon agency, these are argued to be fundamentally inadequate. With methodological individualism, 'society' disappears to be replaced by the conceptualisation of powerful aggregated individual action.

4.3.6 Retroduction

Retroduction is a key imperative of the analytical process that is creative but systematic (Bygstad & Munkvold 2011). When applying a critical realist perspective to research, causality is expressed as *mechanism*, which is a causal structure that explains a mechanism (Bhaskar 1998c). He describes the structures and objects of the real giving rise to causal powers, called *generative mechanisms*, which cause the events that we may observe. The basic objects and mechanisms that pertain to the

real are not usually observable, for example, a doctor-patient interaction may be observable, but the underlying service mechanism of exchange of benefit is not. The investigation of these unobservable mechanisms, however, is the aim of critical realism, and not (contrary to positivist research), the investigation of patterns and regularities in empirical data according to according to Bygstad & Munkvold (2011).

As a philosophy of science, critical realism aims to generalize to theory to offer a description of underlying mechanisms and structures in order to hypothesise about how the observed events in the empirical domain can be explained. This occurs through the technique of retroduction, where a 'theoretical explanation proceeds by description of significant features [of an empirical observation and hypothesising through] retroduction to possible causes, elimination of alternatives and identification of the generative mechanism or causal structure at work' (Bhaskar 1998b, p.xvii). For critics who argue that retroduction or abduction are not strictly methods, Bygstad and Munkvold (2011) argue that retroduction to identify mechanisms extends from Popper's conceptualisation of conjectures as engines of scientific enquiry because 'many scientific concepts do not "occur" in our empirical data'.

It is important to explain that for critical realists, and in sympathy with the process over variance theory views (Langley 1999), the term mechanism does not imply linear causality modelled on variance theory, i.e. that it triggers the production of the same outcome every time. Rather, the mechanism's outcome is contextually dependent on other mechanisms. This view of contingent causality (Smith 2010 in Bygstad & Munkvold 2011) applies to all open systems, which reduces the use of mechanisms to explain phenomena rather than for prediction. Therefore, all mechanisms are 'stuff-dependent and system-specific' (Bunge 2004, p.195) and they are described in terms of a *context-mechanism-outcome* pattern (Pawson & Tilley 2004). The concept of emergence is central to the workings of mechanisms; it is often a combination of objects that will trigger a mechanism, and produce an outcome that is dependent on, but not reducible to the objects.

The application of critical realist perspectives in empirical research has been developed by Sayer (1992) as a research method in social theory, and Danermark et al. (Danermark et al. 2002) in social welfare, Bygstad and Munkvold (2011) offer a framework for conducting technology research, and Peters et al. (2013) apply critical realism to marketing and the study of business networks. The main 'steps' of research, such as data collection, analysis and theory-development are situated within the context of exploration, where they are constantly revisited and reworked rather than undertaken in a pre-specified sequence (Danermark 2001).

In Table 6 I have imported Bygstad & Munkvold's (2011) framework for critical realist data analysis in technology research and their definitions for critical realist conventions. The table also provides details of how it was applied to the current study.

TABLE 6 APPLYING BYGSTAD AND MUNKVOLD'S (2011) FRAMEWORK FOR CRITICAL REALIST DATA ANALYSIS (BULLET POINTS ADDED)

(1) Description of events	Events in critical realist research are clusters of observations which have been made by the researcher or the participants (Sayer 1992) • interview transcripts, videos, field notes, documents, and researcher identified themes that emerge through iterative analysis
(2) Identification of key components	Key components are the real objects of the case • the phenomenon of telehealth use conceptualised as an experience of interactions with machines and human elements of healthcare services These constitute structures or networks of objects with causal powers that may emerge as entities from the data in a grounded way • patient access to economic, cultural-cognitive, social, physical and emotional resources or may be embedded in a theoretical framework • value co-creation processes arising from service user interactions in the 'joint sphere' (Gronroos and Voima 2013), and their interactions in the lifeworld or 'customer sphere' (Ibid.) within a service ecosystem (Vargo and Lusch 2016) • technology as operand (material) and operant (cultural-cognitive) resource influencing healthcare service as a socio-technical system (Orlikowski 1992; Akaka & Vargo 2013)
(3) Theoretical re-description (abduction)	To be able to work with retroduction, the case must be abstracted, exploring different theoretical perspectives and explanations. A case is a case of something which transcends the actual events. Theoretical re-description could be based on social theory • structural determinism or resistance and patient agency • morphostatic reproduction or morphogenetic transformation or more limited middle-range theories • co-production, value co-creation, value co-destruction and compare and integrate them when possible, in order to increase theoretical sensitivity and understand the events in more depth.
(4) Retroduction: identification of candidate mechanisms	(Part 1) The interplay of objects The interplay between social and technical objects (identified in step 2), which allows for the identification of socio-technical mechanisms. Objects have internal attributes (structure) and external attributes (interfaces, modes of communication), which allows for interplay with other objects. We should focus on these in order to identify relations of exteriority. How social entities interact with technical entities to produce the observed outcomes (socio-technical change). (Part 2) Looking for micro-macro mechanisms (an object is macro related to sub-level components, but micro related to higher levels) Micro-macro mechanisms which explain the emergent behaviour (how different components interact to produce an outcome at a macro level Macro-micro mechanisms which explain how the whole enables and constrains the various parts
(5) Analysis of selected mechanisms and outcomes	In an open system there are a number of mechanisms. When we have found a new mechanism we can identify others by asking how the context (i.e. other mechanisms) influences the triggering of the mechanism (Sayer 1992) • the paradox of technology consumption (Mick & Fournier 1998) as an epiphenomenon within the sociohistoric context (Askegaard & Linnet 2011) of healthcare services and cumulative antecedent service experiences as potentially transformational or reproducing • critical importance of extrinsic system and intrinsic lifeworld experience as structural conditioning influencing structural elaboration (Archer 1995) Detailed analysis of the selected mechanism(s) could employ the Context-Mechanism-Outcome form (Pawson & Tilley 1997) where the outcome could be analysed with forward chaining in order to understand intentions and backwards chaining to understand results (Pettigrew 1985). Context includes other active mechanisms; at a deeper level there is continuous interaction between causal powers which will change contingencies (Yeung 1997) • forward-chaining according to a framework for goal-related consumer resource integration (Arnould et al. 2006) • backward-chaining according to the conceptual application of a process analysis framework (Langley 1999) to narratively identify plausible causal relationships
(6) Validation of explanatory power	The aim is to identify a key mechanism with the strongest explanatory power related to the empirical evidence, i.e. the causal structure that explains best the events observed (Sayer 1992). A proposed mechanism should be treated as a candidate explanation and the data collection and analysis should be repeated until closure is reached. Other validation techniques like participant feedback could be employed (Bygstad & Munkvold 2011). • Discussion of interim findings with nursing practitioners and academic audiences • Examination of doctoral thesis

The discussion of the identified explanatory mechanism's similarities with other possible explanatory mechanisms and the theoretical and practical implications of the analysis conducted under critical realist conventions follow the aim to generalise to theory via case research.

4.4 Immanent critique of patient experience

Critical realism originates from the tradition of critical theory and springs from an immanent critique of positivist science that involved the analysis of its assumptions about epistemological objectivity and the ontology of reality, highlighting their insufficiency. An immanent critique is:

> a form of social critique that evaluates both the empirical behaviour constituting social practices and the explicit self-understanding of their members according to standards that are, in some sense, internal to those practices themselves. By doing so, immanent critique aims at a transformation of such practices that encompasses both actions and self-understandings (Stahl 2013, p.7)

This approach is used to identify contradictions that justify the need for fresh thinking to resolve problems arising in patient experience research. Repeating mainstream approaches would result in a weak internal critique within one school of thought. Similarly, to assert without careful justification that a service marketing framework is a sound alternative, is to ignore the justificatory problems of external critique, as it risks being exposed for being insufficiently committed to the incremental development of objective truth about the healthcare context which has developed through the interpretation of empirical observations within a considerable body of context-specific research.

This thesis is built from the immanent critique in the patient experience literature review (Section 3.1), making explicit the assumptions that influence the social practice of research that make it untenable for this thesis to apply mainstream approaches. The critique underpins the thesis and justifies the application of interdisciplinary theoretical perspectives. They are adopted, therefore, in order to avoid committing to the same philosophical inconsistencies but also to contribute a perspectival shift.

It is worth reiterating a critical realist approach can still consistently acknowledge the influence of extant knowledge claims while refuting the universality of their epistemological claims. Rather than rejecting previous findings, the realist philosophy of stratified ontologies both serves to explain their value and limitations, whilst acknowledging the reality of their influence. This influence is manifest in the research design process which is abductive because research must acknowledge the influence of the literature as a structural reality. A further advantage of critical realism is its inclusiveness which makes defensible the suggestion that studies of 'subjective' patient

perspectives may co-exist and be as valid as the knowledge claims based upon 'objective' evidence from non-patient-centred studies.

As the immanent critique dissents from current approaches to patient experience concepts, it identifies problems of consistency between research methodology and the validity of its findings as truth claims. In order to emancipate patient-centred telehealth studies from following the same habits, the immanent critique advances an alternative and explains how it is applied to telehealth research using a realist lens in order to highlight the role of methodologies in research methods (Alvesson 2003). The outcome is an explicit outline of assumptions underpinning the conceptual framework for the empirical study.

The literature review identified different schools of thought based on philosophical approaches to ontology and epistemology that inform research approaches. Their methodological assumptions can be said to construct knowledge consistent with various perspectives, but few if any studies contend with the body of knowledge as a whole to generate theory explaining patient use of innovative technology-based healthcare services. This is important for understanding how healthcare systems might be structurally affected by self-care technologies given that similar technology-based services in other service contexts have proved disruptive.

Although more recent literature has considered the patient perspective (Brunton et al. 2015; Cook et al. 2016; Dario et al. 2016), it is not clear that they move forward the critical engagement with the structure-agency dialectic set out by Ong et al. (2014). This critique explains how the study of patient agency is essential for understanding patient experience in order to explore the effects of self-service on micro level process interactions. It also shows how a realist methodology enables consistent ontological and epistemological treatment of agency and structure. Finally, the critique explains how a realist ontology is also equipped to progress the findings from the literature that relate to the phenomenon of patient experience of telehealth, which is that time and resources appear to affect patient agency.

We begin with the large body of positivist studies using a psychology-based evaluation of patient satisfaction. They provide little insight for the purposes of understanding the patient perspective of telehealth due to an ambiguous and very narrowly framed concept of what the patient does when being or feeling satisfied. This is partially because scholars disagree about whether satisfaction is transaction-specific or a meta-concept that is a general view of the service experienced (Gabbott & Hogg 1998). What satisfaction scores fail to clarify is whether they relate to an exogenously determined response to stimulus or are the result of intrinsic processes such as reflection. The concept of satisfaction is also ambiguous because it is unclear whether the psychological state that

is being measured refers to the event itself or the expectation surrounding it (Palmer 2010). This ambiguity suggests that satisfaction scores may ontologically conflate observed empirical findings (which are the product of the scientific data collection tool) with the actual experiences, motivations and feelings of the patient. Inconsistency with the positivist approach stems from its premise that the real is empirically observable, yet the state of satisfaction as an outcome of a mental process is not easily observable. Therefore, this knowledge heavily relies upon subjective self-report without considering the construction of the response, e.g. diffidence, or other constraints to the respondent's self-expression when using language and concepts that are unfamiliar and potentially far removed from their own awareness of their experience of events (Williams et al. 2002; Dario et al. 2016). Studies using positivist approaches for patient perspectives therefore provide an unstable basis from which to derive insight into the phenomenon of satisfaction from patient experience of telehealth services, and therefore offer few meaningful managerial implications, although they themselves can be said to emanate from a managerial perspective. This is due to their inherent usefulness as a tool to identify confirmatory information regarding the extent that interactions conform to expectation. Identification of levels of satisfaction without further exploratory analysis therefore, are not formatively useful for innovation or verification of market orientation as they do not explore the factors of satisfaction with telehealth experience, and are more appropriate as a method for auditing service delivery (Black & Jenkinson 2009). Therefore, these studies do not aim to capture nor deliver formative knowledge about key mechanisms influencing the patient perspective as much as they measure what they expect to find.

The critique now turns to the interesting findings that motivate this study and are the result of interpretive approaches used in the telehealth and self-management literature. Both social-psychology based and sociology-based approaches appear to be based on constructivist ontologies. The former (cf. Lorig et al. 1999; 2001; Bodenheimer et al. 2002; Greenhalgh et al. 2013) is less concerned with accounting for the origins of the cultural context that pre-existed the individual actor and constrains and enables their experience of life circumstances. This approach therefore fails to account for or analyse the simultaneously existing underlying structures of which actors themselves may not be aware (Peters et al. 2013) (e.g. provider's back office service intentions and technological functions) yet influence their actions. The latter focuses on these structures as deterministic mechanisms over time (e.g. Mort et al. 2008). These more sweeping approaches are interested in large pattern detection. This forces a zooming out perspective which is blind to heterogeneity at the individual level. They can also be said to ontologically conflate reported experiences, motivations and feelings with real social structures and mechanisms (i.e. the transfactual intransitive objects of the real). The consequence for patient-centred studies is a failure to consider the potential of cellular level detail as potentially significant *because* it comes from a

structurally disadvantaged set of actors, meaning it is likely their enactments will be socio-historically incidental, or short lived, according to the broader sweep of the sociological lens.

With the exception of Greenhalgh et al.'s (2013) phenomenological study, supposedly patient-centred studies present a bias against clearly observing *what patients do* (cf. Rogers et al. 2009; Rogers et al. 2011; Ong et al. 2014). This nuance is observed in their apparent reluctance to conceptualise innovative patient practices as existing in and emerging from its own patient experience. Rather, what patients do is categorised according to pre-existing structural entities of practice, such as through close comparison to existing healthcare service structures. Although this may relate to the parsimony of the journal article, or the conventions of writing to an imagined practitioner audience, there is an opportunity to make a nuanced argument suggesting this example of conflation of agency into structure disarms the purpose of patient-centred studies, which is to obtain insight from a different perspective. Conflation as a result of the research methodology makes it difficult to identify in any detail what the individual actor's contribution to the constructed lifeworld is, much less how a relatively radical technological intervention could cause a structural change in that interaction. The potential contribution of telehealth to structural change in healthcare services is a highly relevant research question raised in the telehealth literature (cf. Rogers et al. 2011). It can be argued that both social-psychological and sociological approaches are guilty of providing analytical models that commit what is described by Archer (1998b) as an analytical problem of conflation of agency into structure, or conversely structure into agency. This critique does not aim to jettison the baby with the bath water, however. The realist critique's aim is to highlight inconsistencies, which supports the view that the real is imperfectly apprehensible, yet allows for the possibility that unstable forms of transitive knowledge can provide limited yet valuable insight into invisible generative mechanisms that make 'the real' real, and to highlight the pitfalls to be avoided in making knowledge claims.

In order to avoid conflation, it is necessary to maintain the analytic duality of structure and agency. The necessary elements of knowledge about the phenomenon of telehealth use are described here and redrawn using a realist ontology. The social psychology-based telehealth and self-management literature appears at first to be a promising approach for studying the patient perspective as it presumes that patient agency exists by privileging the framing of a patient's ability to improve health outcomes from co-produced healthcare interactions. The framing of knowledge and skills through patient-led interaction opportunities are mechanisms through which patients can transform their personal volition for improvement into knowledge and capabilities developed in social cognitive learning processes (Bodenheimer et al. 2002). Hence individual action is imbued with and situated within context as a structural influence for learning that is socially conditioned. Depending on the contextual conditioning, this branch of telehealth and self-management literature, therefore suggests that individual patient reflection through learning processes can result in

changing the context of ensuing action for social interactions that may be emancipatory change from previous structures of social interaction.

Because self-management learning processes resemble the concepts of consumer resource integration (Hibbert et al. 2012) for value co-creation (Vargo & Lusch 2016), where value is meaningfully constructed by actors in context (e.g. through social cognitive learning and meaning making) and is determined phenomenologically, it exhibits parallel conceptualisations with those from the tradition of CCT scholarship. CCT similarly asserts that consumer experience can be seen as agentic processes of consumption experiences. These experiences have the potential to transform entities (e.g. consumer transformation through transcendent experiences (Schouten et al. 2007)) and relationships between the consumer and the provider (Martin et al. 2006). The determination of value that results from the experience process is therefore characterised by the cultural context of the lifeworld, which is also subjectively and phenomenologically determined (Akaka et al. 2013). However, a major criticism of the social-psychology-based body of patient-centred telehealth literature (and extending to healthcare service studies applying the value co-creation framework to focus upon individual co-creation practice styles by McColl-Kennedy et al. 2012) is that its account of agency is not sufficiently nuanced by consideration of strong institutional influences that characterise healthcare service roles and constrain behaviours (Ong et al. 2014). This argument is articulated in calls for deeper consideration of the sociohistoric contexts and institutions' influence on consumer experience in CCT and S-DL literatures (Askegaard and Linnet 2011; Vargo and Lusch 2016). In the self-management literature, failure to consider social structures while focusing on patient perspectives risks discussing context-less agency to explain how social change in healthcare occurs. Social change may occur as a result of social cognitive development but these effects are not durable to withstand services structured to provide different outcomes (Ong et al. 2014). Their effects on structural elaboration are as yet under reported although they are assumed to be negligible due to their being observed as short-lived. In other words, the literature suggests that patient agency 'alone' is insufficient for social change without complementary structural change (Rogers et al. 2011). Individual agency, according to this worldview, is short-lived, destined to be smothered over time by impervious, countervailing institutionalised arrangements.

These explanations are compelling, however, there are problems with this branch of research related to the scholars themselves taking relatively homogeneous institutionalised perspectives. This is because their analytical perspective is observed to be biased by the mental framing that privileges and sustains healthcare structures. This is evident when describing 'low level' patient practices as if framing them to show the extent that they approximate and eventually could replace professional

practices (Rogers et al. 2011). They conflate them with the professional framing of ideal types[7], rather than considering them as analytically separable, which means patient practices inevitably will be 'less than' professional practice. They go on to suggest that institutional arrangements (such as years of medical training) make it too difficult for patients to agentically change or transform service interactions because they are structurally disempowered to leverage their interests over those of the clinician. Those that manage to exert change, subsequently find the cost of maintaining initially transformative interactions to be too resource intensive to continue over the long term. By suggesting that self-care is not commensurate with professional care, they imply that the nature of high institutional barriers makes the personal cost of obtaining commensurate levels of care excessive, rather than emphasising self-care's own attributes. As a side note, the emergence of two dimensions from this body of work, i.e. resource implications and temporal aspects, are insights incorporated into the conceptual framework for this research, as will be explained below.

In considering how the healthcare literature has shifted focus from patient perspectives of required resources toward studying ways of inducing structural change in social networks that are theorised to show influence upon chronic illness experiences (Vassilev et al. 2011; Rogers et al. 2014; Kennedy et al. 2015), it can be interpreted that the acceptance of the relatively passive (or at least disempowered) patient as a descriptor is still well-ingrained in their conceptual approaches to the self-management phenomenon. Consistent with a bias toward structures as influencing individual behaviours, the leaders in this sociology-based research area have moved away from further consideration of patient agency as a relatively inappropriate lever for changing the healthcare context.

However, studying agency is salient to understanding how resources are drawn upon from social networks, and the agentic consumer interacting with a network of actors is also conceptualised in the co-production of service and co-creation of value frameworks. This field of marketing literature, therefore, can be understood to highlight the areas for conceptual development of patient agency in service interactions through empirically studying *how* patients are using the service, drawing on what network resources, over what time period, and *why*, to the extent possible. By considering the role of cultural contexts and including institutional structures within the analytical frame, it can guard against a sloppy and potentially unethical conflation of rational consumer and patient concepts (Mol 2008). The why question (i.e. why they are using the service) refers to exploring subjectively conceptualised reasons for using telehealth. Although this implies an end goal or intentionality, this is understood as more nuanced and socially constructed than means-end rational

[7] 'An ideal type is an analytical construct that serves the investigator as a measuring rod to ascertain similarities as well as deviations in concrete cases. It provides the basic method for comparative study' (Coser 1977, pp.223–4).

choice concepts, which have been critiqued as less relevant with illness that subverts rationality due to symptom unpredictability (Mol 2008).

Therefore, a methodological approach that squares the current state of knowledge and integrates these various strands of knowledge must also be able to contend with tension between agency and structure, and relate to both resources and temporality as potentially contributing factors in order to offer a coherent explanation of how they interact, why they are related to satisfaction, and if possible to explain the mechanisms that underpin the *de facto* change in institutional arrangements that is occurring through growing provision of telehealth services to greater numbers of patients.

A critical realist ontology is suitable for capturing the patient perspective interpretively in order to surface the emic meaning they readily ascribe to their descriptions of the service and how they relate to it. It can treat this as ontologically real and separate although other perspectives of the same or related phenomenon may be perceived as entirely different. It is also offers a consistent and analytically useful epistemology because it can tolerate recognising the patient perspectives in a morphogenetic model of social transformation while also considering invisible mechanisms that influence interactions as real. It enables the consideration of patients as social actors embedded in structures that condition them (T1) and with which they interact (T2) to change or reproduce them more or less knowingly (T3) (Archer 1998) because it assumes, 'Every social actor knows a great deal about the conditions of reproduction of the society of which he or she is a member' (Giddens 1979, p. 5).

This thesis assumes that there are multiple manifestations of micro level and macro level structures for consideration, which are: technological design, healthcare services, and wider social structures (culture, language systems, norms, etc.). Technology use is an ideal way to study patient agency because it can be conceptualised as either:

> (a) users *responding* to the way the interface is structurally designed to interact with users (i.e. deterministically introducing constraints to other forms of interaction) (Oudshoorn & Pinch 2006), or
>
> (b) whether users are utilising the technology as a resource to be integrated with others within a *subjective schematic* of purposive and discretionary consumption processes (Greenhalgh et al. 2013), which implies relative autonomy.

In order to move from the micro level interaction to consider the macro level implications for social change, (a) is conceptualised as an example of morphostatic agency, and (b) morphogenetic agency.

Technology is understood to influence social actors and therefore can be understood to be both a form of structure as well as a social actor in a network of actors (Akaka & Vargo 2013). I suggest

that the difference between these two forms of technology use as action relates to the *intentional* nature of their actual usage and how they surface the invisible connections between social forms (or structure) and agency. Both forms of action may be conceptualised as relating to patient agency to autonomously reproduce or transform the connections between social actors.

Apart from satisfying the convention of clarifying the ontological and epistemological assumptions that underpin a research design, explaining these issues is a key part of my engagement with the philosophical implications of the chronic disease management policy (i.e. the Chronic Care Model) discussed in the literature review, whereby patients are being encouraged through a proposed strategic reform of chronic disease healthcare systems to become activated and engaged in their own care. This suggests that a changing structure of healthcare service interactions will transform patient actions by being informed about self-management strategies to prevent worsening conditions and reduce overall demand for care.

This more agentic identity for the patients as co-producing a healthcare system strategy is understood to be a change from the still prominent reproduction of paternalistic models of care (Fox 1989; McDonald et al. 2013), which conceptualises the patient as passively capitulating to the authority of qualified professional care (cf. Parsons' (1957/2010) 'sick role'). Such paternalistic models have been explained according to structuralist or functionalist accounts of medical professionalism (Scott 2004; Scott 2008). I acknowledge there are competing theories, such as the conflict model of professions, e.g. (McKinlay 1977; Freidson 1970a; Freidson 1961) that explain different motivations for maintaining the influence of professionals over patients, however, rather than reviewing these debates, I refer to them in order to suggest that the organisation of healthcare services and the relationships between social actors are understood to be highly structured by powerful and potentially competing interests.

From a socio-historical point of view, patients have not been privileged as structural influencers and decision-makers about what treatments and interventions benefit them. Therefore, healthcare is persistently understood to be either led by professionals interacting with patients according to biomedical approaches (i.e. object-oriented) to care. Alternatively it is understood to be dominated by tensions between professionals and managerial attempts to introduce systemic reform of healthcare, resulting in the co-existence of competing and conflicting approaches to healthcare (McDonald et al. 2013). Healthcare according to these organisational models influences patient interactions by introducing changes to the services they can access. Thus, by looking for the interactions between social structures, (i.e. telehealth and usual healthcare services), and patients as social actors, this thesis aims to make inferences about the mechanisms of social change that are depicted in the Chronic Care Model.

My focus upon telehealth use is conceptualised at the macro level as an interaction with a bureaucratic socio-technical system, or social structure. The treatment of telehealth services as a token of a simultaneously abstract and concrete social structure is consistent with the treatment of examples of social structures like class-positions and role structures by Bhaskar (e.g. 1998) and his followers, (e.g. Archer 1995) whereby the concept of structure is used

> 'to refer both to the abstract form or type and the particular concrete instantiation or token of it' (Bhaskar, *The Possibility of Naturalism*, 3rd ed. 1998, p. 169-170), the latter of which has been variously referred to as "social system", which refers to concrete interaction groups, organisations and some larger social entities (e.g. national economies that are ultimately composed of interrelated and interacting human individuals and the artefacts they use in their interactions (Kaidesoja 2015, p. 368).

Social system, or structure, includes the social conventions of formal healthcare services described by the 'sick role'. Another example is clear evidence of a purposive societal move toward a market orientation subsuming healthcare services either from the top-down, i.e. through public (Greener et al. 2006) and organisational strategic policy initiatives (Laing & Hogg 2002), or through multiple fronts, as osmosis-like processes draw consumerism into all aspects of daily life, including healthcare (Sulkunen 2009). A third way that structure presents itself is in the form of designed technologies, where users interface with machines and services according to plan, e.g. architectures and blueprints. For example, the conceptualisation of healthcare services as ingrained by deeply embedded divisions of labour that exist between providers and recipients of healthcare have been well-studied (Rogers et al. 2011); and although the patient's 'sick role' continues to persist in the general understanding of healthcare delivery (Fox 1989), debates about the changing aspects of healthcare (McDonald et al. 2013) discuss a model of structural change towards an increasingly 'marketised' healthcare organisation emphasising patient choice (Mol 2008) as an alternative to the deeply hierarchical relationships prioritising provider choice.

The methodological advantage of applying the theory of morphogenesis is that it acknowledges how processes of change occur for agents and social structures in ways that interlock and are temporally complex. Agents are formed within sets of social structures (norms, language communities, power relationships) and the structures change as a result of the activities of the historically situated individuals that are inhabit and construct them. Archer (1998) describes the ontology of structures as occurring through cycles with different time frames. The first stage is structural conditioning (T1), followed by social interaction (T2), and what follows is structural elaboration (T3) which is either the forming and reproducing or transforming of structures. Archer (1995) argues that insight into micro and macro levels is necessary because they can be understood to have a degree of autonomy from each other, which she refers to as 'emergence'. This dynamism is integral to maintaining that evidence of morphogenesis may or may not endure or be observable as social change.

This idea of dynamism in the relationship between claiming evidence of observable micro agency simultaneously with showing evidence of macro structural determinism is centrally important to the research design that is employed here. For the aim of the research is to collect evidence of and analyse the patient experience and attend closely to the patient voice, studying their narratives and their stories expressed in their own words in the context of their personal living spaces. Any information they impart about changes they experience on an individual level are important and revealing as micro cases of structure and agency interactions. They are treated as real, with full ontological status, and that is of importance to the structure of the local micro interaction as well as systemically (macro) because they are irreducible to one another:

> '…social realism which accentuates the importance of emergent properties at the level of both agency and structure, but considers these as proper to the strata in question and therefore distinct from each other and *irreducible* to one another, replaces the terms of the traditional debate with entirely new ones. Irreducibility means that the different strata are *separable* by definition precisely because of the properties and powers which only belong to each of them and whose emergence from one another justifies their differentiation as strata at all' (Archer 1995, p. 14).

By aggregating the micro level voices and views across the sampled cases, it is possible to obtain a mid-level view about their interactions with social structures and their potentially causal effects. Social structures include the innovative telehealth service and their usual healthcare service interactions, both of which can be considered as concrete 'tokens' of the bureaucratic socio-technical system where they play a part as functions, but also as it may relate to the abstract social structures, such as market orientation in healthcare (supply-driven), or consumerisation in health care (demand-driven).

Through conjecturing from empirical examples about intended and unintended consequences of their telehealth-based interactions we may speculate about telehealth effects in terms of their emergent properties, and their implications for wider social change at the meso and macro levels. This social change would be reflected as telehealth use underpinning morphostasis (no change) or morphogenesis (change).

4.5 Conceptual framework

The literature review alerts us to several research gaps. Our knowledge about the phenomena of chronic disease care management suggests that in order for it to be sustainable, changes need to occur at the level of patients and clinicians, working together in a different way that involves an emphasis on prevention. Prevention is said to require greater self-management of conditions before the need for formal care arises. Telehealth is said to offer supported self-management at home with greater situational benefits, including improved condition monitoring, cost savings, convenience and empowerment. These identified benefits appear to come from a provider perspective, in that they are informed by modernist, political-economic, change management or humanist ideologies

(Greenhalgh et al. 2012; Kozinets 2008) that may be espoused by telehealth designers and policy-based advocates or critics, in other words, provider-based views that are assumed to structure consumption experiences, with scant evidence from clinicians and even less from patients themselves.

The problem statement therefore is: what is patient experience of telehealth for self-management of chronic disease? How can this be undertaken given current approaches are either a) overly individualistic, mainly cognitive framings of experience that fail to adequately account for social context about which they may not be aware, or b) overly deterministic, attributing all individual experience to reactions and responses to environments that structure interactions, thereby losing a view to micro level detail that may offer insights into changing structures as they occur? It is suggested that critical realism is an appropriate metatheory because it has been developed to consider structure and agency in equipoise for the purposes of analysis. This includes a nuanced view of agency as reproducing structural arrangements through morphostatic agency, as well as introducing changes, through morphogenetic agency.

The next problem statement is: how can the patient experience concept be constructed to avoid provider-led bias? Provider-led concepts of patient experience and patient value are argued to be misconstrued and misleading and require a rethink. The thesis addresses this by stepping away from of the disciplinary prejudices against qualitative patient experience data as merely anecdotal in the healthcare research context which values objective evidence to satisfy a subject-object orientation between providers and patients. By using a marketing lens, it is possible to see that a more accurate definition of co-produced services requires a perspectival shift to see that patient-provider relationships relate to intersubjective interactions. Intersubjectivity is relevant to our understanding of patient experience as related to relational and functional dimensions, which are currently ancillary to an object-oriented clinical focus prioritised by providers. This means a marketing perspective sees patients as subjects ascribed with agency and subjectivity, and recognises the importance of their opinions and experiences as central to the provider's relationship with them, and ultimately the provider's success. It is argued that the S-DL perspective is framed to consider relationships between the provider-service user dyad as fundamental to firm performance, as well as ascribing agency to the service user to influence the structures of interactions as well as to respond to them.

Therefore, the conceptualisation of this patient-centred telehealth study assumes patient agency is central in the conceptualisation of patient experience of telehealth services. In order to establish the validity of this assumption, we look for evidence of agency according to its influence in the co-creation of experiential outcomes that may be related to their subjective experience of the interaction with the home-based service, or experiential outcomes related to further healthcare

provider interactions. This approach is enabled by applying S-DL's value co-creation concept. This involves a resource-based view of users integrating necessary resources, which can be identified as conditions for the emergence of value from service interactions. It also includes a process orientation that incorporates a sense of time including a goal-oriented chronological ordering of events, to enable consideration of value the extends beyond the interaction itself. This later stage is conceptualised as a stage of structural elaboration. It situates the telehealth user experience in contexts that explain the conditions that influence access to resources that can be considered antecedent events, as evidence of structural conditioning. These contexts are salient furthermore for identifying the dimensions of value that emerge as outcomes of the co-creation processes, which are also understood to be part of structural interaction and elaboration stages.

Figure 9 depicts iterative processes of value co-creation integrating patient agency and patient experience. Agency relates to active resource integration. Patient experience is depicted as a resource or input, which is evaluated according to functional and relational aspects. These aspects are conceptualised as determinants of subjective value that emerges from healthcare service interactions. Evaluation is subjective as it relates to the patient in context. This evaluation is an input to the expectations that a patient has of telehealth services, establishing the value proposition that is contextualised to the patient's understanding. Interactions with telehealth and wider services require further resource integration in the process of consumption and co-production of services. Latter consumption stages include reflections about the telehealth consumption experience and its effects on wider service interaction experiences. These guide their ensuing actions with telehealth.

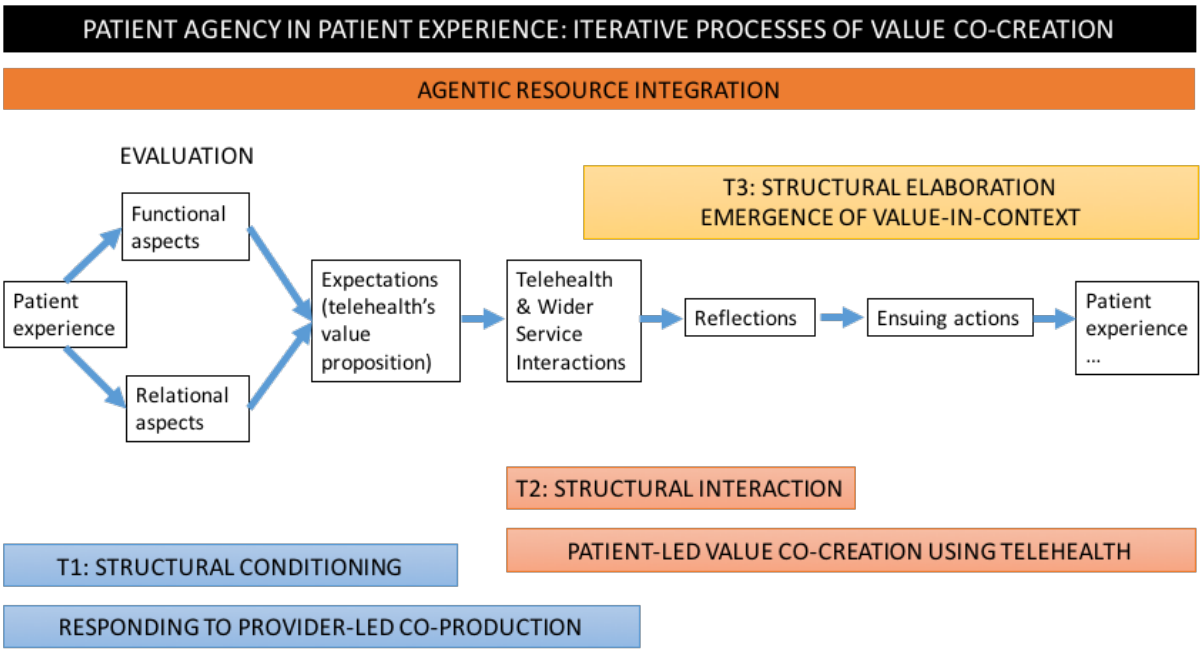


FIGURE 9 CONCEPTUAL FRAMEWORK FOR THIS RESEARCH (ORIGINAL WORK)

Telehealth, as an SST is an intermediary service that is introduced within the context of past and ongoing full-service patient experiences. Telehealth is informed by antecedent service experiences, which is an example of structural conditioning. Through telehealth use, a micro level process of value co-creation as structural interaction, we may consider the patient-led determination of value-in-context based on antecedent experiences, and how it relates to ongoing patient-provider relationships. The extent that these relationships change in ways that are valued by patients is the outcome of telehealth use at the macro level (structural elaboration). The thesis conceptualises emergent value-in-context taking place at two levels: endogenously within the telehealth service, and exogenously with multichannel services. The emergent value can be assessed in terms of convergence with or divergence from provider-led value. We may consider value convergence as reproduction of provider-led structures, and divergence as structuring change that is patient-led. These are instances of structural elaboration through patient agency.

4.6 Research aim, questions and objectives

The aim of the research is to investigate patient experience of telehealth services for self-management of chronic disease. The research questions and objectives based on the conceptual framework are articulated in Table 1.

Table 1 Research Questions And Research Objectives

Research Questions	**Research Objectives**
How do patients co-create subjective value with telehealth services? How does patient experience affect co-creation of value with telehealth? How does value co-created using telehealth influence relationships with healthcare service providers? How does the debate about structure/agency relate to the context of patient use of telehealth?	• To describe patient experience of telehealth in relation to the contexts and conditions of chronic disease self-management • To explore how patients co-create value with telehealth • To examine the resource implications of telehealth services on patient experience • To identify the dimensions of subjective value that is co-created • To examine the influence of telehealth on patient agency • To examine how telehealth use affects patient-provider relationships in a multi-interface, multichannel healthcare service

Chapter 5 Methods

This chapter explains the methods used to conduct the research. They are consistent with the realist ontology of social actors in possession of subjectivity, whose interactions are understood to construct and be constructed by social structures although their experience of them may be no indication of their awareness of them. The methods described are suitable for the identification and interpretation of patient perspectives. This approach is consistent with the interpretivist methodology and epistemological aims regarding the interaction between agency and structure described in the previous chapter.

5.1 Multiple case study within a single case study

The research design applies a multiple case within a single case study design (Yin 2014), which enables treatment of each telehealth user in the sample as a separate case to allow rich ethnographic data about the context of the telehealth experience to be analysed. The case study is a qualitative research design to explore a contemporary phenomenon within a real life context, where the phenomenon and the context are not clearly evident, and in which multiple sources of evidence are used (Yin 1994, p.23). Context situates the case within its setting (physical, social, historical, economic, etc.) (Dopson 2003, p.218). Case studies try to illuminate a decision or set of decisions, explaining why they were taken, how they were implemented and to what end (Schramm 1997 in Dopson 2003). Case studies are selected on the basis of intrinsic uniqueness, or using cases instrumentally to illustrate or illuminate (Dopson 2003). A further distinguishing characteristic of the case study approach is 'the extent to which a longitudinal perspective is taken, where researchers purposefully seek to take account of the impact of 'history' on the present' (Dopson 2003, p.218).

Using process methods with case study data is appropriate as they aim to examine 'how and why events play out over time' and use 'fine-grained [typically] qualitative data' as a way to understand 'patterns in events' (Langley 1999, pp.691–692). Through a narrative strategy to process analysis it is possible to consider chronologically embedded biographical events without a longitudinal research design (Langley et al. 2003). Focusing on process data (i.e. the telehealth usage process that underpins patient experience) includes analysis of *in vivo* observations, memories and interpretations and artefacts, which relay varying degrees of temporal embeddedness (Langley & Abdallah 2011).

The form of case study research can vary, from number of cases studied and the role of comparison, the size of the case(s) dealt with, and the extent to which researchers use the case context to document the phenomenon of interest in terms of wider society or historically for description and explanation, or evaluation and prescription (Dopson 2003). Understanding the advantages of this research design was useful as I relied upon the definition of a collective case study (Stake 1995) or a multiple case study within a single case study design (Yin 2014) to provide guidance through

analytical thickets, because it allowed for the selection of and focus upon extreme cases of complex interdependencies, while also encouraging the contextualisation of findings across cases.

There are two 'templates' for theorising from case study methods: the Eisenhardt Method and the Gioia Method (Langley & Abdallah 2011) which employ different epistemological approaches for qualitative management research. The post-positivist Eisenhardt Method is designed to maximise credible novelty by contrasting findings with previous research, and offering explanation in order to integrate the contribution. Data analysis begins with the construction of complete within-case narratives and these are then compared cross-case in iterative processes until a set of constructs that explain the similarities and differences emerge (Eisenhardt, 1989a in Langley & Abdallah 2011, p. 208). The final analytical step is to ask why the observed relationships are a credible explanation in a conversation with prior theory and research.

While the study is guided by the Eisenhardt principles of comparability across cases, it is informed by the principles of the interpretivist Gioia Method, which is designed to maximise revelation, richness and trustworthiness. Unlike Eisenhardt, Gioia tends to use a single rather than multiple cases. The Gioia method builds a horizontal tree-shaped 'data structure' to reflect a disciplined coding and analysis process toward progressive abstraction. 'Finding the twist that will pull all the ideas together is of course necessarily a creative act […] and the emerging models tend to be neatly parsimonious despite the mass of data that generated them' (Langley & Abdallah 2011, p. 215). Trustworthiness relates to insider-outsider roles, member checks and triangulation. The rhetoric used to write is to establish the gap, distil the essence, elaborate the story (by presenting the narrative and providing additional quotes in tables), and reaffirm the contribution. These principles and descriptive processes reflect the methods used in the analysis and narration of findings.

5.2 Case Study sampling method

The selection of this case of telehealth services was through theoretical purposive sampling, in which cases are selected according to predetermined criteria relevant to a particular research objective (Guest et al. 2006). My reasons for choosing this case of telehealth rather than studying users of a passive telehealth service (e.g. using ubiquitous ambient monitoring Telecare technology or video conferencing) or those linked with services requiring ownership of a mobile phone and ability to use SMS text functions, were theory-based. This telehealth service was theoretically interesting because it was a more inclusive service (e.g. by avoiding potential effects of a 'grey digital divide' by requiring users to be regular text message users), and introduces key changes to the traditional healthcare service delivery roles, such as who has access to clinical data and who measures vital signs. Firstly, the selected telehealth service actively involves patients in co-producing the remote monitoring using clinical machines; this use regularly exposes patients to their own clinical data. Secondly, the use of machines to measure vital signs to obtain 'a clinical

view' of the patient's health and justify subsequent treatment decisions is normally the professional domain of trained healthcare providers. In this service, the patients are encouraged to participate in this practice as a result of machine and service designs.

Prior to selecting this case, I had investigated and set up meetings with several examples of telehealth services from an NHS electronic patient records portal offering patients and carers the opportunity to obtain remote access via the internet; a remote monitoring service using patients' own mobile phones to transmit readings and respond to questions using SMS texts; a videoconference enabled 'patient briefcase' for temporary support of patients discharged from hospital; and two forms of virtual clinics, where video conferencing with clinicians could take place in a 'telehealth pod' in rural Scotland, or housed in a third sector organisation's premises linked with a local health champion equipped with an iPad to serve the traveller community who rarely registered with GPs and presented at A&E for their health needs. The selected case was identified initially through my PhD mentor, who was formerly an NHS chief executive, who told me about a telehealth project manager.

This service provided clinical monitoring equipment to patients and a simple to use telehealth machine for the purpose of uploading data to a remote server for analysis by clinicians. While attending an event for the mobile phone based texting telehealth service, I introduced myself to this project manager and eventually engaged him as a local research collaborator. In follow up meetings he explained that they had past experience collaborating with another university on a RCT and that there were issues he would be keen to avoid in future, such as nurses' reluctance to assign a likely candidate for telehealth to the control group, and the study findings emerging years later in an academic format that was no longer relevant to the operational decision-making process. We both attended a presentation of findings from the world's largest telehealth RCT and by then he had reviewed my research proposal based on the identified research gap and was happy to proceed. At the time he was negotiating approval for a large scale telecare and telehealth evaluation involving a combined telehealth and telecare longitudinal cost effectiveness study. A patient experience study was scoped within a wider integrated care programme evaluation with all three studies scheduled to complete in 2015 with findings presented to the NHS on 6 April 2016.

Before applying for research ethics approval, we agreed that my research could act as the patient experience study with two interim reports and a final report as deliverables. I was invited to attend quarterly meetings as a regular member of the assistive technology evaluation steering group, which provided me with updates on the service, the evaluations undertaken by two independent consultancy firms, and the commissioner's concerns about its future in a time of economic austerity. As stakeholders in the research, they supported my access to the telehealth service workers and introduced me to nurses who would be involved in recruiting patients as participants in the study. I

explained my interest in focusing on the telehealth service, and he agreed a contribution toward transcription costs (£2,200). The rest of my costs (travel, printing) were covered by my ESRC and university research and training grants.

5.3 Case study context

This qualitative study explores telehealth user experiences within a single telehealth service. The selected telehealth service is a free-to-use, NHS telehealth service in operation since 2006 to serve a large English city centre population. The total number of users at any one time has grown from roughly 40 to supporting 240 patients with the service by September 2015.

Patients become users when they agree to be referred to the telehealth service by their usual healthcare providers (e.g. specialist nurse, Community Matron, GP). The study found that potential telehealth users may also be approached directly through marketing presentations aimed at residents of serviced accommodation, although it is not clear whether this was conducted by the telehealth service studied, or a competitor. Two participants (Molly, George) described being invited to opt-in to telehealth as part of a telecare or warden assistance package offered by the residents' coordinator. The terms 'telecare' and 'telehealth' are frequently used interchangeably by service users, as well as reference to the service as 'the blood pressure' (Molly, Colin).

The telehealth service operations altered significantly during the study (described below), which would introduce variation in service experiences. However, because this patient-centred study explores individual patient experiences, and then makes cross-case comparisons, this change did not impede the study's ability to answer the research question. Two practical adjustments were made to the research protocol in order to accommodate temporary disruptions to the service due to time needed to install new equipment and provide user training. These were gaining ethical approval to extend an expected 12-month period for data collection to 18 months (December 2013 – July 2015) and ensuring a minimum of 2-months' experience with the new service had elapsed before users could be considered eligible for participation in the study. A third adjustment occurred where it became apparent that participants were not always familiar using an additional function (AnyTime Tests and Questions) that was planned for use during demonstrated use for observation. In order to avoid bias, their familiarity was screened when making the interview appointment, and interviews and observations were scheduled to occur during their normal time of telehealth use.

During my study telehealth users were also being contacted by other researchers as part of the cost effectiveness study, the integrated care study, and for marketing purposes: to obtain case studies for information leaflets, journalistic articles and to make videos for web-based marketing initiatives. These marketing products were aimed at GPs, nurses and social care organisations to increase their patient referrals onto the telehealth and telecare services. The participants I contacted did not express any negative feelings about overlapping attempts to obtain their feedback on the service.

5.3.1 Background: Service characteristics

During the first four months of data collection (January - April 2014), the free-to-use NHS provided telehealth service went through a planned change to their equipment suppliers. The use of the Honeywell (Genesis HomMed) equipment purchased in 2008 was changed to an updated model from Docobo (Doc@Home) equipment commissioned in 2014. The main differences between the systems were the user interface, equipment portability and wireless data transfer.

The Honeywell telehealth (left) was a fixed, wired-into-the wall box with six simple command buttons and an on-off switch. The Doc@Home (right) is a portable, dock-to-recharge, handheld device with the choice of touchscreen or button controls, and a reset button (Figure 10).



FIGURE 10 TELEHEALTH EQUIPMENT (L: HONEYWELL, R: DOCOBO)

The upgrade to Docobo did not entail obvious changes to peripheral medical equipment for taking vital signs measurements (i.e. digital blood pressure monitor, digital weighing scales, finger-mounted digital pulse oximeter). One major change was that the Docobo system was Bluetooth enabled to wirelessly transfer data from peripherals to the main device. The Docobo has other functions and features, such as foreign languages, electrocardiogram testing (ECG) and video calls, but their use was not observed in the sample. Both systems can be enabled with different mechanical voices speaking aloud the machine-based questions and confirming input functions. This prevented users with poor vision and low literacy from being excluded from the service.

The second change to the service experience was a shift from nursing teams to non-clinical staff providing the monitoring of readings and alerts for the telehealth service (Figure 11). Previously an NHS Health Technology Assistant (HTA) sitting within a clinical team office (e.g. Heart Failure Nursing Team) in an NHS building would monitor patient data transmitted to the remote server and respond to alerts by telephoning users and/or following up with them at a regularly scheduled home

visit. The HTA may or may not have been involved in referring the user to the service, but it is likely that a colleague from the same team was.

This was changed to the service being operated by call centre employees and installation engineers from a subsidiary business of an arms-length management organisation under contract to the local city council.



FIGURE 11 TELEHEALTH SERVICE SUPPORT WORKERS (L: HONEYWELL, R: DOCOBO)

5.4 Sampling method

I used a purposive sampling method for participants. They were known service users who were approached by their usual service providers to participate voluntarily and without payment in the study. Although there is risk of self-selection bias, there was a mix of satisfied and dissatisfied users in the sample to suggest that potential bias was controlled.

The research did not aim to achieve statistical representativeness nor generalisability to a population but to capture the richness of the sample population with a range of life and service user experiences and a wide range of demographic background. The focus of the sampling method therefore was sampling adequacy, and the resulting sample was appropriate as it comprised participants with knowledge of the research topic (Bowen 2008). Guest et al. (2006) suggest that 12 interviews should be enough to assess common perceptions and experiences amongst a group of relatively homogeneous individuals but larger samples are needed if the goal is to assess variations between the groups. This number is based on a study of technology usability by Nielsen & Landauer (1993 in Guest et al. 2006) who quantitatively demonstrated that 12 evaluators can uncover 90 percent of the major usability problems within a system.

Further details in Section 5.8.3 describe how patterns became evident in the accounts after 22 interviews with new information producing diminishing returns (no changes to the code book) and data replication and redundancy after 27 interviews suggesting data and theme saturation was achieved and the categories emerging from analysis were adequately explained (Bowen 2008; Guest et al. 2006). Arguments against saturation as a marker for the quality of qualitative research

suggest it is 'not always an appropriate criterion for all types of analysis' (O'Reilly & Parker 2013, p.194). They argue that if saturation is not reached, this means 'the phenomenon has not yet been fully explored rather than the findings are invalid'. This suggests it is acceptable for any limitations of sampling adequacy to be transparently reported.

5.4.1 Eligibility criteria

Eligible participants were identified by the telehealth services and approached by their usual healthcare providers about participating in the study. Participants came forward through self-selection, as telehealth users voluntarily gave their written consent to being contacted about taking part in the study. There was no payment for participation. Inclusion criteria was:

- Informed consent
- Adults (aged 19-90 years)
- English-speaking
- Experienced telehealth users with one or more long-term condition

Patients were excluded if they have dementia or other neurodegenerative diseases, otherwise lack Mental Capacity for informed consent, have extensive comorbidities that make participation too risky according to healthcare professional opinion, and are non-English speakers (since the telehealth equipment uses English language).

5.4.2 Participant recruitment

I presented the study at two regularly scheduled nurse meetings to discuss the aims and to request their assistance in recruitment processes and communicated with telehealth support workers for updates and queries. To safeguard vulnerable chronic disease patients, recruitment was through regular carers (e.g. nurses, Community Matrons, telehealth support workers) approaching users with the opportunity to participate in the study. Mid-recruitment, growing concern about sharing patients' personal data with the researcher emerged and were addressed by creating an additional consent form which was signed and dated by the telehealth user and countersigned by the person taking the consent. An unforeseen advantage of telehealth installers using the additional form to obtain consent to sharing contact information was that it provided the date of installation enabling the researcher to ensure contact by telephone took place after a minimum of 2 months had elapsed. The telephone call was to introduce the study aims, the process, the independence of the study, how confidentiality works, and that participation was voluntary and withdrawal was possible without providing reason. A convenient date and time for the visit to the patient home was arranged to coincide with their regular use of telehealth if possible.

5.5 Ethics

Ethical approval was obtained from the National Institute of Health Research Southwest/Frenchay Research Ethics Committee (Ref 13/SW/0253). The study was accepted to the UK Primary Care Research Network Portfolio and funded by a doctoral studentship at the University of Nottingham from the UK Economic and Social Research Council (Ref ES/J500100/1). The research was conducted according to institutional codes of research conduct ensuring participant welfare, participant and researcher safety, confidentiality, protection of anonymity and secure storage of data at all times.

5.5.1 Secure data storage

All data were securely stored in compliance with University and NHS ethics policies. Personal data was stored in locked cabinets in secure offices on University premises. Electronic data was stored using Study IDs in a password protected folder on a University network drive. Any data that was not stored or otherwise in use was anonymised.

5.6 Sample characteristics

The total sample size (n= 27, 1 withdrawal) reflects a 38.6 percent response rate and was demographically diverse:

- aged 40-90 years
- 16 males, 11 females
- 13 living alone, 14 cohabiting
- 1 Asian British; 3 Black British; 19 White

The majority of sampled users tend to be old and frail although there are two younger participants in their 40s (Table 7). Users typically suffer from multiple chronic health conditions and their effects mean they may find it difficult to negotiate life both inside and outside the home and have had to adapt their lifestyles significantly compared to their activities before the onset of illness.

TABLE 7 SAMPLE PROFILE

Study ID	Age	Ethnicity	Gender
Alastair	82	White	Male
Aziz	78	British Pakistani	Male
Brian	63	White	Male
Cleo	90	Black British/Afro Caribbean	Female
Clive	78	White	Male
Colin	77	Black British/Afro Caribbean	Male
Darren	43	White	Male
David's widow	n/a	White	Female
Elizabeth	77	White	Female
George	77	Black British/Afro Caribbean	Male
Graham	81	White	Male
Howard	66	White	Male
Julia	63	White	Female
Kate	74	White	Female
Marion	83	White	Female
Molly	83	White	Female
Nigel	66	White	Male
Peggy	83	White	Female
Phil	59	White	Male
Rachel	68	White	Female
Ray	66	White	Male
Robert	70	White	Male
Russell	82	White	Male
Ruth	76	White	Female
Stacey	40	White	Female
Stephen	70	White	Male
Ted	81	White	Male

Unlike most telehealth studies, which tend to target groups on the basis of a single chronic disease, this study was designed to be maximally inclusive in order to capture voices of patients with a range of health issues. In one tragic case, the scheduled participant's story is captured by his now-widow as he was hospitalised the weekend before the interview took place and he eventually died in the following months. At the time of his scheduled interview, in his absence his wife shared her telehealth experience with the researcher.

The health issues listed in Table 8 provided by participants during the interview show the breadth of the sample's health conditions. The list was observed by the researcher to be selective, depending on what participants decided was relevant to disclose. For example, patients with obstructive sleep apnoea did not also report underlying obesity as a health issue. To ensure anonymity, participant health conditions are not presented in the same table as the sample profile.

TABLE 8 PARTICIPANT-REPORTED HEALTH CONDITIONS AND TYPE OF TELEHEALTH IN USE AT TIME OF INTERVIEW

Health issues	Type of Telehealth
Psoriasis, asthma, back pain, T2 Diabetes, waiting for 2 arterial stents op	Docobo
Heart attack, weak heart, arthiritis, hard of hearing	Docobo
Diabetes T2, Angina, CHD	Docobo
COPD, angina, T2 diabetes, asthma, Obstructive Sleep Apnoea	Docobo
COPD	Docobo
T2 diabetes, alcohol dependency	Docobo
Asthma, COPD, stroke, pacemaker, kidney disease, osteoporosis,	Docobo
AF, Stroke (x 2), knee replacement, primary carer for husband in psych hospital, cataract surgery, gastric flu	Docobo
HF	Docobo
Diabetes, Osteomyeloma, COPD, Asthma, Osteoporosis, Strokes, Heart attack, Blood problems, Arthritis of the hips, legs, hands and feet	Docobo
HF, osteoporosis, COPD, bad fall, colostomy, metal spine inserts, peritonitis, broken femur, appendicitis, tonsilectomy	Docobo
COPD, angina, abscess, arthritis, hips, osteoporosis, diabetes	Docobo
Lung cancer, AF, knee and leg pain	Docobo
Spinal surgery, T2 diabetes, kidney disease, erratic BP, chronic back problems (25 years), asthma	Docobo
3 prolapsed discs in lower back, sciatica, T2 Diabetes, chronic kidney disease, menorrhagia, anemia, lymphodema, morbid obesity	Docobo (planned swap to FLO)
HF, sleep apnoea, asthma, COPD, angina, fibromyalgia, thyroid problems, heart attacks, strokes, depression	Honeywell
COPD, Diabetes, HF	Honeywell
COPD 30 years, DVT to PE, Heart disease	Honeywell
COPD	Honeywell
HF, Crohn's, ulcerative colitis, polyps removed, spinal and cerebral meningitis, heart attacks, falls	Swapover to Docobo
Stroke, T1 diabetes, erratic BP, blind right eye (diabetic retinopathy), Charcot's bone disease, 2 toes amputated, coeliac, wheelchair bound, suprapubic catheter, neuropathy, anxiety	Swapover to Docobo
COPD, pseudomonas, bronchiectasis	Swapover to Docobo
Diverticulitis, arthritis, HF (triple bypass), gastric colitis, hip replacement (will be 2), knee replacement	Swapover to Docobo
COPD, pseudomonas, T1 diabetes, Bronchiaecstasis	Swapover to Docobo
COPD, anal polyps, basal cell carcinomas, heart failure	Swapover to Docobo
Psychiatric, pacemaker, fibroids, hysterectomy, bad nerves, depression, osteoarthritis, scoliosis, AF, valve problem, diabetes, IBS	Swapover to Docobo
T2D, angina, Tachybrady syndrome, 3 strokes, neuropathy, COPD	Swapover to Docobo

5.7 Data collection: Sensitisation, Interviews and Observations

5.7.1 Sensitisation

The ethical approval process for patient studies focuses on safeguarding patient interests, therefore 30-minute interviews were planned to avoid over-burdening vulnerable participants. Good Clinical Practice guidelines suggest that obtaining informed consent requires 10 minutes. Given time constraints, my main concern was establishing rapport quickly, because it is extremely important in conducting interviews that informants feel at ease to share their thoughts, stories and feelings candidly.

The use of sensitisation techniques were intended to improve my skills as a researcher by making key features of the context familiar so that I was more receptive to nuance. These included immersion in patient stories using written and video accounts, and studying projective techniques[8] used in marketing to enable participants to express their opinions rhetorically as a lay expert or interested observer, without asking them to risk personally disclosing their opinions as if they were grounded in their own experiences.

Prior to conducting interviews, two half-day work shadow visits with two telehealth installers took place once the ethics approval was received and I waited for nurses to share details of potential participants. The visits began at the telehealth service headquarters at the bottom of a cluster of high rise social housing buildings. I was introduced to various members of the telehealth and telecare teams, gathered their opinions of the service, saw the back office facilities, including how equipment was inventoried, and how the support workers went about their work. I spoke informally with the Manager before accompanying installers to six patient homes (two occupants did not answer the doorbell) for scheduled installations, replacements, repairs, and retrieval of unused equipment.

The visits helped acclimatise me to the ambience of service users' home settings, to get a glimpse of their lifestyle and gauge their willingness to receive a stranger into their home, and to observe the service operations from the provider perspective. I observed service interactions between providers and service users and listened to the opinions of telehealth workers during the car journeys, which provided ample time to ask questions before, during and after patient visits. The roster of visits covered a considerable amount of the city, including large residential areas that were unfamiliar to me, and gave me time to consider the types and condition of housing stock, the local

[8] 'Projective techniques allow respondents to project their subjective beliefs onto other people or objects. Individuals' feelings are inferred from what they say about others. These techniques, originally developed by psychologists, provide non-threatening ways for participants to indirectly explore and discuss their feelings' (Hines & Lee n.d., p.2).

topography, and to obtain an impression of the local community, including type and accessibility of local amenities and public transportation that physically surrounded the telehealth service.

5.7.2 Semi-structured in-depth interviews

Interviews are ways of gathering participant perspectives of the research topic, and to understand how and why they have come to that perspective (King 2004). They are ideally suited to examining phenomena in which different levels of meaning need to be explored and is a form of interaction that participants readily accept. Interviews are flexible to accommodate different modes of expression and digression which may provide routes to rich unforeseen data. Interviews aim to impose a low degree of structure, use a preponderance of open questions, and focus on 'specific situations and action sequences in the world of the interviewee' (Kvale 1983, p. 176) rather than abstractions and general opinions. The interviewee is understood to be a participant in the research, 'actively shaping the course of the interview rather than passively responding to the interviewer's pre-set questions' (King 2004, p.12).

Realist, radical constructionist and phenomenological interviews bring different assumptions about the accounts that are produced. Realist approaches assume that the accounts produced provide insights into participants' psychological and organisational lives, and have a direct relationship to their real experiences in the world beyond the interview situation. This requires care regarding the accuracy of the accounts and the use of triangulation with other forms of data is a common strategy. For this reason, realist interviews may be more structured in order to ensure accounts and other types of data can be systematically compared. Radical constructionist approaches assume the account to be a text that is produced in the specific setting of the interview that requires analysis of the discursive strategies employed and resources drawn upon by the interviewee. Using such an approach would not lead to any claims about the participant's personal experience (King 2004, p.12). Phenomenological interviews are typically longer, with collection and analysis stages overlapping. Foremost this type of interview requires researchers to be aware of and 'bracket' any presuppositions about the phenomenon of interest to avoid biasing the accounts. Users of these methods recognise that the text produced is shaped by the interview context and accept that it has a direct relationship with the participant's personal experience (King 2004).

In choosing to make realist and phenomenological epistemological assumptions about the ability of participant accounts to provide insight into their actual experiences of telehealth services, an interview protocol (Table 9) was a loose guide to facilitate cross-case comparison by ensuring conversations addressed the research questions using a core of standard questions (Mitchell & Jolley 2010). The critical incident technique (CIT) (Flanagan 1954, p.327) was used to ask participants to recall and discuss a positive or negative experience of telehealth services, enabling the collection of specific and significant conditions and responses as 'facts', providing 'a sound

basis for making inferences as to requirements' to be used in place of direct observation of the events (Gremler 2004). The use of open questions allowed for new themes to be shared, capturing patients' own words and topics for further investigation. CIT is used to elicit participant accounts from their own perspective, which increases the reliability of the data (Chell 2004; Gremler 2004). Open-ended semi-structured depth interviews combined with CIT are accepted data collection methods used in consumer-centric value co-creation in professional services research (Greer 2014). Although the use of a stock of prepared questions may seem too directive and closed (Willig 2001 in King 2004) an awareness of the time constraints of the interview meant parsimony from the interviewer would allow more time for the interviewee to respond. Probes moved discussion onto related areas or to follow-up responses where necessary to elicit greater depth and detail.

TABLE 9 INTERVIEW PROTOCOL

Q1 Tell me about your health nowadays	How has this changed from first diagnosis? Any problems?	Context of use
Q2 How did you learn about telehealth?	Who recommended it and why? How do you feel about it?	Context of service, Referral mechanism, Value proposition
Q3 Do you find telehealth useful? Why?	a) If you could change anything about it, what would you change? b) If you were going to tell someone you know about telehealth, what would you tell them? (benefits) c) If you were going to warn someone about the potential drawbacks of telehealth, what would you tell them?	Subjective value, Suitability
Q4 Do you talk about telehealth with anyone?		Embeddedness
Q5 Can you show me how you use the telehealth equipment whilst explaining what you're doing?		Human-machine interaction
Q6 Is there anything else you'd like to tell me about your experience of telehealth that we haven't already covered?		Emergence

A case study making realist assumptions about the interview data would want to include a sample representing important distinctions within the service user population in relation to the phenomenon of interest, and would 'assert that the analysis gains in validity by increasing the number of different viewpoints collected via interviews' (King 2004, p.16). As discussed in Section 5.4 links between quality, validity and sample size relate to the sufficiency of the sample data and systematic analysis for thematic saturation about the phenomenon of interest.

The validity of interview data is strengthened by cross referencing with other data sources including: two hours of short video-recorded demonstrations of telehealth use by 22 participants, photographs, field notes and reflective journal entries from participant observations. Videos and field notes allowed me to review user-machine interactions for detailed cross-case comparisons (Section 5.8.2). Consent for the use of video recording and to take handwritten field notes was also obtained.

The sample data was comprised of 27 individual patient case studies comprising 531 transcript pages from more than 29 hours of audio-recorded interviews. Methods of data analysis to achieve thematic saturation are discussed in Section 5.8.

These patient-centred data were combined with a qualitative study of the health system providing the telehealth services using interviews (see Table 16 Additional data sources
Additional data sources) and document analysis. As appropriate to an exploratory study, an interpretive approach to analysing the data was used. Basic demographic data was collected to obtain sample characteristics (see Table 7 & Table 8) to report the representativeness of the sample.

5.7.3 Participant observations

The interview is a social construction where researchers and participants are presenting themselves to strangers to discuss difficult topics, and interests in communication are partially declared (Alvesson 2003). Given the short time to establish rapport, participant observation provided a different source of data useful for checking validity and reliability of verbal accounts. Participant observations occurring before and during the interviews efficiently captured rich contextual detail compensating for relatively short periods of exposure to participants (approximately 60-90 minutes each).

Participant observation 'involves social interaction between the researcher and informants in the milieu of the latter' (Taylor and Bogdan 1984, p. 15 in Waddington 2004, p.154). The observer studies participants' experience and behaviour in particular situations, and has the opportunity to talk to them about their feelings and interpretations if necessary. The observer-as-participant (Burgess 1984 in Waddington 2004) maintains superficial contacts (e.g. asking occasional questions) with the subject being studied, and positions the researcher in a way that enables their own experience to be considered an important and legitimate source of data (Brewer 2000, p. 59 in Waddington 2004). For example, my inexperience with telehealth allowed me to ask questions, thereby positioning the patient as expert during the interview. This enabled them to disclose frankly their opinions in a helpful way to make me understand, without fear of judgement.

Participant observation uses an inductive strategy, which means the researcher utilises initial observations as a starting point from which to formulate hypotheses which may subsequently be

discarded or refined (Jorgensen 1989 in Waddington 2004). It is suggested that observers 'pay homage' to participant routines by not requiring them to depart from their usual schedules or contexts of interaction, and that these ploys help the forming of a 'bounded reciprocal relationship' based on mutual trust and cooperation (Roper and Shapira 2000, p. 17 in Waddington 2004, p.156). This method can be more sensitive for understanding what people do and how this influences their experiences and can be less influenced by attempts to communicate edited versions of their experience through linguistic summary. It provides a means to validate what people say by studying what people do. People may be reticent to voice negative opinions that may reflect badly on themselves, and they may also be unaware of or lack access to comparators to moderate their opinions. As a participant observer, I was in a position to gauge what they say and do against other cases, and assess whether verbal expressions were 'banter' to deflect further discussion, clichés for expedience, or other expressions of expected social norms (niceties, role performances, impression management) in layers of lived experience and reality that might be hidden from public view for fear of hostility or criticism (Goffman 1959; Scambler 2009). By asking them clarifying questions in reference to the local features I'd observed, it was possible for them to speak more familiarly about specific details that could provoke their further reflection. This often led them to share contextualising details about their actions and narratives more clearly, leading to more candid and interesting revelations.

5.7.4 Validation procedures

Validation procedures were informed by Lincoln and Guba's (1985) evaluation criteria for establishing trustworthiness of qualitative data. Credibility refers to confidence in the truth of the data and researcher credibility. This was established through persistent observation even after the interview was concluded, triangulation, peer debriefing, and searching for disconfirming evidence. Dependability refers to the stability of data over time and over conditions, and the controlling of unstable conditions (equipment changes and introducing new criteria for 'experienced user' classification) were transparently reported. Confirmability refers to the objectivity or neutrality of the data such that independent reviewers can reach an agreement about the data's relevance or meaning. Transferability essentially refers to the generalizability of the data and the extent that the findings can be transferred to other groups or settings (Im & Chee 2006).

As Section 5.3 explained, the telehealth service undergoing several major changes including the: contracted service providing organisation, telehealth support workers, equipment manufacturer, available types of equipment. This means the findings relate to a case of a telehealth service in flux, which is characteristic of all open systems. This meant that the inclusion criteria for 'experienced users' (i.e. at least two months of use) could be misleading, as they were introduced to novelty at a relatively constant rate throughout the study as a result of service (re)introduction, repairs,

replacements, and upgrades. These issues were iteratively identified and controlled for in the collection and analysis stages.

Interim findings from the analysis of patient data were validated by iterative triangulation by tacking back and forth between a range of additional data sources. These included obtaining feedback on observed behaviours, and patient narratives and opinions from a variety of clinical and academic experts as well as key informants from the telehealth service (see Appendix 1).

These data sources provided a view of expected use, provider-identified issues affecting telehealth users, and provided a mode of validity checking of emergent findings describing subjective interpretations of healthcare service experiences, clinical decision-making and accepted use of diagnostic equipment encountered during the conduct of fieldwork in the patient lifeworld.

Interim findings were presented at academic conferences and in guest lectures delivered to practising registered nurses during their Learning Beyond Registration courses (Table 16 Additional data sources). These presentations on interim findings took place over 3 years to 5 nursing cohorts during *Contemporary Issues in Long Term Conditions* and *Clinical and collaborative decision-making* modules. These sessions involved interactive discussion on patient perceptions of user experiences in order to look at patient practices from a clinical perspective. This was useful for framing the actions and stories emerging in patient stories against provider descriptions of similar events.

5.8 Transcription, data coding and iterative analysis

5.8.1 Transcription

More than 29 hours of audio recorded semi-structured interviews with telehealth users were transcribed. Analysis began as I transcribed the first 8 interviews, and a further 18 interviews were professionally transcribed. Transcripts were carefully checked for accuracy. For one interview (Kate) I took handwritten notes, finished them in the car, and wrote up full field notes immediately after, directly into the NVivo for Mac 10.2.2 memos folder. This was my practice after every trip to the field. I typed my observational field notes directly into this programme for easy cross-referencing to the case transcripts.

5.8.2 Video and photographic data

The use of video observations was included in the research design in anticipation that the short patient interview (30 minutes + 10 minutes to obtain informed consent) might not result in sufficiently rich data if the participant was not able or unwilling to answer questions in detail. This was not the case. Because five participants did not consent to video recording, its systematic use

across the sample was not possible. Practical reasons[9] dictated that the use of video data enabled some systematic cross-case comparisons but was mainly an *aide memoire* for cross referencing between what they were physically doing as they interacted with the machines, what the machines were doing, and to check for contradictions between their verbal descriptions and commentaries, and their actions and reactions as they explained what they were doing and why.

During demonstrations of their telehealth use, I would ask for clarification about what they were seeing and thinking, as providing a running commentary did not seem to be a natural practice. This non-naturalistic sense was heightened by the use of video when participants described their usage as not representative of their usual experiences. The combination of suspected Hawthorne effects, White Coat Syndrome in response to be observed and participants engaging in impression management (Goffman 1959) meant that my initial eagerness to closely analyse physical user-machine interactions were eclipsed in interest and importance by the invisible interpretive practices that were surfacing, which appeared to indicate what participants are doing with telehealth is informed by and directed at different levels of service interactions. This midstream clarification of focus to a modified phenomenon of interest (i.e. interactions between telehealth service and usual healthcare services) is common in ethnographic research (Hammersley & Atkinson 2007).

Photos of participants' written patient records were not systematically obtained. My recognition of their unanticipated importance occurred after observing a few examples of their practice. Latterly I began to ask for photos as evidence of variation between level of detail, evidence of literacy, regularity of use, etc. Neither the video nor photo data files were uploaded to the NVivo project file due to overall file size making the programme unstable.

5.8.3 Coding and iterative analysis

Coding is used in qualitative consumer research to systematically categorise units of data into rich theoretical categories that enable researchers to move beyond identification of themes and unrelated constructs (Miles & Huberman 1994). The coding process was iterative and multi-staged following a simple process of inductive thematic analysis. A first round of readings without a predefined scheme or template for analysis involved hand analysing 531 pages of interview transcripts thematically (using highlighters and marginalia). This was followed by the elaboration of simple criteria to systematize the second round of readings to identify telehealth use experiences in context, according to themes, or 'chunks of data' that are 'representations of reality described by the data' (Spiggle 1994, p.493). Themes are used for

[9] Having familiarised myself with the area of multi-modal transcription, I had intended to upload the photos and videos of participants demonstrating their use of telehealth machines to the NVivo project file in order to use multi-modal analysis, but these functions were not part of the Mac version of the software and although project files can be converted to Windows or Mac versions, they are not designed to be used across-platforms.

> understanding and interpreting the meanings and experiences of informants. [They can be used to] decode cultural meanings in interpreting how the display of symbolic codes and performance of cultural rituals affirm and reproduce cultural themes and motifs […] *thick description* […] relies upon understanding informants' points of view (emic) to portray broader cultural meanings (etic point of view) (Spiggle 1994, p.492).

Handwritten summaries on a cover sheet for each printed case began a process of naming and detailing emergent themes, and brought together details about the context from field notes. This inductive procedure led to the generation of etic constructs that link empirical and conceptual domains.

To organise the links, the coding process was then transferred to an NVivo for Mac 10.2.2 project file, to further categorise, abstract and constantly compare (Spiggle 1994) evidence from the data and my systematically growing interpretation in a visible structure. A provisional categorisation began to form through the organisation of first order coding and drawing axial connections across cases. Some clustering of experiences was noted, but this process was complicated by passages of text being seen to represent multiple provisional labels, which suggested that categories of telehealth usage experience were not mutually exclusive, and that user experience was dynamic within their own narratives (e.g. when their condition or the equipment changed). Every participant had a different story based on a wide range of biographical experiences that they were encouraged to relate to their illness experience in order to understand the role of telehealth in their lives. This introduced complexity when trying to clarify transparently the analytical method that enabled adducing themes on the basis of comparability and/or extreme insights into the phenomenon of interest (Dopson 2003). As this research is an exploratory study of cases that broadly follows the Gioia method to obtain rich insight into the phenomenon of interest but is aware of the Eisenhardt comparative method's advantages, the decision to be inclusive of extreme cases was influenced by its abstraction (zooming out and losing focus on contextual details) into aggregate constructs. This meant the whole sample is represented in the aggregate constructs.

This decision to zoom out, was specifically operationalised in the treatment of variation evident from the role of carers in telehealth experience (i.e. their experience was different), which could potentially introduce questions about the data, e.g. on the basis of comparability. However, although this thesis aims to produce a 'voice of the patient' study, the social construction of *the telehealth user* in many cases is actually a compound entity 'in the field'. This complication was the result of the loose structure of the interview, which allowed for carers to be present in order to ensure patient participants were comfortable. However, this decision introduced a great deal of variation in the observed proficiency of using equipment and opinion if the primary user was the patient or their more able-bodied carer.

Differences resulting from the positioning of the equipment in the home also meant certain issues were highly relevant in one case but not in others. Finding strong cases of commonality between cases in terms of coding frequency could be misleading because certain dimensions could be contradictory but still present in the same case, depending on who was speaking (e.g. carer or patient). Analytical decisions had to be made about how to interpret the data: a) when there were many clear references to the same theme discussed repeatedly (creating multiple chunks of similar data) and whether this supported or exaggerated the significance, and b) when there is singularity of an extreme experience; forcing me to decide whether it mattered in a small sample that this could be an outlier example, rather than a common experience across the sample. These decisions were made iteratively as coding schema developed from an exploratory tool into an instrument that assists an explanatory narrative, i.e. when writing this thesis.

Abstraction to higher order constructs involved collapsing empirically grounded categories into conceptual constructs (Spiggle 1994), and blurring detail by zooming out (Nicolini 2009; Leroy et al. 2013) to identify commonalities between the representations of participant 'realities' and their perspectives of 'other realities' (e.g. the care they receive, provider values). First and second order codes, or constructs, served as broad themes that were repeatedly questioned, renamed, rejigged and reordered in iterative triangulation between the data, the literature, and my reflections on them. When a coherent interpretation or 'story' was able to explain the connections between the different constructs and their domains, the bulk of analysis had been accomplished. The meaning of dimensions (and their limits) continued to develop throughout the reflective writing of successive drafts and presentations for discussion.

5.8.4 Generating inferences through abstraction

I used Nvivo primarily as an organisational rather than analytical tool. The benefits of the software during writing were immeasurable, enabling efficient location of text. It provided a single repository for primary and secondary data, and organised processual and analytical notes during close reading of the transcripts.

Using NVivo enabled me to move from handwritten themes to create nearly 300 separate codes detailing practices, processes, service interactions, attitudes, and contextual details that were also annotated with analytical and procedural memos, and field notes. Unsurprisingly, the project file became increasingly unwieldy to use analytically due to diminishing returns making it energy-intensive rather than -conserving or adding visual clarity. I had to iteratively resolve analytical dilemmas that followed after using inductive approach to open code initially identified themes. Section 5.8.6 explains how this was done. The most analytical clarity came as I wrote drafts for the thesis developing the theoretical contribution while revisiting and updating the literature review.

5.8.5 Coding summary

Table 10 shows the systematic interpretation of what participants were doing and describing (Open codes) and how connections were drawn from these snapshots of their reality (based on their actions and their narratives) to show commonalities in the sample between cases. These were systematically collapsed into higher order conceptual constructs. These emergent constructs confirm some findings from previous studies as well as highlighting novel insights that were drawn out through theoretical framing devices, such as categorisation according to the level of interactions to depict the patient-led interaction between telehealth and different service channels comprising the wider healthcare system. These patterns provide evidence to address the under-theorised *how* and *why* research questions.

TABLE 10 CODING SUMMARY (ORIGINAL WORK)

Open codes (examples)	First order	Axial codes	Second order	Aggregate constructs	Level of interaction	Chapter
Falls, inability to do usual things, restricted mobility, anxiety, reliance on equipment, familiar environments and situations experienced as hostile and risky, support of family, friends, neighbours, meals on wheels, local shops, social services, shrinking world	Fear of harm Needing help Reordering activities Social support	Losing control Disorientation Increased technology consumption (products and services)	Regaining control in lifeworld by customising technologies	*New/Re-orientation in lifeworld*	User-machine	6
Telecare, CCTV, Intercom, Emergency mobile, Pendant alarm, Own monitors, Telehealth, dispensers, C-PAP, scooters, online shopping, home visits	Choice and combinations to suit preferences Customising	Ubiquitous technologies Reordering spaces	Constructing lifeworld context by introducing technologies	*Mastery of lifeworld*	User-machine	6
Moving to telehealth, Stopping in all day, Answering calls, Repeat readings, Long delays, Frustration	Physically, mentally, emotionally, temperamentally accommodating machines and service demands Effortful use	Positioning in house (machines over user)	User being shaped by technology	*Effortful use*	User-machine	6
Detecting problems, Re-inflating, Poor time keeping, Not working, Inaccurate, Did not transmit, Devising Workarounds, Manual entry, Calling for help, Asking questions, Seeking witnesses to corroborate, Technical trouble-shooting	Going beyond simple user interface that was expected Effortful use	Fickle machines Confrontative coping strategies	Goal-orientated consumption	*Task-based technical mastery*	User-machine	6
Feeling frustrated, Asking, Questioning machine results, Comparing between machines, Comparing with how they feel, Cross-referencing with previous experiences, Going through the motions without understanding, Trusting the experts, Wondering why,	Imperfectly interpreting Progressive discovery Learning through use Gaining confidence	Applying home version of clinicised view (lens) to their subjectively perceived health status	Personalised health literacy as clinicised self-knowledge Translating clinical rationality into lifeworld rationality	*Reorientation of worldview* *Straddling boundary between lifeworld and system world*	User-machine	6

Mispronunciation/Using domestic terminology, Misinterpreting set questions		Sympathetic but untrained biomedical gaze				
Unexpected technical trouble-shooting, Doubting, Blaming self, Blaming machine, Blaming system, Questioning value of telehealth, Cross-referencing machine results with subjective feelings and other machines, Evaluating telehealth for what it does (not what it doesn't do)	Frustration at limitations of service compared to imagined/sought value Lowering expectations	Growing importance of patient self-report From controlled by machine to control of machine	Repositioning telehealth in the home (gaining upper hand over machines and service) Mutual shaping, moving from object-oriented to intersubjective orientation	*Process of effortful use of system technologies for positive outcome (subjective value)*	User-service	6
Finding machines awkward to use, Habitually choosing which reading to send, Questioning sense of results, Repeating readings, Mimicking clinical practice, Showing awareness that clinical data is a self-portrait being used to judge need for care	Choice, reflection, ensuing action Controlling and dictating what data is analysed by algorithm	Moral dilemmas to avoid false alarm and wrongful self-portrayal that risks undermining their needs	Translating clinicised lifeworld rationality into system to influence how system will affect their lifeworld	*Mastery of technologies (machine and system)* *Translation I & II*	User-service	7
Experiencing: Clinical errors, Abusive treatment, Dehydration, Neglectful treatment, Wrong diet, Wrong pills, Poor stoma care, Kept in longer than necessary, Incidental harm, Conflicting opinions, Experimental treatment, No continuity of care, Sleep deprived, Doctors speaking gibberish, Challenging, Complaining, Avoiding, Trying and failing, Confusion, Fearing consequences, Changing prescriptions, Withholding prescriptions	Hospitalisation requires ceding control Extensive knowledge of what happens in hospital setting Life-saving treatment and fear of harm Injury, Emotional upset, Confusion about what's right Coming up with post hoc explanations, rationalising what happened to them	Systems knowledge Fear of non-care (Emotional, relational, functional) Cultural, physical and social resources integrated for understanding	Regaining control Service recovery Avoidance of non-care by increasing self-care Division between value systems: lifeworld and system world,	*Mastery of system rationality (as different to lifeworld rationality)* *Developing Personalised health literacy as systems knowledge*	User-service	7

	Attributing blame to hospital system functions					
Doing their bit, Helping, Giving back, Writing down results, Answering quickly, Sharing results, Avoiding wastefulness, Taking photos, Collecting samples/evidence to argue for more or less care, Attending regular appointments, Carers as telehealth users, Seeking guidance, Wanting to be trusted/believed/perceived positively by clinicians, Wanting to be listened to, Self-initiating 'rescue meds' use (antibiotics and steroids) and reporting	Task-based clinical work-sharing Citizenship behaviours Sophisticated patient-led team work titrating medications/triaging call-outs Building evidence base for own use/analysis Empathising with nurses Demonising doctors Managing relationship with usual carer (intersubjective)	Using system knowledge to align consciousness about resource scarcity and barriers to access with subjectively perceived need Assemblage and orchestration of the healthcare team of social actors	Co-producing wider system (outwardly) Co-creating subjective value privately (contingent on level of system knowledge, what they are empowered to do)	*Mastery through managing relationship with system (subject-object relationship maintenance)*	User-service	8
Questioning and Interpreting vital signs, Recalling clinical advice/observations, Explaining condition, Self-diagnosing, Predicting outcomes, Using telehealth to make their own clinical decisions by denying, delaying, deflecting, defending themselves, asserting own opinion, Knowing who and when to call for help/info	Regaining control over how they are treated, what happens to their bodies and when Self-managing Meaning making Domesticating clinical language	Self-protection, resisting objectification by machines Access to further healthcare at their own instigation	Controlling access to healthcare resources Patient self-report rules decision-making Lifeworld values changing system world interactions	*Mastery of system (domesticating it, making it less strange)* *Strategic forward planning about when to cede control*	User-service	8

5.8.6 Iterative analysis: process analysis and realist retroduction

Transcripts and field notes were iteratively analysed using a three-stage method. First using inductive thematic analysis, followed by an abductive narrative strategy to process analysis (Langley & Abdallah 2011), and lastly conducting abductive realist retroduction (Bygstad & Munkvold 2011) to generalise to theory. Emergent themes within cases were systematically coded to improve internal validity of aggregate constructs that describe findings from the data across cases. Using multiple case sampling and replication logic (Eisenhardt 1989; Yin 2011) to increase validity and generalizability of within case themes (Miles & Huberman 1994), rigorous and systematic analysis was performed to enable complex networks of conditions and outcomes to be analysed (Olsen 2009; Bygstad & Munkvold 2011). By framing the results using a narrative strategy to organise chronological events into cause-and-effect process models, it was possible to identify antecedent or probable cause variables as contextual conditions (Langley 1999) explaining patient experience of telehealth and to conceptualise conditions for the emergence of patient value and to identify conditions triggering generative mechanisms for social change (Archer 1995).

Applying a process analysis strategy (Langley 1999) to organise the themes emerging from the data into concepts relevant to extant theory was strategically useful in two ways. Langley's (1999) analytical framework requires that temporal aspects of data to be considered. This enabled the current snapshot of patient experience to be conceptualised within the participant's narrative chronicle of events. An advantage of considering temporality is that the effects of telehealth services can be judged against the dynamic conditions that affect the patient and their relationship with features of their lifeworld without necessitating a longitudinal design. The privileging of rich data imparting clues about context across time enables a researcher to delve beneath face-value impressions, to look for emergent tendencies that may signal interactions with socio-historically embedded structural arrangements, such as attitudes, beliefs and routines (Scott 2008). This view of a service within an ecosystem includes acknowledging the possibility for influential institutional arrangements (Edvardsson, Skålén, et al. 2011) that influence and underpin experiences resulting in certain types of consumer value over others (Askegaard & Linnet 2011). Applying a process framework also helps in the practical application of the S-DL framework by breaking it into its constituent components of resources that are relevant to a goal or project, value co-creative interactions and emergent value (Vargo & Lusch 2016). With reference to critical realism, the socio-historically constructed institutional arrangements are conceptualised as intransitive transfactual powers belonging to the imperfectly apprehensible real (rather than the actual). These causal powers are argued to display observable tendencies that may be understood theoretically as generative mechanisms that may be triggered as a result of necessary conditions being satisfied. Retroduction is an admittedly creative process (Bygstad & Munkvold 2011) which aims to theorise about plausible causal connections between conditions and outcomes at the micro level while also

suggesting that they may reflect tendencies that imply otherwise invisible transfactual powers at the macro level. Thus retroduction is a conceptual tool for the analysis of social action through empirical study (please refer to 4.3.2 Intransitive Objects, Transitive Products, Transfactual Powers and Emergence).

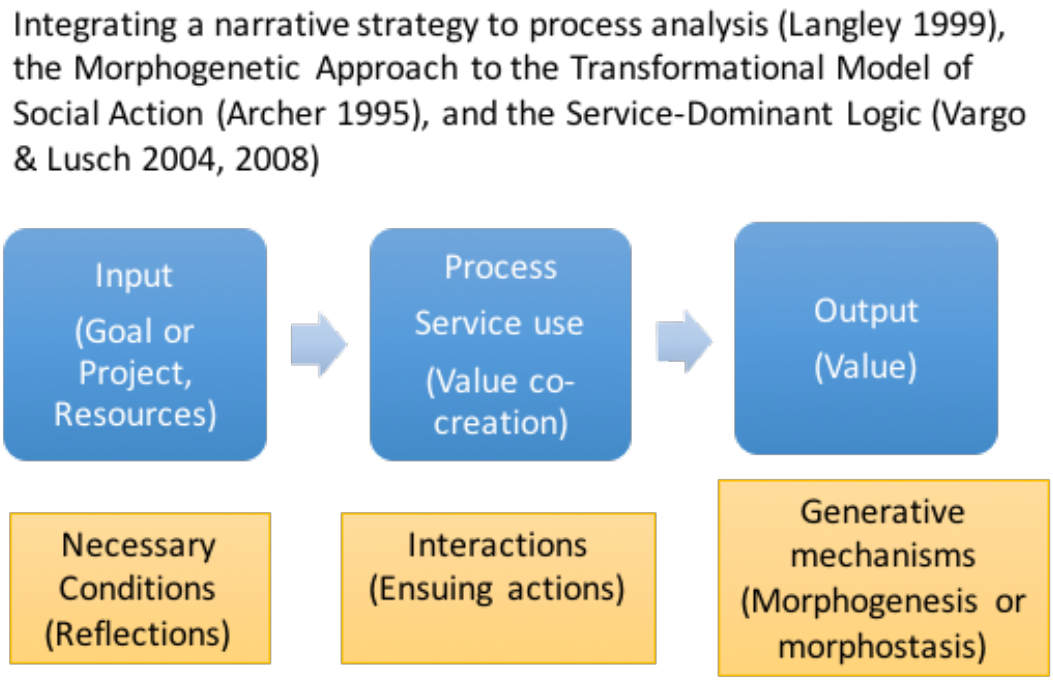


FIGURE 12 INTEGRATING PROCESS ANALYSIS, SERVICE-DOMINANT LOGIC AND THE THEORY OF MORPHOGENETIC TRANSFORMATION (ORIGINAL WORK)

Figure 12 shows the three analytical perspectives together. A process approach frames the fundamental component of the telehealth experience as relating to three analytically distinct stages of the consumption process. This conceptualisation helps the analyst to consider patient experience in terms of a process that is oriented toward functional, variously outcome-related goals. Therefore, items (quotes, observations) were constantly abstracted as either related to:

(1) having access to the necessary elements for telehealth use (input, including expectations, functional and process goals),

(2) what happened when they used the service (the telehealth service experience as a technology-mediated service process), and

(3) what are the benefits from the patient perspective of using the service (output, latter stages of the consumption process, functional achievements of value).

This framework together with the identification of emergent themes from the data made it apparent that the study of patient experience of telehealth was analytically separable to three levels:

- user-machine interactions
- service user-healthcare service interactions
- telehealth service-healthcare service interactions

This meant the approach to answering the research question (what is patient experience of telehealth services for self-management of chronic disease?) involved being led by the data, which showed a clear link between telehealth experiences and previous healthcare service interactions. This early pattern recognition and conceptualisation then informed the analysis of what abstract resources (e.g. system knowledge) were influential 'inputs' to telehealth use, as well as the perception of 'outputs' (e.g. expected benefits) that the telehealth users sought.

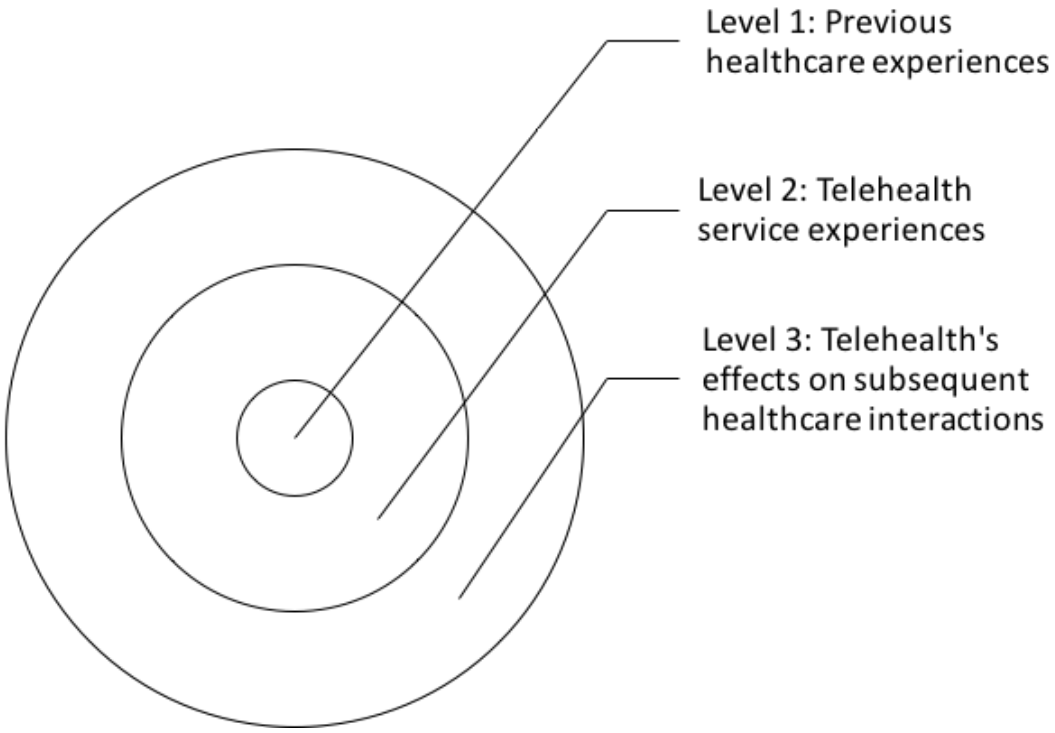


FIGURE 13 PATIENT EXPERIENCE OF TELEHEALTH NARRATIVELY SANDWICHED BETWEEN PREVIOUS AND SUBSEQUENT HEALTHCARE EXPERIENCES

Figure 13 depicts the integrated approach by showing that understanding their antecedent healthcare service experiences (Level 1) is useful for explaining why they experience telehealth services in the ways they describe (Level 2). Analysing Levels 1 and 2 provides richer, detailed interpretation of how telehealth service users relate telehealth use to other healthcare service interactions (Level 3).

In summary, thematic analysis entailed linking narrative accounts of personal histories in a loose event chronology involving multiple and varied healthcare service experiences. This usefully shows that participants relate these previous experiences in order to inform their telehealth use experience (Translation I). The use of telehealth is then observed to exert change in their relationship with healthcare service providers (Translation II).

5.9 Reflexivity

Reflexivity is important in research to acknowledge the implicit biases that researchers bring to their work and has historically affected knowledge production. Throughout the thesis, I discuss ways researchers introduce subjective bias in the research design -- from conceptualisation of constructs, the selection of the methodology to the crafting of the research design and the conducting of the research. The researcher's imprint distorts and therefore, consistent and transparent explication of the approach and assumptions are required for truth claims to withstand scrutiny.

Reflexivity also relates to the limitations of research methods to obtain an accurate version of what is occurring in the field. For example, it emerged that a participant had hidden her cigarettes in anticipation of my visit and I had noted: *There is a sense that there's a 'show' or performance, which is confirmed when they tell me that Kate hid her fags and lighter before I came, and James tells me as much, telling her not to hide it, I'm not coming to see if she smokes*. It's a minor example that underscores the difficulty of expecting strangers to disclose private thoughts and habits to a researcher in such a short time, which can have a bearing on the quality of findings that emerge although I believe my priming for the field helped me to control for risks to quality and validity as much as possible.

My interests in social justice and social change are detectable in my efforts to challenge assumptions by incorporating marginal perspectives, hence the focus on patient perspectives to advance a philosophically-grounded and managerially persuasive understanding of a service experience as patient-centred and substantively important for firm performance. The subjective nature of telehealth experience is epistemologically consistent with my own attempts to agentically reconceptualise the world we live in as a basis for the way we approach change for mutual benefit. I am therefore aware that my politics influence aspects of my interest in subjectivity. I am a cultural insider and outsider, and I reflect on the relevance of subjectivity to the assumption that social actors may not be fully aware of institutional arrangements influencing their perceptions, actions, and positioning because actors are subject to shift as they inhabit different contexts. Asserting my own opinions is an extension of my approach to privileging participant 'voices' and insisting that they be 'heard' in their own words.

Despite this conviction it has been challenging to ensure that the patient perspective is captured consistently, which involved mindfully suspending judgement about observations of idiosyncratic practices, and to stick with the face value of their words and acts as representations of their subjective perspective. Through lingering mentally in their worldviews, and looking for repetition and patterns throughout the study, what initially appeared exaggerated became understandable as my exposure increased my empathy even when participants were asserting extreme views. In order to validate my interpretive analysis, I would seek commonality in the accounts of later participants. When patients described mysterious events I took advantage of interactions with clinical experts to seek explanations and obtain validity. This tended to confirm the 'reality' of what seemed to be a clinical bias against patient efforts, knowledge and social change. The 'distance' I perceived participants to experience was being experienced by me as I presented their stories both defensively and protectively from potential ridicule among clinical audiences. In presenting their voices to practitioners it was more important that clinicians understand the humanity in their patients' experiences.

Finally, undertaking interdisciplinary research means recognising that I am challenging disciplinarity while trying to establish disciplinary expertise. It is a complicated stance that has made the mental framing of this research and PhD challenging because I seem to be undertaking a political act without having experienced disciplinarity as a constraint although I have identified it as such within the conceptualisation of the research problem.

Practically interdisciplinarity involves tacking back and forth between several different disciplinary audiences, especially when considering how the reporting of findings should be structured, what requires explication and what could be assumed as prior knowledge. This concern also applies to various practitioner audiences, and I have been aware that the presentation and politics of writing up, knowledge formation and knowledge dissemination, has the potential to be received firstly, as an indictment of current practice, and secondly, risks exposing patient practices to harsh judgement leading to the imposition of managerial controls as much as it has potential to show how much creative labour (Huws 2010) these participants undertake in co-producing services that allow those controls to continue. My intention is to show why patient efforts should be accorded with more respect. This normative outlook explains the political project of emancipating the ontology of disadvantaged service users from the confines of paternalism.

A challenge for all patient-centred research is the distance between the capture of the patient voice and its alteration through researcher interpretation. The influence of the researcher introduces an overlay of distortion resulting in an inevitable loss of empirical detail. Interpretivism involves analytical dissection, a process introducing violence to data, at times ruthlessly discounting the subjective influence upon observable data, in order to maintain its essence in the finished product.

This is because iterative processes of restorying, interpreting and abstracting through the researcher's theory-tinted analytical structuring reconfigures 'life in the field' when it is sampled, collected and removed to the 'laboratory conditions' of analysis. The empirical 'truth' is then moulded in order to 'speak to' different aspects of the literature. Through this reflective process I have learned to identify the *emic* by sensitising myself to the idea that I am a context that structurally conditions the *etic* conceptualisation of *emic* experiences. My aim is to maintain interpretive responsibility to ensuring the conceptualisations are closely grounded in the data to establish the knowledge that is co-constructed by the participants and me.

5.10 Conclusion

This section explained the methods used to conduct the research and discussed the experience of their merits and limitations when applied. We now move on to discussion of the empirical study's findings.

Part II

Introduction to the Empirical Chapters

The empirical chapters discuss key findings from studying patient experience of telehealth services applying a value co-creation approach. The findings, presented using illustrative cases, are focused upon two aspects: explaining salient resources patients integrate in order to use telehealth services, and explaining the formation of subjective value, particularly as it relates to their relationships with healthcare providers. A discussion integrating the findings and their significance is reserved for Chapter 9.

Figure 14 shows the organisation of findings to address different levels of structure and agency interaction that are argued to affect value co-creation.

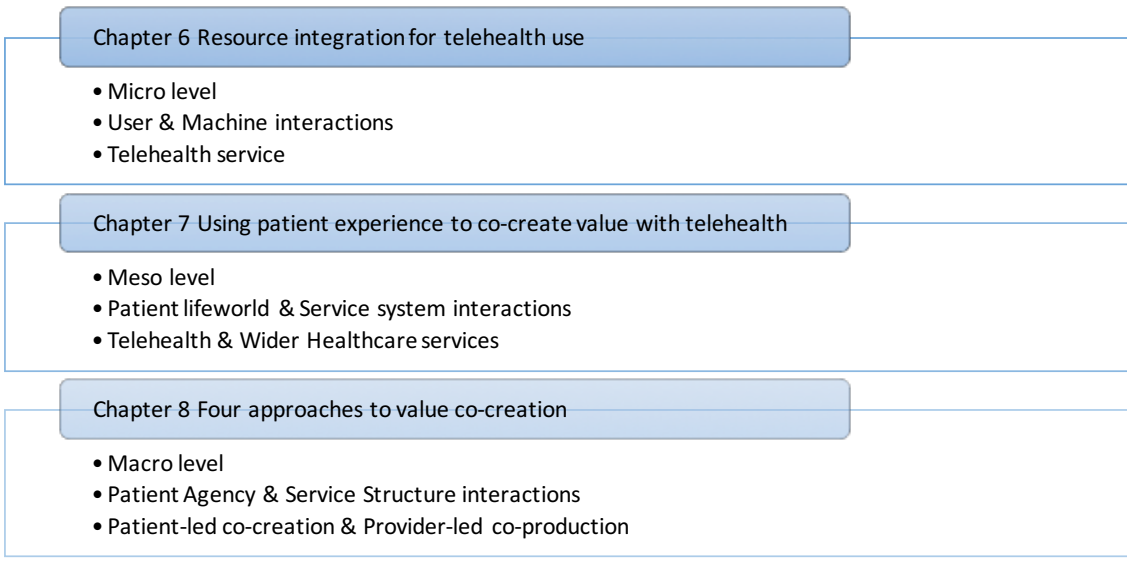


FIGURE 14 HOW THE EMPIRICAL CHAPTERS FIT TOGETHER

Chapter 6 Resource integration for telehealth use

Introduction

This chapter explains the main findings from the micro level analysis of patient-service interactions. It uses illustrative cases to explain key components that make up the patient experience of telehealth: user-machine and human service interactions. It begins by introducing the patient-in-context to describe a prominent theme of losing control as a result of their illness experience. This is followed by observations of dependence upon assistive technologies as a reaction to the illness experience, because they enable patients to personally adapt in order to regain control and independence situationally. The discussion then provides detailed examples of how patients are observed to adapt 'easy to use' telehealth machines, which are actually experienced as effortful, i.e. requiring resource intensive processes to use. The findings suggest that patent experience of telehealth use is highly contingent on the effortful experience of accessing and integrating necessary resources to co-produce the service. This suggests the determinants of patient value-in-context from using telehealth relates to the extent that the experience of trade-offs involved are perceived to be acceptable.

6.1 Losing control

This section provides an introduction to the participants in the context of their lifeworld, and describes what we mean when we conceptualise complex chronic comorbid patients as resource-constrained users.

At the start of interviews, it was common for participants to discuss their current health by drawing comparisons with their lives before the onset of illness, particularly how they have lost the ability to pursue their usual activities. For example, when participants are asked to describe their health condition, they provide a biographically relevant historical perspective to communicate loss of function and decline in capability.

> Marion: They keep saying, when I had my second stroke, "What would you like? What's your aim in life?" I said, "To get back to how I was originally." Because I used to love, my passion was gardening. Of course, other things as well. I mean I used to love gardening and I can't do that now because I can't bend down, I can't get on my knees, and I can't bend over because I go dizzy. I have dizzy spells all the time. Really my way of living, my way of life is very limited.

Many describe devastating effects of illness for themselves and their families. These include finding themselves in situations where they lose control over decisions to do with their health, their work and how they live. Losing control includes loss of physiological bodily control (e.g. balance, continence, blood loss, mobility, dizziness, breathing) and control over the body in social and physical environments (e.g. concentration, moods, ability to communicate). Loss is therefore described in terms of a disorientation and dislocation from their usual interactions.

Functional debility is not limited to loss of physical mobility but also refers to experiencing hardship completing personal projects and fulfilling social duties. This can be as simple as feeling anxious about going out (Brian), or answering the doorbell when there is an unexpected caller (Julia), taking a shower (Clive), to more complex social interactions. Part of the illness experience, therefore, includes attempting to recover elements of control over their lifeworld as a sign of recovery from illness, enabling patients to return to an easier and more naturalistic interaction with familiar physical and social environments.

Living with debility is observed to involve the use of an array of adaptive technologies to regain physical and social functioning in order to maintain independence. This independence is paradoxical because it involves dependence on alternative products and services to replace activities that they used to do themselves. For Marion, this means using a walking stick, engaging and orchestrating a daily personal carer to wash and dress, a gardener, a woman to iron, and a regular meal delivery service. After the second stroke, she finds feeding herself and her husband home-prepared food more difficult as she can't summon the required focus.

> Marion: … the carers they come in every day to make sure I'm-- they come in seven days a week, they provide me with meals every day. […] When he was at home and not very well, we used to have [Meals at Home] because I can't cook now. I used to do but I tried to cook a meal once a few weeks ago and it was like a mammoth operation. I thought, "Oh, gosh," I couldn't remember what I was doing…

Being able to feed herself is critical not only for basic survival but also for her ability to stay at home and to look after her husband, who was in the psychiatric hospital at the time and needed things to be brought in to him now he's agreed to shower, like clean clothes, razor and deodorant. Marion describes the keen sense of loss in her ability to manage her family obligations, which means her illness is experienced as preventing her from meeting her own and her husband's needs.

> Marion: He's been in two months and it's very difficult. I can't always get to see him because about a fortnight ago, I had this gastric flu and I wasn't allowed to go to the hospital to visit. People [health visitors] that came here didn't stay because of me having this infection.

We see that the experience of illness is socially constructed as it bars her from inhabiting certain spaces or interacting in the usual way. For example, Marion describes the irony of having the wrong kind of illness barring her from receiving her usual care, leaving her to fend for herself when she is unwell. The healthcare service is shown to extend its jurisdiction beyond clinical boundaries and impose upon her lifeworld because she cannot have her cataract corrected or visit her husband with gastric flu because healthcare associated infections (HAIs) are difficult to control precisely because the way healthcare services are arranged creates the perfect conditions for the spread of infection between patients. We can understand that this healthcare system control pertains to managing the physical environment of the clinical setting. The next quote shows how a patient's lifeworld is also

affected by the healthcare service's system design. Marion's quote describes the effects of being on a treatment pathway comprised of multiple healthcare interactions that deal with different aspects of her care according to the system's clinical specialisms. They require administrative and logistical resources to accommodate them.

> Marion: I have to keep [a diary] because I have so many appointments. See I have a lot of people coming to see me regarding my health. […] After my stroke, I've had people come to see me [and] have to go for exercises. […] somebody that comes to test me for my memory. […] I've got to start going to the hospital shortly again. They made arrangements for me to go, I think September some time. The exercises were before. I was going every week for eight weeks, but then I wasn't well, and I think I'd got this stroke coming on or something. They said, "Don't come again now, we'll leave it. Go home and just rest." I am going on the 10th of September to the rehab unit, and I'm told-- now let me see if there's a letter here with it. Yes, the appointment that I had for the 27th of August which had to be cancelled yesterday, has now been rearranged for me to go on the 8th of October 10:15, and it says ... I thought it said in this letter, but it doesn't. Apparently I've got to book for transport to take me there because I obviously I can't catch a bus or anything, can't walk, so they come and pick me up. I wonder where it refers to the... it said that I'm there all day and provided with a meal. It's the Trauma and Ortho Physiotherapy Department. I have that many letters and appointments, it such a job keeping them all in--

Marion sits on a sofa strewn with piles of bills and appointment letters, patient information pamphlets and diaries within arm's reach. Mid-conversation, she would look afresh at these items and have to reread them to remind herself about the details, such as whether the stroke rehabilitation appointment included a midday meal. These were issues she needed to stay on top of, and her confusion and repetition, together with her confession that she is very 'stressed' indicate how illness diminishes the coping skills she needs to meet the considerable demands of using the healthcare service.

Marion's case is representative of how patient experience of debilitating illness does not absolve chronic disease patients from their usual obligations. Indeed, being ill includes being expected to co-produce an increasingly burdensome rehabilitative routine integrating many different service schedules. She illustrates how patients experience a loss of personal control over their usual activities while increasingly becoming controlled by the healthcare service's priorities, requirements, one-way modes of communication and timescales.

Therefore, we can see how losing control is also related to the sense of not being on top of things that are perceived to be important because the organisation of tasks and the extent that they can be completed is dictated by technical exigencies that need to be met first. This means the experience of personal hardship from illness is made more difficult because personally important projects are overruled by exogenously introduced priorities that introduce more demands on an already

demanding personal situation. Hence, the illness experience of losing control is related to being subject to increasing control by the healthcare system.

From describing key themes in patient experience in terms of their changing relationship with features of their lifeworld as well as interactions with healthcare services from the patient perspective, the next section moves on to discuss the use of assistive technologies to regain control over the physical and social features of the patient home.

6.2 Telehealth in the home

We begin by introducing the context of the telehealth service in the patient home to illustrate the personal and situational factors affecting participants' ensuing interactions with the installed telehealth service components. This evidences that participants are adept technology users, which helps to nuance later discussions of telehealth use involving resource intensive processes. The use of technologies to regain control over physical and social aspects of the lifeworld continue from the theme of losing control. It will be shown that the same components of patient experience (losing control, technology use, regaining control) take place as a result of effortful resource integration. We pay particular attention to a by-product of the telehealth use process: the development of clinicised self-knowledge, as a result of telehealth use, which is conceptualised as technical mastery.

6.2.1 Ubiquitous technologies

Upon entering patients' homes, one of the most notable common features of the environment was evidence of numerous technologies in constant use. Technologies are defined as the application of scientific and/or technical knowledge to a problem and can involve products and services. Therefore, although telehealth is an innovative technology-based service, it joins an array of health-related technologies that are already in situ in users' living environments. Ubiquitous technologies highlight an important aspect of living with chronic disease, which is increasing dependence on assistive technologies.

Examples of dependency include the formal move from a private home into different levels of serviced accommodation known as assisted living. Although housing types varied between the participants, for many involved in the study, the home environment showed architectural features providing health-related solutions. This included sloped floors, stair-lifts, handrails, and ramps to allow wheelchair access; security gates to allow entrance to authorised visitors, such as qualified health professionals, prescription and meal deliveries. That participants were understood as socially vulnerable was observed through use of security gates, electronic intercom and door entry, bogus caller alerts, and CCTV installed to protect against unwanted callers.

Graham and his wife Esther explain how they experience various physical and social environmental threats to their well-being. They mentioned that when illness left him unable to work, they had to

leave the linked accommodation and were put by the council in first-floor accommodation although she was pregnant with their second child and she wears a metal brace on her lower leg. Having resolved some of the physical mobility issues with their move to a bungalow, they now suffer acute anxiety about anti-social behaviour. Graham was putting glass into the recycling bin outside when he was verbally threatened by visitors to their young paralysed neighbour. Feeling victimised, their television narrowcasts a live CCTV-feed of their car in the drive which enables them to provide evidence to the Courts if there is a breach to the restraining order placed on them.

Other environmental threats to well-being described by participants include falls in and around the house. To avert further injury from a fall, many participants said they always kept a mobile phone in their pockets (Elizabeth, Alastair, Ray, Russell) in case the telephone, pendant alarms, telecare or button for onsite warden assistance were out of reach. Julia explains her pacemaker keeps a performance record which is checked at the cardiac clinic. Connecting it to the computer enables the clinicians to recalibrate the pace if they find that a fall may have been related to an inappropriate pulse rate, leading to dizziness from low blood pressure. The information about the fall is also detected by a gyroscopic falls sensor that is tracked by the telecare service and would trigger a call to make sure she is okay. She wears the device on a belt at her waist. A piper alarm is around her neck in case she falls out of reach of the telecare box in her living room.

These examples of living situations furnished with overlapping technology-based services show how participants avail themselves of all manner of adaptive and assistive technologies that are already part of the accommodation (George, Molly, Stephen), or have been additional safety features they have sourced independently (Nigel, Ray, Graham). Many describe being referred by other services, simply requiring their consent to have them installed in their homes as a condition of safe discharge from hospital after a health crisis (Peggy, Marion).

With so many technologies in evidence, it is unsurprising that the stock of various medical technologies were observed to alter the appearance and fabric of the domestic environment, from having oxygen pipes and sensors plumbed through the walls (Howard, Clive), clinical furniture and furnishings (hospital beds, wave beds, C-PAP machines, nebulisers, commodes, compression pads), mobility aids (wheelchairs, canes, crutches, walkers, elevated toilet seats, hand rails) and equipment affixed to or implanted in their bodies (fistulas, catheters, stomal bags, artificial joints, pacemakers) (Julia, Peggy, Nigel, Elizabeth, Marion, Molly, Rachel, Clive, Brian, Russell, Stacey, Kate). With one exception (George), participants describe taking a ‘sackful’ (Howard) of pharmaceutical technologies, and discussed self-care regimens that include the use of self-pricking, fluids testing, dosage calculating, injecting, and rehabilitative technologies.

Even the most mundane technology becomes a feature of health and social care. For example, Molly suffers from depression, and finds television useful for distraction and combatting isolation.

> Molly: I'm always getting depressed for nothing. […] The smallest thing depresses me if it goes wrong, like that television. I've had that television wrong for a week. Nobody out to it. Kept ringing the wardens, and they told me to ring someone else. They've tried. Nobody helped. Can you imagine living on your own without a telly?

Participants also explained that their familiarity as users of complex technologies was established earlier in their working lives. From regularly using mining explosives, textile dyeing, welding and spraying, electrical and electronic soldering, to installation of heating and plumbing, participants provided multiple examples of prior experience as technology users, often decades before using telehealth. In addition to being responsible for using complex machinery, they explained use of problem-solving processes to ensure that the outputs produced were fit for purpose.

> Molly: [I worked] Machining mostly. Making dresses and [crosstalk]-- First of all it was baby dresses, and then I started some underwear, some blouses and dresses. Then I went on to examining the dresses […] So that it was, everything was got to be right. And at that stage we got to-- we was working for Marks and Spencers when they used to be tip-top.

Thus far, evidence of ubiquitous technologies in home environments involved examples of multiple health-related technologies, and the way participants were observed to orchestrate their use to suit their needs, but participants also describe using multiple consumer services to try and improve their health. For example, Nigel described using a shopping trolley for support during slow walks around the supermarket for exercise in the winter months. Alastair had a series of bad falls in his kitchen and in hospital which resulted in bangs to the head, cuts and bruises.

> Alastair: I don't know when I'm going to fall. Sometimes I turn and I fall. I've got these shoes rather than slippers […] they keep me more stable and they're gripping good. You hear them squeak on the kitchen floor. They do help me to keep my balance. It's frustrating, you know. I've several my friends they walk at the side of me to catch me. In fact, I went to a retirement meeting […] just locally at the community centre […] and I turned, fell over, and a chap caught me right in his arms and he said: 'Behave yourself!" [laughter]

Therefore, participants describe using adaptive technologies and adaptations to their social support arrangements in the case of catastrophic loss of control over their bodies in environments that used to be safe, familiar and relatively risk free.

Participants also indicate that technologies can create disadvantages when they are not used as instructed. Rachel describes rushing home, putting her oxygen bottle on her lap and falling off her stair-lift in her entryway and blocking the front door.

> Rachel: I'd been out for my treatment for breathing and we had to wait 35 minutes for a taxi so by the time I got home I was absolutely bursting for the toilet. I got on my chair at the bottom. I've got my portable oxygen on my lap ready for bringing up and I didn't sit on the chair. I got about three steps up and I hadn't sat on the chair properly and I fell. I fell in a heap at the bottom of the stairs and I was there for about 20 minutes before I didn't move. I banged my head on the door. Nobody could have got in at me. […] I pee'd myself.

These examples show how participants' usual activities in familiar environments become health-threatening due to losing control of the behaviour of their bodies, e.g. due to dizziness, breathlessness, weakness. This changed contextual orientation is addressed through increased consumption of technology-based solutions, like stair-lifts and high-grip soles on shoes. Their altered orientation with their surroundings also prompts participants to share the burden of illness through customising social networks (friends, neighbours, relatives) to be alert to their vulnerabilities and to be prepared to help in the event they lose control of their bodies (Alastair, Cleo, Rachel, Russell). Participants also described using Skype (Rachel) and online shopping to avoid the increased costs and risks associated with travelling or shopping in person (Graham, Alastair).

> Alastair: if I want something ... it's easy to go onto Amazon and get what I need. I wanted - what was that- some tablets for the machine. To clean the machine, I just had a new machine, and I went on there, and with Amazon I don't pay P&P 'cause I have a yearly contract with them and they came the next day, and it only cost £2 something, so it was hardly worth me going out of the house for them.

These examples show how participants are highly adept at arranging and combining available social resources together with support provided through technological products and technology-based services to cope. This activity relates to the experience of losing control because their selective technology consumption helps to mitigate against the effects of their illness and to regain some functional ability to participate in social and lifestyle activities of their choosing.

6.2.2 The position of telehealth in the home

This section discusses the physical relationship between user and machines. It first discusses how participants respond to telehealth in the home as a material object. By discussing issues arising from the physical positioning of telehealth machines in the home, we question the assumption that telehealth is convenient for patients because it is home-based and avoids cost and inconvenience of travelling to appointments. The evidence suggests that the advantages from having it conveniently at home is more complicated. We draw parallels between the aforementioned examples of demanding healthcare service designs and telehealth technologies that seek to limit patient interactions to electronic informational exchanges.

The position of the telehealth equipment within the patient's home was largely dictated by the needs of the equipment, which meant the design of the telehealth machines immediately influenced how and where the equipment would be used. For example, the older Honeywell machines require an electrical outlet and a telephone socket with outgoing calls (if this is not available, then a mobile GPRS connection is installed, requiring a second electrical outlet) (Ruth, Julia). Because it is a small set of devices without legs, the main box needs to rest on a surface, although the peripheral devices could be flexibly stored elsewhere. This meant the position could make use awkward. For

example, Alastair's telehealth was installed at the bottom of the stairs near the entrance. This meant he would need to walk to it for use, when his primary health concern is dizziness, lack of balance and falls risks. George's sits on a small side table where the nearest armchair was a few feet away. When doing his blood pressure readings, he was observed to stand throughout the process. Guidelines for taking blood pressure readings include sitting down with the arm supported at heart level.

> INT: Can you show me how you use the blood pressure machine? Just do it as you normally would. [silence] Do you do it standing up?
>
> George: Yes.

Robert, who was very breathless from COPD, moved a dining chair several meters from the adjoining room to face the sideboard where the equipment was in order to use the machine. Ray, who uses crutches because of his osteoporosis, bent down to retrieve the weighing scales from underneath a sofa where he stores it, and moved it to the entrance hallway where there was a hard floor. Julia's telehealth box was positioned beneath her television on a low shelf, with the GPRS modem propped against the window behind her. She would sit on the floor in the middle of all of her furniture to use it. The positioning seemed suboptimal for someone with a pacemaker, breathing problems, obesity, fibromyalgia and a risk of falling if the pacer isn't set right.

> Julia: I have to sort of crawl on my knees to get up. That's the only drawback.

Apart from Julia, none of the participants remarked that the positioning of the equipment was in any way inconvenient, but it did seem clear that using the equipment often required a physical adaptation of the user's body and behaviours to accommodate the use of equipment. Positioning mattered less if the user cohabited with a partner/carer or was used only when a carer was visiting. Brian, Clive and Stacey had their partners bring the removable Docobo portal to them from the charging stand in another room. These cases suggest that problems for users arise due to the demands of the machines. In the next case, user discretion dictates the positioning of the equipment in his home, but the resulting effort still requires significant user adaptation.

Howard's case shows that finding the most suitable place for the equipment for use can be difficult. He had requested that the portable Docobo telehealth equipment be installed bedside so he could get back into his warm bed in the morning after transmitting his readings for the service to process. Although he did not complain about this arrangement, it was observed that, if he has to do a retest in the late morning because his readings are abnormal and trigger an alert (where the system algorithm flags a potential cause for concern from the transmitted reading and requires further investigation), he needs to go back upstairs (which increases blood pressure, risk of falling, etc.). Howard is very breathless from COPD and heart failure so crossing his living room is very

physically taxing; his slow, sideways, shuffling progress across the room involved grasping tightly with both hands onto the mantelpiece for stability. In the excerpt below we can see that the positioning of the telehealth upstairs in his home has a direct impact on the readings he submits to the service.

> Howard: 157 [systolic reading]. **Yeah, that's pretty high because of the stairs I think, if we believe that**. At the moment now, I would sort of do that again. I mean, I don't want to do it again, but I would.
>
> INT: Okay. How many times would you do it again?
>
> Howard: Well, the most I'd do is three, and then I just throw it against the window or something or out the window [chuckles]. No, I would do it probably three, and then I would just give up on it. Or the best of three, you know.
>
> INT: If it's best of three, do you choose the lowest?
>
> Howard: Of course, yeah. That's only natural, yes. But not the lowest, I choose the best one.

Although the telehealth's positioning means Howard must physically accommodate it, he shows several ways in which the machine's authority as a reliable source of health information is subjugated by the user's thought processes. Howard's case illustrates three common themes emerging from the data that show user-machine interactions can lead to the social construction of doubt about the accuracy of the machines. The first is that Howard's blood pressure monitor has been replaced three times due to 'faults'. In several cases, users mentioned multiple experiences seeking replacement equipment, which has contributed to a reputation for general machine unreliability among users and telehealth support workers although the causes are variable. The second is that participants' current experience of machines is informed by their previous experience of healthcare services. This includes participants remembering when clinicians did routine clinical observations with similar machines they often mentioned that they needed to repeat the reading because the machine was not behaving as expected. Memories of these experiences seemed to influence participants' approach to handling the machines as requiring some tolerance for misreadings. A third reason for doubting the machine seemed to result from their regular exposure to their vital signs reading through telehealth creating occasions for the comparison of variable readings while cross-referencing what they saw displayed with the way they physically felt at the time in order to assess whether their personal experience corroborates or conflicts with the displayed reading. We will now discuss the significance of these reasons to explain Howard's reaction to the elevated reading.

The displayed blood pressure reading is suspiciously high to Howard, and he reasons that it makes sense because of the exertion of coming upstairs, unless he is currently more unwell than he realises, which is also a possibility considering his complex comorbidities and changing responses to medication. He explains that if he were inclined to believe this third machine is functioning

properly, he is then forced by the appearance of the high reading to consider whether to repeat the reading several times and to choose between the results according to what he believes is sensible and more accurately reflects his condition at rest. He is mimicking what he has seen the nurses do when they come to the ward during hospital rounds; if they are in anyway suspicious about the results, they do repeat tests.

Howard's case is an example of how effortful experiences with fallible technology create the conditions for developing a 'clinicised' self-knowledge (distinct from clinical knowledge, which is obtained through formal training). It is argued that it develops through experiential learning, and practical exposure to vital signs monitoring equipment. His explanation for disbelieving the high reading suggests that he believes he has sufficient confidence in his health literacy to make a causal link between the exertion from climbing the stairs and the appearance of elevated blood pressure readings. He applies this knowledge through customisation of the telehealth equipment user protocol by using repeat readings in order to ascertain which of three readings should be used for transmission. The use of repeat readings enables him to control against the implications of the telehealth being located upstairs, although doing so means the act of using telehealth consumes several scarce resources: physical energy, emotional regulation, cognitive focus, mental calculation, time to use machines that potentially cause discomfort, and remembering to stay calm in order to recover his breath rather than panicking.

The interaction with the machines forces Howard to consider whether it is his body, his body's response to his activity, or the machine that is causing the abnormal reading. As this is a private interaction with the machines leading to his own ruminations about physiological causality, there is little opportunity to obtain real-time feedback from the service provider to support his self-directed learning process and either explain or allay any anxieties at the point when measurement of physiological functions is displayed. He must work these things out himself in the moment, although he says he asks his healthcare providers questions when he sees them. From this case, we get a sense of how users exert practical control over the machine functions while developing new ways of seeing their bodies through a clinicised lens as part of experiential learning through use.

6.2.3 Domesticating machines

As well as it being interesting for the study where people put the machines, the findings also suggest people have gone through a process of accepting and domesticating the machines in various ways. This section focuses on how telehealth initially appears to exert authority over users by introducing various demands in order to co-produce the service. This echoes the healthcare system demands on the patients as previously discussed. First, we discuss how the machines' user protocols dictate to users what needs to be done, at what pace, in which order, at what times. Apparent tension from potential enslavement by machine-led routine appears to lead to the gradual inversion of control, as

users domesticate machines by introducing a set of privately devised workarounds to customise and potentially subvert several aspects of the expected service interactions.

It is suggested that once the control has shifted from the machine to the user, it makes the positioning of telehealth in the patient home additionally advantageous to patients, not only because it saves them costs of transport and inconvenience, and avoids effortful face-to-face interactions, but because it ensures privacy, obscuring certain things from the service provider's view, while enabling users to surface the things that matter to them. This is argued to be part of a process of recovering their independence within long-term healthcare relationships. Controlled independence is illustrated using cases of users describing how they cope with anxiety about telehealth's regular reminders of how unpredictable and needy their bodies are in objective clinical terms. Participants' various coping strategies are observed to involve processes that domesticate the clinical machines, thereby regaining relative autonomy from a clinical perspective that regularly dictates their healthcare needs.

Participants describe various ways of coping with telehealth in order to avoid feeling anxious about the readings that appear on the machines. Nigel's case reveals several tactics for resisting machines' unquestioned clinical authority in order to minimise anxiety from using it. He and his wife say the Honeywell telehealth is not accurate, remarking that its poor timekeeping is getting worse, and that the results are not as accurate as a self-bought blood pressure monitor, saying the telehealth gives a 'false reading'. He also clownishly mocks it and shouts back at the box's robotic voice in a comedy double-act, making his wife laugh. In the excerpt below he explains two more reasons for distrusting the telehealth machines (despite confirming that he thinks the telehealth service is beneficial): the first is his perception of an *irrational* change in the blood pressure readings three days apart, and the second is his perception of erratic behaviour of the blood pressure cuff itself, based on its deflating and re-inflating ('re-energising') twice during use.

> Nigel: Well, when you have a blood pressure going right down to say 110/168, sorry over 68, on the Wednesday and on the Friday you've got it at 151-stroke-over 92 then there's something drastically wrong with the machine. Or it's not doing it right. I also notice on that machine [meaning the official telehealth kit] that sometimes it'll re-energise on your blood pressure, sometimes it'll go up to like 170 and then it stops pumping and it'll go down to like 146 and it'll pump again til it's 190 something. And then it'll come down, come down, come down again and give me a false reading.

Nigel's interpretation of vital signs is self-assured; and he is apparently unwilling to consider valid alternative explanations for big changes in blood pressure other than machine malfunction because his own machine provides a more consistent reading. His self-confidence in other areas of his self-care include the assertion of empirically derived expertise concerning the benefits and harmful side effects of what he alternatively calls 'Fluzamide' or 'Fludamide' (it is officially known as

Frusemide or Furosemide). Asserting his knowledge seems to be an important part of his growing independence from formal healthcare. Seeking independence is vitally important as it is related to his recovery from a series of traumatic events related to poor hospital care 18 months ago, when he was mistreated by a nurse and his wife was left to challenge the doctors' decision to discharge him when he was not responding to antibiotic treatment for a suspected chest infection. By refusing to care for him at home, she forced his doctors to carry on investigating, and eventually they discovered an underlying heart condition and implanted a pacemaker. In part because they attribute the effectiveness of their own actions in what they and his doctors describe as a remarkable recovery, it is possible to interpret why they place such strong faith in his ability to administer his own knowledgeable preventative self-care, where the goal is to stay out of hospital and thereby avoid vulnerability to further risk of clinical errors and what was experienced as inhumane care by nursing staff. His self-confidence is described as major progress from being aggravated by crippling anxiety. He maintains a rigorous self-care regimen, using many monitors to regulate his intake and excretion of fluids, carefully using the 'right' amount of diuretics to avoid further kidney damage while making sure his heart condition doesn't result in dangerous swelling. So although Nigel seems to distrust the telehealth machines, he shows that he is actively involved in a clinicised self-care routine of his own devising.

Peggy's case illustrates a different approach to domesticating the machines by minimising the potential disruption of telehealth to her peace of mind, by refusing to be overly concerned by the results showing on the machine because there is no clear indication of how to act in response to them. Peggy suffers from heart failure and is waiting for surgery. She explains that she knows what to look out for to avert emergencies (swelling ankles, weight changes, diet) but makes it clear that she is otherwise dependent on her healthcare providers. This is because she is waiting for her cardiac surgeon to figure out a way to remove and replace her 14-year-old pacemaker. Without this issue being resolved, there is little she can do to improve her health through self-care. Additionally, she explains that she knows blood pressure changes all of the time, having learnt this from previous interactions with her nurses, 'So there's nothing I can do, is there?' She reiterates the practical limits of her self-care role and therefore she understands that the readings supplied by telehealth do not have to affect her mood or activities beyond registering readings to telehealth and helpfully sharing the results that she jots down on a scrap of paper with visiting nurses to save them time and save her from the exhaustion from 'the endless questions' that many participants mention when describing healthcare interactions. Peggy says she does not record the results for her own analytical purposes. Therefore, it can be inferred that, unlike Nigel whose self-care intentions are to prevent need for formal care, Peggy's use of telehealth is not for independence from clinical care. At least not yet, as she could not replace her own pacemaker. Instead her focus is on applying her clinicised understanding of what is normal for her condition (a changeable blood pressure). This knowledge

enables her to refrain from being too bothered by changes to her blood pressure that lead to calls from the telehealth workers who tell her they are 'keeping an eye on it'. In fact, she finds it irksome when they call to tell her that: 'Why tell me?' Peggy's case shows how full-service healthcare interactions can be experienced as essential as well as intrusive and unnecessary. It seems this depends on the extent that the care that is being provided is only based on her objectively perceived needs (i.e. life-saving surgery and regular health monitoring) rather than considering her subjectively perceived need to be left in peace to rest.

Participants are observed to minimise effects of unwanted aspects of telehealth, like inconvenience from machine unreliability and anxiety from abnormal readings. They also identify aspects of full-service healthcare that they dislike, like endless questions or pointless information sharing. However, although participants identify aspects they dislike, their actions to change their current services are constrained by their understanding that certain forms of expert care could not be replaced by technologically assisted self-care. So Howard, Nigel and Peggy recognise that their condition requires monitoring and they proceed to use telehealth for this goal.

These cases show how different users have different responses to machine-based authority in their homes, and how they domesticate telehealth's intrusion in their lifeworld in order to regain some independence in a controlled way. Some participants understand that independence requires more sophisticated self-care including using various health-related technologies and improving their clinicised self-knowledge to provide an alternative to formal care. Others consider the wide gulf between medical expertise and their limited self-care abilities in the given situation, and are therefore more resigned to care by qualified professionals and use telehealth to step-up their access to professional care through regular remote monitoring until a formal solution can be found for their problems enabling them to step-down the frequency of professional oversight which must be effortfully co-produced.

6.3 Effortful user experiences

Thus far the findings have highlighted cases where using healthcare services and telehealth machines were observed to be resource intensive and effortful to use given the technological design interacting with personal and situational factors affecting this user group. In this section, we consider the interplay between patient preference and the perception of costs involved in using telehealth. Participants who discussed telehealth's disadvantages seemed most sensitive to the effect of service use on their lifestyle and then proceeded to evaluate its cost of use, given their life-limiting illnesses, as more or less valuable to them. This section begins to link patient experience of telehealth with subjective assessment of telehealth value.

It will be shown that the connection between use and lifestyle was understood to be a component of the motivation to introduce workarounds to reduce the effort involved in integrating telehealth

into their lives. For example, some described a drawback of the telehealth as the experience of boredom with the routine of using it. Julia mentioned negotiating a less frequent use of telehealth due to feeling 'monotony'. Others felt any sacrifice in time taken by telehealth was worth enduring because they felt the service worked for them (Nigel), they believed it was keeping them out of hospital (Darren), and just part of the service to be tolerated so 'tough if you're bored! […] nobody is forcing them to do it' (Howard).

The experience of using telehealth machines depends on the number of prescribed 'questions' the users are expected to answer. This is decided by the protocol suggested by the referring clinician. So, for example, Stacey only used telehealth to record body weight and blood pressure and it took her approximately 6 minutes to do. This is probably because she is currently experiencing a great deal of full-service healthcare interactions with multiple medical disciplinary teams working to diagnose the underlying cause of her complex comorbidities. However, many users in the sample had heart and lung comorbidities and their protocols involved more extensive question sets and needed users to upload many responses regularly requiring the measurement of pulse, blood oxygen saturation, breathing, coughing, fatigue, swelling, sputum quality, the use of relieving and usual medication adherence, in addition to the routine of using peripheral machines (blood pressure monitor, pulse oximeter, weighing scales) and registering them to the main telehealth unit. In the sample, regular usage ranged between less than 5 to more than 20 minutes, with the lower numbers relating to patients whose able-bodied family carers were the primary handlers of telehealth equipment (Brian, Aziz) or users of the simpler, manual entry Honeywell equipment (Robert, Ruth). Although the newer Docobo equipment was Bluetooth enabled, it was slow and unreliable, so manual entry of data from peripheral machines was often required. The longest times to use telehealth relate to two Docobo users who live alone and were recovering from acute health events: stroke (Marion) and hospitalisation for a worn out pacemaker (Peggy). The latter case, excerpted below, did not finish submitting her readings during the observation because she was exhausted, frustrated and confused by the Any Time Tests and Questions function.

Machine: [loud robotic voice] *Any Time Tests and Questions. Breathlessness. Is your breathlessness as usual? Swelling. Have you had any ankle swelling in the last 24 hours? Medication. Remember to take all your prescribed medication.*

Peggy: [navigates questions quickly and with ease] Yes. [laboured breathing] […] We just got to wait now.

[silence]

INT: What's it telling you to-- is it telling you to weigh yourself again?

Peggy: Well it does, it goes on like that until it comes up.

INT: It seems a bit confusing, that.

Peggy: Yes, well it could be, yes. Probably it was for me at first, until I got used to this waiting. When the man [installer] came to explain to me he says, **"You're too impatient. You've got to wait** [chuckles]. **It doesn't do things straight away."** […] **That's where you used to make the mistake. I got impatient and get on the scales again, and you shouldn't once it's registered, it's in there**. […]

[silence]

INT: Is this roughly how long it takes?

Peggy: It does take a while. […] That's going through on Bluetooth now. […] Yes, it was waiting for the Bluetooth. Now the Bluetooth's transferring it from there to there, isn't it? […] And you just have to wait. […] **Oh! It's not found it, so now I've got to put it in manually. What was it we're doing?** […] You see, and this is why-- I'm all right on my own, but when people [chuckles]-- yes, it's funny. […] And it's just that **I've not been out of hospital long, I'm very tired, and people keep coming and asking me questions and it really wears me out**. […] People keep questioning me and questioning me. […] everybody who comes and I have to go through all the details again. Oh, goodness! [exasperated] […]

Machine: Blood pressure.

INT: We've already done it, yes.

Peggy: It's telling me to do it again. […] [inputting onscreen] 115.

Machine: Systolic, systolic, sys-, sys-, sys-, systolic is 105 millimetres of mercury. [The machine repeats 'systolic' loudly six times in response to her use and is very insistent sounding and annoying. Her breathing is getting quicker from being stressed by the experience]

Peggy: **Where am I? I'm getting confused now. What am I doing? […] We've done this, haven't we? […] Oh! [wailing] It wants to do it again now.** [She is driven around in circles by the order of questions in an endless, noisy loop]

During her demonstration Peggy kept suggesting that her typical usage was not as confusing and frustrating as it was that day. She attributed this to disorientation and still finding her feet from a long stay in hospital. It also could be because she is unfamiliar with Any Time Tests because the regularly scheduled monitoring protocol automatically steers the user through the questions in sequence rather than giving the user the option to decide which specific test to do.

Despite these explanations, the long pauses that she endures waiting for the machines to relay information to each other via Bluetooth connection indicate that the process for every test is slower than she would like and that she was told by the installer to not be too impatient with the machine. The experience of delays or slowness in transmitting the data between the machines and/or to the remote server was reported across the sample.

When the personal and situational factors of telehealth use mean it is experienced as resource intensive, this has a bearing on the evaluation of outcomes from using the service. This is illustrated by our next case. Clive has advanced COPD and uses various assistive technologies for most of the

day to ease his severe breathlessness which often leads him to panic. He told his referring nurse that he would only accept telehealth if he derives benefit from it. Having used it for a while, he and his wife, Ann, are now highly sceptical about the value of telehealth because it has failed to increase his understanding of his condition and how to care for it. They suggest that it may benefit users who live alone, but Clive lives with his wife and their grown sons living nearby are used to taking him to the hospital. He is upset that the only thing that the additional monitoring does is result in calls from the telehealth service demanding more readings from him and telling him to do things he already knows to do, i.e. use his oxygen therapy. Therefore, he is unhappy about additional demands being made on his severely depleted stores of mental, emotional and physical resources.

> Clive: … my [oxygen saturation] readings are low and they say, "Put your [oxygen] machine on and then do your readings again and tell me when it's 90." That to me is wrong. […] It's only [an acceptable] reading [to the telehealth system] because I've […] put my oxygen on, made it go up to 90, if you like, but as soon as I move it'll go down again. […] So that's not a true reading as you are. Do you know what I mean? […] **The service [is frustrating me] [laughs] […] Because they're not telling me to do anything that I don't already know I can do.** I just used it to stick [the pulse oximeter] on my finger, put my oxygen on, wait until it gets to 90 and then send off [the higher reading]. […] Because it's right and they're happy. ***They're*** **happy**.
>
> […]
>
> Ann: The only time they're interested is when his oxygen is on 90. So if we went to the hospital with these numbers then they'd say to him, "Well Clive, for the last week your oxygen's been 90 every time you've been on your monitor." But that's only because he sat there and waited until it's gone up to 90 […] Do it again, you see, until you get it to what they want, not the actual reading. **I have had this out with them and they said "It's not a true reading" and [the telehealth worker] said, "No I agree with you. It isn't. But that is the way we're working it**."

If telehealth could tell Clive what he wants to know, i.e. why his oxygen saturation is so sensitive to movement, he asserts that he could use that information to improve his quality of life. However, telehealth doesn't help him to achieve that goal. Therefore, the lack of subjectively perceived benefit from telehealth use is clear to Clive, who suggests that he is not a primary beneficiary from telehealth, and they are serving others through the telehealth system by regularly co-producing the 'right' telehealth monitoring protocol to show that his care is adequately responsive to his condition of low oxygen saturation. For Clive this is routine management rather than helping him to improve. They even suspect it might be doing him a disservice in the long run because they believe it contributes to a false picture of his lung function and overall health status, implying that doctors would reassess his clinical needs as less serious or under control.

These examples show how problems arising during user interactions with telehealth machines can unexpectedly require users to integrate multiple resources when using the service, including effort to evaluate the actual benefit to them of the work involved and to decide whether the service is beneficial to them or not. Issues related to access to resources, resource integration and value

determination are consistent with an S-DL perspective. It is apparent that in order for users to value telehealth, it is better if they can agree with the provider's intended value proposition, which suggests that more monitoring is equivalent to better care. Where the value proposition is perceived as destroying potential user value, or unsympathetic to their resource constraints by making excessive demands, the experience of using the service can lead users to perceive diminishing value especially if it risks their access to future care.

6.4 Coping with fickle machines to regain control

This section continues with the theme of patient experience comprised of effortful resource integration processes to use telehealth machines, conceptualised as coping with fickle machines. Cases are used to illustrate how resource integration leads to the emergence of subjective value in terms of regaining control and a by-product of telehealth use: clinicised self-knowledge development.

We begin by showing how the work involved in telehealth use involves a trajectory in the user-machine relationship that starts with users being diminished subjects suffused with suspected user error and characterised by a self-blame response. Howard describes the process of technical trouble-shooting involved in telehealth use that involves initial confusion and self-doubt.

> Howard: …I thought, 'Hang on a minute, I might be doing something wrong', so I go through it dead-slow, dead-steady, make sure the cuffs are on right, you change arms, took the side out and put it back in, off we go again, and now it's definitely not me. So then when I've established—a right thing I've established is [it's] not me, it's the machine, and it's coincidental that the second machine is faulty as well. […] So you have to eliminate yourself […] You know, is it you? Because it could very well be […] 'You are doing that wrong,' or whatever.

This self-blame appears to change through use and experience, as users become confident enough to blame the machine and reassert the self as competent and confident subjects able to instigate meaningful change to service interactions. Although Howard was shown to be suspicious of the machine readings, other users choose to trust the machine and blame their bodies for being faulty – either unruly (Rachel, Julia)

> Julia: … my weight can go up and down for no apparent reason, because I'm doing nothing, and so, uh, that like if my oxygen level drops, […] it dropped to 88 the other day, and they said, you should have called us in, and I said: No, I'm fine.

or mysterious (Kate, Stacey, Alastair, Clive, Aziz). Clive and his carers were mystified by his readings until they successfully diagnosed the cause: a faulty machine.

> Ann: **If it goes wrong we're supposed to phone them but you don't know when it's gone wrong.** It was about a fortnight ago – the readings on his oxygen – every time we put it on [his finger] it was [reading] about 85 or 86 [percent arterial blood oxygen saturation]. **After a time,**

> **you think, 'Well, that must be what it is, then, 85 or 86'.** Then somebody's phoning me up, 'Can you tell Clive to put this thing on because - let's read it again.' Well it wouldn't move, it didn't matter how long he sat there, it still stayed on 85/86. **In the end I said to them, 'Look it just doesn't work.' And she said, 'Well it must do.' Even the nurse said that [low level of oxygen saturation] must be all right for Clive, [to Clive] didn't she? It got to last Friday and she phoned and she said, 'Has Clive been on his monitor?' I said, 'Yes.' She said, 'Well the readings aren't come through.'** And the blinking thing had gone wrong and I didn't know and they didn't know! Anyway they sent somebody out, didn't they [to Clive], and they said the battery was flat and it needed a new thing altogether […] **it's so frustrating when you keep doing it and it just doesn't make any difference**.

What this passage shows is how everyone's (including Clive's usual nurse) first instinct was to trust in the equipment and blame the user (in this case his disease-compromised body's surprisingly declining function), and subsequently to be convinced of the patient's decline as 'all right' or acceptable, or simply 'what it is, then', and thereby assuming it is 'normal' for someone with Clive's advanced COPD to have such low blood oxygen saturation. The second instinct is to suspect user error: has Clive used his monitor as he's supposed to? This means there were effectively two types of blame directed at the user: his body is blamed for being more poorly than expected (according to the set parameters), and Clive is suspected of some kind of user error (from not using it correctly to not using it at all) because it was assumed that the monitor 'must' work.

As Howard and Clive show, telehealth machines are experienced as fickle, a description based on observations that machines were noted to occasionally behave irregularly, strangely, idiosyncratically, or were in some way awkward to use, and not experienced as neutral. This theme is related to the earlier example of Rachel falling off her stair-lift because she did not sit down as instructed, whereby experiences of technologies like telehealth and the healthcare services generally present their own particular demands on users to interact in the ways anticipated by the designers and providers. Users are then confronted by a need to respond.

Although cases show participants struggling to use the equipment, it was striking that only a few mentioned experiencing any recurring problems that subsequently came to light during observations of their demonstrated use. Through observation of their experiences using the equipment, it became clear that in contrast to the image of frail and elderly patients as victims or passive users of technology, the study found a great deal of evidence of active use. Indeed, it is suggested that such active use was required *because* the machines were found to be frequently fickle and difficult to use. In order to successfully submit readings, users were required to actively and creatively engage with the machine-based service process to ensure that they were able to co-produce the service as effectively as they wished. This observation is consistent with the processes of resource integration underpinning the co-creation of subjective value in S-DL.

The next sections provide detailed examples of micro-interactions between users and machines showing how the experience of fickle telehealth machines results in four types of customisation to realise different forms of value that is prioritised in the lifeworld context.

6.4.1 Customisation

The majority of users explained that they initially encountered a few issues (Clive: 'bugs') getting used to the machines in the recent past, which they learned to overcome. However, their verbal accounts either omitted or downplayed the use of interesting customisation processes: manual overrides, repeat readings, sourcing and integrating human support, and accidental customisations. These were employed to cope with machines that are perceived to misbehave in some way.

6.4.1.1 Manual overrides

The most common workaround was to avoid using the default Bluetooth wireless data transmission option and choosing instead to manually enter the readings to the Docobo portal. This enabled them to avoid long delays when transmitting their data to the service because manual upload was perceived to be quicker. Participants described the machines as 'slow' although they were not demonstrably comparing it directly to anything beyond their own sense that the machine was slow to respond and slow to send (Aziz, Marion, Peggy).

> Marion: No, it's quite slow really. […] It is. I often stand here [by the scales] and I keep thinking, "Has it done it? Has it done it?" […] It is slow; it appears to be slow to me.

Similarly, when participants mentioned helping their nurse visitors to record their vital signs, they would hand them a handwritten account because it was faster to do this than to experience the 'rigmarole' (Peggy) of using the equipment again when the nurse is there.

Aziz's daughters are the primary users of telehealth and they discuss their perception that the machines are slow was reinforced by the installer's visit to 'speed it up a bit'.

> Fatima: It's a bit slow.
> Sakina: Apart from that, it's okay.
> Fatima: It's been upgraded. […] It's still a bit slow. [crosstalk] They came and done something to it.
> Sakina: Speed it up a bit.
> Fatima: It never catches his weight sometimes, or his blood pressure so you have to put it in manually, don't you?

Despite additional servicing, they prefer to override the default Bluetooth setting to upload his readings to the server. This suggests users are happy to adopt workarounds like manual uploads to force the machines to accommodate user preferences, like time saving.

It was observed that the manual upload as a workaround might emerge in three ways:

- organically through the user's own trial and error learning processes;
- because participants were explicitly taught by the telehealth installers (i.e. once the Bluetooth issue was known to the service provider after noticing repeat transmission failures with Bluetooth use across the client group, they taught people to use the manual option);
- or a mixture of the two, with the former being validated by subsequent interactions with service experts.

The case examples show that speed relative to lifeworld preferences was valued by participants and that workarounds can be self-instigated and that participants may seek approval from experts about their workarounds if they think it is necessary.

6.4.1.2 Repeat readings

The second most common workaround was the use of repeat readings, as previously illustrated by Howard's case. It became clear that the observed use of repeat readings was an 'invisible' practice, i.e. the service provider was not aware that this was occurring until the findings from this research were reported. This finding was validated as especially interesting to clinicians, service providers and academic audiences during presentations and is argued here to be an important component of the aggregate construct of developing clinicised self-knowledge through telehealth use. The notion of repeat readings seems to cause surprise because it is a sign that patients may be engaging in maladaptive behaviours suggesting misuse of telehealth. However, the thesis suggests that this is a provider perspective of what is occurring in the field with its own managerial implications. Therefore, the analysis continues to detail the findings according to the patient perspective and thence to describe the value of these actions to patients.

When machines were perceived to behave strangely, users would often resolve to take multiple readings with the now-suspect equipment in order to control for the appearance of extreme measurements. Repeat readings enabled users to submit something like the average (Marion), or the one that made the most sense to them (Howard, Nigel). This provides evidence that users contextualise the readings to their understanding of issues that pertain to their understanding of things according to their lifeworld perspective.

> Marion: With me having atrial fibrillation, you can't very well – have to take a medium reading of this one because the pulse is irregular. […] Because it dodges around from 90 on to— […] I try to get a medium figure of when it [unclear]. Sometimes can go up to 90 and then 74. Look now. 76. 78. 79. 83. 87. [sighs] […] It is really-- this is a judgment call. It is. I think I'll make it a little bit more than 70. […] Think about that, I should think.

First, because the results on the machine do not produce a constant single reading due to irregular heartbeats (atrial fibrillation), Marion makes a judgement call about sending what she describes as a 'medium' reading but her actual selection appears to come from the lower end of the range. Based on a single observation, it is difficult to ascertain whether Marion consistently applies the same analytical method for deciding which reading of her heart rate to convey. Although some confidence in her ability to maintain a consistent approach to deciding what reading to transmit may be assumed from her educational background and previous work as a financial accountant for a major bank, the fact that she is recovering from a second stroke and worrying about other personal hardships means her cognitive focus is less than it was. As explained previously, she finds she cannot concentrate well enough to cook because she forgets what she was doing. Therefore, her intention to consistently apply sensible workarounds to the problems presented by the telehealth machines may be undermined by her constrained cognitive resources as well as her compromised physical energy and coordination. Her selection of a conservatively low estimate as an accurate pulse rate may also be a mixture of wishful thinking and another form of subjective assessment (i.e. I am not feeling as bad as I was in the past). This evidence of the use of subjective self-report to influence the process of transmitting what is assumed to be objective clinical patient data is another important theme emerging from the data.

Sometimes abnormal readings were treated with apparent disinterest by participants because they were not perceived to provide information that participants could use to inform their ensuing actions (Peggy, Clive), and were described as only significant to the clinicians who were looking after them. However, it was clear that abnormal readings often increased telehealth work for patients because it meant they had to participate in submitting more frequent readings of their condition, which was tiresome (Clive, Russell, Peggy), and could cause anxiety (Kate, Brian, Elizabeth, Ted), unwelcome disruption to their day (Cleo, Russell) or add to the routines of their already busy carers (Brian, Kate, Cleo). Abnormal readings therefore frequently triggered a request for repeat readings in order to ensure that the result wasn't due to a blip in the machine function or the result of exogenous influences when taking the reading, such as rushing around (Ruth) or climbing the stairs (Howard). If the readings were consistently abnormal, then the patients and carers in the patient lifeworld would be more actively involved in closer monitoring (Ray, Russell, Stacey, Brian, Nigel) and they would expect closer monitoring through the telehealth service (Phil, Howard, David, Colin, Robert). Some participants suggested that the parameters set for them by their referring clinicians were not reflective of their current state, causing 'false alarms' to be triggered (Stacey), which could be annoying (Russell) if not anxiety-inducing (Graham, Ray). Adducing the cause of false alarms to set parameters was plausible based on the observation during a work shadow visit in the telehealth support centre that a nurse wasn't worried about the trend of elevated readings causing the telehealth alerts for a patient undergoing a course of chemotherapy. The patient's

parameters were not changed to reflect this treatment although a note was made on the system. To the nurse, therefore, the telehealth alert was redundant information, but for the patient, the regular alerts added to his work because he was expected to submit repeat readings at a time when he was experiencing resource intensive treatment.

Interestingly, users did not just react to the displayed results to consider for themselves whether repeat readings were required. It was also common for users to interpret idiosyncratic machine behaviour as significant even if they weren't sure if it was a real indicator of technical malfunction. For example, if the blood pressure cuff would stop midway through inflation, then re-inflate, this instilled doubt in the user regarding the accuracy of the subsequent reading (Howard, Nigel). Stacey describes how the machine's strange behaviour was used to predict the end result. She describes her interpretation of a blood pressure monitor's onscreen graphical animation as the cuff inflates.

> Stacey: So, that's a good sign, because it stopped one block before 150, but--
>
> INT: Is that a good sign? I've never read that.
>
> Stacey: It is with me. If it goes up by 170, 180 then I know that one of the numbers is going to be high. […] it's just what I've found. 134 over 89.
>
> INT: What's your reaction to that?
>
> Stacey: That's fine. It's just under the parameter at the bottom number. If I was having that down at the hospital, they'd say that was good for somebody with kidney problems. My pulse is 80.
>
> INT: What do you feel about the pulse?
>
> Stacey: I don't really keep check on the pulse. I know if my heart's going, "boom, boom, boom, boom," then there's something the matter.

Stacey's case shows how users were unexpectedly observed to 'read' the way machines operate, in some ways mirroring the way the machines are meant to read and measure their physiological condition. It is suggested that this way of coping with the perceived fickleness of machines is one way that participants were becoming conversant with vital signs through using telehealth. Their learning involved interpreting what they saw the machine do, interpreting its actions against the result displayed onscreen, and to iteratively compare these combined results against their recall of what they observed nurses and doctors to do in their previous healthcare experiences (e.g. questioning the result, resolving to repeat the reading after resting for a little while). As illustrated by Stacey's case, participants use a combination of cognitive and sensory-based (i.e. knowing what it feels like when her heart is beating quickly) self-monitoring processes which partially liberates users from over-dependence on fickle machines, thereby making the perception of the actual functionality of the machines relatively less important. This means that users can treat abnormal readings in an abstract way, rather than responding to it with anxiety in the first instance.

Stacey's case illustrates how users combine different sources of information in order to empirically

determine predicted outcomes. This can be interpreted as evidence that users construct theories of causality about the machines in use, which is observed to underpin their coping strategies. So, for example, if they suspect that something regularly occurs, it becomes part of what is normal for them, and it does not necessitate their being anxious when an alert is raised. It is suggested that this usage process leading to understandings of probable causes illustrates one form of self-learning that occurs as a result of applying coping strategies when experiencing paradoxical machine interactions. Although their assumptions about causality may not be externally valid, they are observed to be personally useful to participants in their lifeworld.

Furthermore, although participants were observed to treat potentially malfunctioning machines with tolerance by applying a form of clinical distance, and abstracting themselves from the results, this does not mean that users were able to abstract themselves from feeling acute frustration with perceived faults in the design or functioning of telehealth machines and services (Clive, Russell, Howard, Nigel). Repeat readings is one way of coping with frustration and controlling against anxiety. Therefore, rather than losing control, the self-learning process enabled by repeat readings helps them to regain control.

Unusual results meant that some distrust in the way they were using the equipment, or a fault in the equipment itself could lead to the need to do more telehealth work in practice (Clive). More significantly, the hidden use of repeat readings was observed to include users having learned to apply a series of private sense-checking procedures before transmitting readings to the remote server (Phil, Howard, Stephen) in order to avoid false alarm calls. Perceiving and resolving equipment and service faults is an important dimension for understanding how service users experience telehealth service failures and effectively participate in their own service recovery. Service recovery with telehealth using repeat readings is conceptualised as part of patients' participation in making sure the service is calibrated to their subjectively perceived needs.

6.4.1.3 Sourcing human support

In this section, we provide evidence that user-machine interactions are enriched by being interspersed with supportive human interactions apparently leading to more sophisticated use. These human interactions appear to be important to develop confident use of customisation processes. Confidently using telehealth is suggested to be part of a process of regaining controlled independence to operate the machines for self-care after initial doubts about capability to use the service. Access to human support also seems to be a component of building clinicised competence to self-care.

Across the sample, the importance of corroborating self-learning through access to 'expert' support and feedback was observed to be an important part of building competence as users. This user competence is conceptualised as a form of mastery relative to prior experience of problems.

Graham's case shows how having access to service provider feedback to reinforce user competence and self-learning is appreciated by users. He explains that he was convinced the service's failure to receive his transmitted readings was due to the old equipment being 'touchy' or temperamental rather than a sign that he was not using it as directed. He mentions a memorable occasion when the telehealth installer's actions corroborated his own independent assessment:

> Graham: It didn't always send information, and the girls used to phone me up and say, 'We haven't received them.' I said, 'Well, I've done it.' And I just redo it to try and get any information to them. It was a bit touchy, that one. When [the installer] brought this one, and he said, 'Show you what we're going to do with this one,' he said. Well, it went straight in the bin.

Graham's opinion that the Honeywell equipment was touchy and not fit for reliable service was clearly corroborated by telehealth installers putting it in the rubbish bin. As participants experience the demands the machines make on them as users, expressing their concerns is a way of obtaining validation by experts, who confirm their opinion by addressing the faults through repair or replacement.

Having this kind of feedback loop appears to enhance users' tolerance for perceived technological faults, normalising idiosyncrasies rather than allowing them to become a cause of serious health-related concern. As explained previously, machines that seem to misbehave forces users to integrate workarounds in order to successfully transmit readings and hence co-produce the service. This means that users are faced with occasions when they must question machine accuracy and triangulate between the reading they see, what they recall seems 'normal' for them, and how they feel in themselves.

In order to decide what to do (e.g. to repeat readings, which reading to transmit, to call for assistance) participants frequently rely upon and reinforce learning from previous experiences with telehealth and the wider healthcare service. Therefore, it was observed that access to support from human interaction was in some way vital to their use of telehealth, although this support was typically accessed indirectly. For example, participants often confirmed that their understanding of what was a good or worrisome vital sign reading was usually gleaned incidentally (i.e. through previous experience of having their vital signs taken) rather than through formal education by a trusted source. Evidence of gleaned guidance included short-form, rules of thumb (e.g. only looking at the systolic reading of blood pressure, or knowing to look out for an extreme pulse rate or percentage oxygenation is) and an admission that they were reasonably confident that they were doing things the right way and if not, the telehealth alert would advise them. Telehealth use therefore seems well-suited to guided self-learning. As Ruth's case shows, using telehealth can trigger interest in understanding their bodies from a clinical perspective.

> Ruth: I don't understand the readings. […] I would like to really know.

INT: Okay, have you spoken to anybody about that?

Ruth: No, but I will [ask the Matron] when she comes.

INT: […] when the number said '90' and you said you were sort of concerned...

Ruth: Yeah, well, you know like today, I thought that was a bit up but it might not be. But it seemed high to me, you know. So I don't understand it anyway, but if there is anything wrong, [the telehealth support worker] 'll get back to me.

Therefore, when sampled participants were interested in increasing their understanding about their condition, they often said they could rely on telehealth to monitor their health for them. Having access to simple guidelines enabled users to move from making an individual empirical observation toward creating a domestic version of a clinical baseline to guide their interactions with healthcare providers.

Participants clearly sought corroboration of their personal learning, as evidenced by questions to the researcher during the interview (Nigel, Rachel, Molly), and descriptions of advice seeking from experts (e.g. GP, Matron or Nurse) about interpreting vital signs (Stacey, Howard, Nigel, Peggy).

Howard: Well, I kind of manage it myself. And then when I have a query I just ring up and ask somebody. And if they don't know the answer they know a man who can, so I usually get to the end of it one way or the other.

Howard's case exemplifies some participants' apparent willingness to do more to self-care under certain conditions of being able to access knowledgeable support from experts.

Unavailability of supportive feedback, therefore, is shown to create tension in the relationships participants have with their usual healthcare providers. It makes development of clinicised competence more difficult either by discouraging it from forming or forcing users to integrate their own resources for self-learning without confidence. The following examples show how participants describe a lack of available support from healthcare providers to assist in learning how to self-care effectively.

Molly: Well, they're just starting my blood [testing] again. I was a bit worried because I took myself off Warfarin a few years ago […] Because every weekend I was in hospital. No doctors there to see you. They fetched you in on Friday night, and brought you home Monday after the doctor had done your blood, and it got on my nerves, doing it every week. […] Just for the blood test, and with having no transport they did get the ambulance to get me out there. I used to go to the hospital for it - regular - first off, but then I could get on buses better. So, I asked to come off it, anyway. Recently, my brother's had to go on Warfarin. It made me think, "Should I be having it?" Because nobody's mentioned it, you know? So I asked the doctor about it and he didn't say, "Yes" or "No".

***

Elizabeth: I've got a Matron comes every month, now she annoys me because I said to her, you

> know, the way she's got all of the forms done there. I said to her, 'Can you do me a favour?' She said, 'What's that?' I said: 'You've got all my information on your computer. Can you thingmy up [print out my patient record] for me? So if I go to the hospitals and all that, I've got all that information, 'cause you can't always keep it in your head!' And she hasn't done it! [a bit cross] … [discussing her handwritten patient record] I always do this because if you've got to go to hospital, then they say... and you forget, so I think if I write it down, then I know […] I mean it's […] your operations […] that confuse you. You know what I mean? You can't always think. I mean it's like the heart [nurse?] will go: 'Are you sure? I don't think we'd done hearts there [at that hospital]?' You know what I mean, it's like you're a liar.

Molly describes relying upon the doctor's advice either to support or reverse her earlier decision to stop Warfarin treatment because it created inconvenience to her. However, without his guidance, she is doubtful about her ability to self-care appropriately. She is left to continue worrying about her decision because her concern is unresolved. In Elizabeth's case, the non-response led her to create her own handwritten patient record to have ready during her healthcare service interactions. This enables her to feel more at ease about answering questions accurately and saves her from being challenged about the facts as she presents them. It is clear that she finds being challenged detrimental to her relationships with healthcare providers. Non-responsiveness of clinicians when they seek information or the appearance of withholding necessary resources to help them to help themselves can lead to frustration (Molly, Russell, Robert, Stephen, Phil, Clive, Elizabeth, Rachel) because patients want to do the right thing but feel like they are wrong-footed when they try to improve the way they access healthcare.

For example, in interviews when citing different sources of 'proof' as corroborating evidence of their abilities (including the accuracy of their opinions), participants seemed to be explaining that their understanding, opinions and practices were justifiable, and not wrong (Ted, Kate). This was interpreted to show that participants generally have conviction that the way they use telehealth is both valid and therefore assumed to be valuable to their healthcare service providers. As Kate's carer, James, says: 'the doctors trust us, how we're doing it' and this gives him confidence that his care of Kate using telehealth is appropriate for her according to the clinical perspective of their doctors and nurses. Their insistence was interpreted as a possible sign that participants were afraid that the study would somehow result in changes to their access to telehealth services in some way. This interpretation was based on Peggy's insistence that she could use the telehealth under normal conditions because her usual nurse believed she was suitable for it, and she was implying that the condition of being freshly discharged from a long hospitalisation was an extraordinary one.

In other words, participants did not appear to doubt or question that the manner in which they were domesticating the processes of using telehealth, including their self-justified use of workarounds, was in any way problematic or a sign that they required additional training or oversight. Most participants seemed to assume that persistently muddling through with the equipment was necessary

in order to transmit readings. Successfully transmitting meaningful (i.e. judged to be accurate) readings of their condition, is what is ultimately understood to be helpful and beneficial for the co-production of the service. They don't seem to consider that the validity of the readings they send might be questionable because they are subjectively constructed rather than the objective clinical reports of the patient's condition that might be expected from the telehealth service. The difference being, a subjective report is lower on the hierarchy of clinical evidence (Figure 2). In fact, the only time participants admitted they were potentially doing something wrong with the machines was when they were first installed and lacked experience using them. Therefore, participants described the adaptations they established as reasonable and acceptable because they had occasionally integrated some kind of expert guidance into their understanding of clinical monitoring.

Having described the importance of sourcing human support for self-care practices, and evidence that lack of support leads to poor relationships with healthcare providers, we can see how important it is that users find for themselves sources to bolster confidence in their abilities to self-care.

In order to show how user confidence in their abilities to use telehealth is potentially problematic, we explain how the following case shows the integration of feedback to validate participant views can lead to negative outcomes. Russell's case shows a poor relationship with the Docobo machines. He argues that his dissatisfaction is neither singular nor a result of a personal failing or his unsuitability as a user because his opinion is shared by others.

> Russell: The other [Honeywell] was a lot better. And apparently, when she brought me this new finger thing [pulse oximeter], she was saying that a lot of them - the other people - that she goes to, they're not happy with them. They were better off with the other one. It was more simple; a lot more simple […] You just put it on and you did it and that was it. You haven't got all this lot and everything going wrong. […] And it's the second one of these that I've had. The first one, it was only three days, and it just wouldn't work. They sent a chap out to have a look at it and he said, 'Well, he's got to have a different one. It's no good.'

Although Russell confidently asserts his opinions as backed up by consensus, this conviction seems to miss the point that telehealth is not suitable for everyone for various reasons. In Russell's case, it may have been physical unsuitability rather than cognitive capability that was the problem. During his demonstration it was observed that both the finger-mounted pulse oximeter and the touchscreen Docobo portal are unresponsive to his thickly calloused fingers and he resorts to using quite unnecessary pressure (compared to the researcher handling the same machines) to navigate through the onscreen menu. Although he could use the regular buttons as an alternative, he seems intent on demonstrating how unresponsive the touchscreen equipment is. The unsuitability of the machine for Russell's needs were obvious to him, but because he was previously a satisfied Honeywell user, he was persisting with the new system. His case evidences how machines are not

experienced neutrally during interactions due to mainstream design specifications not suiting heterogeneous needs.

6.4.1.4 Accidental customisation

As discussed in the previous sections, what users purposefully do with telehealth machines seemed to involve experiential learning processes applied to the identification of problems and attempting to understand what might be causing them (i.e. a fault) in order to respond accordingly, e.g. through the application of a workaround. This section, however, describes a different form of telehealth use that surfaced purely through observation of patient experiences.

As most users did not describe experiencing problems, it was found that their verbal accounts contradicted with their observed use (unless the primary users were younger and/or fitter carers, where there were far fewer problems observed). As Russell's case shows, participants using telehealth equipment asserted their competence and competent use even when they were having problems. Russell seemed to base his opinion that it was the Docobo machines at fault due to his capability with the other Honeywell machines. In a similar vein, participants were observed to attribute problems experienced to situational factors (e.g. having just been discharged from hospital (Peggy) or recovering from a stroke (Marion)); user factors (e.g. being 'a learner' (Elizabeth, Molly)); or functional factors due to the machine acting up (Howard, Nigel, Clive, Russell) as a trigger for introducing workarounds.

Therefore, it was striking to observe when participants were not sensitive to the emergence of problems when using equipment. For example, when a problem was identified by remote telehealth support workers, they would ask users to press a reset button on the main telehealth box. During the interview Ruth complained of having 'filmy' eyes affecting her vision in addition to COPD, and when she looked for the 'Retest' button, she kept saying 'Reset' aloud, and struggled a bit to get the Honeywell box to respond to her pressing the button. The retest button (or Any Time Tests and Questions on the Docobo portal) enabled users to repeat all or some of their routine tests. Low literacy could also lead to problems as participants were observed to struggle reading and understanding what 'SpO2', 'oedema' and 'fatigue' meant, which are frequently used words on the telehealth machine. Colin was observed to input the wrong reading when transposing numbers from peripheral machines to the portal. Marion, who was waiting for a follow-up appointment for an incomplete cataract removal, could not see the weight displayed on the scale clearly.

> Marion: Can't see it. […] I can't see the weight because of the reflection on the-- it's 70...huh! […] I don't know why there's a reflection on it but I just can't see it today at the moment. […] Can you see 70? [73.2 was on the display]

From these examples, it is easy to see how participants could *unknowingly* submit responses of questionable accuracy to the remote server, either through the use of repeat readings and selection

and transmission of a reading that (intentionally or unintentionally) breaches the parameters set by their referring clinician.

Similarly, there were issues when participants were answering 'simple' questions enquiring about changes in their symptoms. These were displayed and/or vocalised by the machines. In the case below, Molly explains how she answers telehealth questions normally.

> Molly: Now sometimes I'm breathless, sometimes I'm not, so I don't... My carer always says, "No [laughter]." [sounds like: I mean a little swelling]
>
> *Machine: No. Have you had any breathlessness?*
>
> Molly: You see, it could say, "yes" but I'll do "no".
>
> *Machine: Breathing. No. Have you had any breathlessness? Fatigue. Have you felt more tired than normal today? Swelling. Have you had any ankle swelling in the last 24 hours?*
>
> Molly: That should be "yes", but I don't do it. She tells me not to.
>
> INT: Well it says, "More than usual, much more than usual, as usual."
>
> Molly: I'll put "as usual".

Molly is explaining the influence of her paid personal carer who comes to help her wash and dress in the mornings. The carer's opinion is clearly interfering with Molly's registering of her own subjective assessment of her current health condition compared to her 'usual' experience. Furthermore, because Molly is elderly and frail and has had serious mental and physical acute and chronic illnesses for over 40 years, she described her health history in a way that is consistent with other participant experiences: as a recurring cycle of illness (feeling unwell, condition worsens, health crisis, diagnosis, treatment, recovery, lifestyle change, maintenance of stability, feeling unwell…). This makes comparing 'what is usual' slightly more challenging in practice, especially for persistent issues, like breathlessness, fatigue or swelling. Therefore, if Molly somehow fails to register responses that flag worsening conditions, it may be due to a lack of training rather than her inability to comply with what is expected to be simple telehealth usage of regularly registering answers. This example of accidental customisation results from interpreting the everyday language used in questions differently than anticipated by the protocol. This case also shows how effortful it can be for users to translate complexity into a simplistic response.

The risk of misinterpretation can arise from misunderstanding the diagnostic intention of the questions set for them according to the agreed telehealth protocol prescribed by their usual clinicians, resulting in the transmission of inappropriate information. Because there are no options or workarounds available to users for avoiding the questions during the scheduled protocol (unlike Any Time Tests and Questions, which allows users to select from a menu of tests to retake), impatience with misbehaving machines was also observed to affect the interpretation of everyday language used for diagnostic interview purposes. The quality of responses was observed to be

influenced if participants were answering in a rush or without considering how the answers are being used for monitoring their health. For example, Russell's frustration with Docobo telehealth equipment has led to his perception that its more extensive question set is 'unnecessary' and prolongs the agony of using it. Here he was observed to transmit potentially misleading answers to the remote server.

> Russell: [reading aloud the words on the screen] "Do you have a cough?" Yes. [mocking singsong]
>
> INT: But Mr […], I've not heard you cough once since I've been here. Is that just generally speaking?
>
> Russell: Yeah. Only now and again. I don't have it a lot. […] "The day time?" Yes. "Is it better than usual?" Oh, it's about the same as usual. Right. "Is your cough productive?" Occasionally, yeah. [his tone is like he's not taking this seriously]
>
> INT: But I think it's about now. These questions are asking you now, aren't they? [he doesn't answer]

The diagnostic purpose of answering telehealth's questions specifically is not in the forefront of Russell's mind because he has lost patience with the equipment and the service and seems keen to communicate this user feedback during the interview. His opinion is further influenced from experiencing a memorably inappropriate response to his situation, i.e. receiving a telehealth call on his mobile phone asking if he needed the paramedics when he was out on his scooter doing his shopping. It doesn't seem to have occurred to him that his rote responses might be triggering false alarms, leading to the inappropriate offers of assistance. His perception of the telehealth routine and the service calls as burdensome is clear and it appears to be caused by his poor interactions with the machines combined with the sheer frequency of the demands made on him by the telehealth support workers.

> Russell: [I use it every day] And **every day they phone up and say, "It's wrong; do it again."** When the club went to Doncaster Market, and they even gave me a call there, to ask me to do it again. […] Well, this morning, she phoned back this morning, and she said, **"I bet you're getting fed up to the teeth with me ringing back." I said, "I am." I said, "It's every day."** You don't do it, and then that's the end of it. You do it-- I have to go out and do my shopping obviously. And I don't like sitting here all day on my own, so I do go out. […] And she'll say, "Oh, you out?" "Yes." "Oh, are you out again?" "Yes" "Well, we need it to be done again." And I said, "Well, look, I'm down B___." "Well, we'll ring you later this afternoon then."

This case illustrates the unexpected need to interpret everyday language, with difference in opinion taking an emotional toll on users. Emotions can involve disappointment, disaffection and disenchantment with the service design being perceived as inappropriate to their needs. This interpretation that the service is insufficiently personalised can make using telehealth an extraordinarily effortful experience especially if it is used daily.

It is reasonable to assume that because users can be unclear about the underlying process or rationale behind the telehealth functions and question sets, their divergent interpretations of its diagnostic intention, according to their lifeworld perspectives, may enable them to feel at liberty to customise them through means of using it to suit their own aims (such as saving time).

The cases illustrate how use, misuse and overuse of the machines are potentially co-produced between different service actors (users, machines, telehealth service support workers, telehealth designers, referring clinicians) which can affect the value that is generated from using the service. It is clear that explaining how telehealth works entails more than telling users how to operate the machines. More thought is needed to consider how problems emerging from different interpretations of machine functions, everyday language and specialist language occur when moving monitoring tasks from clinical control into lifeworld settings. We begin to see from these findings how users co-create subjective value that has utility for coping with illness in the lifeworld context, especially as it relates to respecting patient preferences for healthcare service interactions. We also begin to see how subjective lifeworld value may not be commensurate with the clinical value sought by the healthcare system when introducing objective clinical monitoring through home-based telehealth equipment.

6.5 Conclusion

The main finding from the analysis of user-machine interaction is that the effortful experience of using fickle machines is observed to trigger creative coping strategies in order to achieve a form of mastery in use. Consistent with an S-DL perspective, the process of use required users to integrate necessary resources (including physical coordination, mental concentration, emotional patience) in order to achieve the personal goal of successfully transmitting their data necessary to co-produce the service.

Because telehealth machine readings are 'consumed' in the lifeworld, their value to patients is highly subjective, as they are commingled with various levels of homespun versions of health literacy that is observed to include interpreting machine processes and outputs in unpredictable ways. These interpretive gestures appear to be founded upon human support sourced directly from telehealth support workers and clinicians, as well as indirectly, as evidenced by their explanations of personal practices and approaches copied from what they observed in formal healthcare practice.

This evidences their experience of telehealth in the lifeworld is structurally conditioned by their patient experiences in the clinical setting, which is considered further in Chapter 7. By transporting clinicised practices and perspectives into the lifeworld (interpreted as evidence of translating system rationality into the lifeworld, conceptualised as Translation I processes as explained in Chapter 7), participants are observed to establish causal links between the machine readings and their bodies, thus creating a 'clinicised' self-knowledge. This knowledge is shown to help coping with the spectre of vital signs and telehealth alerts frequently reminding them how ill, unpredictable or mysterious their bodies are. For participants who explain that they have overcome initial anxiety from using the machines, experience of telehealth use helps them to cope emotionally and respond with some clinicised detachment to the vital signs they see or the calls they receive in response to alerts.

Many paradoxes of telehealth are evident, including the increased workload for people affected by multiple comorbidities. Another was that due to the perception that telehealth should be easy to use, it means that participants are reluctant to consider themselves as potentially unsuitable despite problematic usage making the service occasionally burdensome. A third paradox is that despite a structured user-machine interface designed to constrain interactions and focus on collecting objective indicators of health and illness, there is evidence of customisation which points to subjective and accidental interference in the social construction of supposedly objective data that is transmitted for analysis by computer algorithm.

Therefore, although the data shows effortful use to be a common patient experience, and instances of repeated monitoring might suggest a time-consuming and resource-intensive practical enslavement by the machine as it regularly imposes itself on participants' domestic life, the

evidence suggests a contrary relationship with the machines. This is because the understanding that machines are apparently fallible has created a sense of scepticism about the results, and this can be interpreted as a type of emancipation from its readings, enabling users to consider it as a tool for their use and benefit rather than a means to impose unwelcome clinical controls over them. Therefore, scepticism about the machine's reliability can help users avoid becoming unduly anxious about the results, as well as showing evidence of resistance to a machine-based clinical authority dominating the domestic space. The figurative positioning of the telehealth machine is not entirely authoritative or controlling the user. Even though it forces the user to respond to its multiple demands, the user may resist by failing to comply. More subtle ways of resistance include users regaining control over the telehealth through 'invisible' customisation practices which enable participants to force telehealth to conform to their preferences through the use of workarounds.

'Invisible' customisation practices are relevant because they pay heed to subjective lifeworld perspectives rather than system preferences for objective data conceptualised as the patient's most valid contribution to the clinical decision-making process. According to the biomedical approach used by healthcare systems, objective clinical data is used to interpret a patient's condition and decide whether it merits access to further healthcare resources. The finding of invisible practices of customisation as potentially deviant to the service protocol was shown to include two processes: questioning the displayed results and feeling the need to do repeat readings before transmitting a portrait of themselves that they deemed to be accurate for remote clinical analysis. These creative processes are observed to emerge from regular use and it is suggested that they were invisible until surfaced by this exploratory research.

It is worth clarifying that suggesting this is a discovery is partially based upon the observation of new equipment installation. During the work shadowing of telehealth installation engineers, topics related to questioning the accuracy of the displayed results and strategies to cope with this eventuality were not covered by training demonstrations, which generally communicate that using telehealth machines is a simple and straightforward process once they get used to it. The new users were then asked to try to use the machine themselves with the installer present to provide feedback and answer questions arising. Although specific guidance related to questioning the results and whether it was appropriate to do repeat readings was neither observed nor described, however, because the machines were tested *in situ* by the installers first, in order to ensure they were functioning properly, participants could observe, therefore, that there could be problems with them. Furthermore, as the service protocol itself often requires users to redo and resubmit readings when a reading breaches normal parameters, it is suggested that service users themselves could be tacitly encouraged to believe that repeat readings increase accuracy of the patient record and are an acceptable part of using the service. This can explain the emergence of the invisible practices.

We may consider all of these practices as relevant to the issue of losing and regaining control as fundamental to the illness experience as an iterative cycle of health-related trigger events from which patients recover. This contextualises the observed transition in participant interactions with telehealth from (a) self-effacing through self-blame to (b) self-assertion through blaming the machine, which are argued to form part of the adaptation and domestication of machines and underpin the development of competent use according to patient perspectives. We show how these interactions are part of learning processes where users become conversant with clinical vital signs in order to diagnose machine faults. This is argued to relate to developing clinicised self-knowledge, which participants apparently value as bringing clinical aspects of care into the preferred lifeworld environment. Their improved self-care integrates mimicry of clinical actions and therefore users attempt to approximate clinical practice including the use of vital signs to accurately represent their lived experience of a physiological condition. The interpretation of vital signs was shown to relate to participants developing individual theories of causality as a result of learning-through-use, e.g. about the idiosyncrasies and interpretation of strange machine behaviours as well as how their activities (e.g. rushing or resting) will be viewed by the clinical measurement device. This two-prong understanding was conceptualised as improved self-knowledge, which is argued to be an increase of a cultural-cognitive resource that provides predictive value that was useful for co-producing the service.

Subjective value most clearly emerged through the co-creation of time-saving workarounds and customisations that reduced the effort involved in complying with service expectations to transmit readings regularly. Therefore, the evidence suggests that it is analytically useful to maintain the distinction between co-production and co-creation processes as the latter better describes the potential that the 'invisible' customisation practices do not align with the service provider intention, although the outputs are argued to be the same: the mutually beneficial co-production of the remote monitoring service. The next chapter discusses findings related to the co-creation of subjective value in multichannel healthcare services by integrating telehealth as an operant resource.

This interpretation describes the aggregate view of the sample, and a cross-case analysis of variation between cases is shown in Chapter 8 to interpret evidence of highly heterogeneous needs exerting dynamic contextual influences on their capabilities and access to resources to self-care. These will be shown to be contextual conditions in which they experience telehealth. This underscores the importance of a context-based, lifeworld understanding of resource implications in contexts of constraint as determinants of patient value. The next chapter considers telehealth services as they are contextualised in multichannel healthcare services, and how patient experience of full-service informs telehealth experience.

Chapter 7 Using patient experience to co-create value with telehealth

Introduction

The previous chapter described the effortful use and mastery of telehealth and how this contributed to clinicised self-knowledge, which is observed to develop as a by-product of using fickle machines to co-produce the telehealth service. Developing a sense of mastery seems to provide participants with subjective value in terms of being able to confidently and competently use telehealth to regain control over aspects of their illness experience.

This chapter discusses findings related to the meso level interactions between patients and healthcare systems framed according to a value co-creation concept. It begins by explaining the main findings that the sampled participants generally have negative patient experiences of the healthcare system. These are interpreted as experiences that structurally condition or contextualise participants' persistence to use telehealth despite its apparent resource intensity. Telehealth use is therefore explained in terms of service recovery from negative patient experiences of healthcare systems. Service recovery includes improving self-care, through clinicised self-knowledge in order to achieve some independence from hospital-based services.

In order to understand the role of patient experience in telehealth consumption, the chapter explains an aggregate construct of personalised health literacy emerging from the data, which is the combination of clinicised self-knowledge and system knowledge. System knowledge is understood to result from patient participation in processes of reflections and rationalisation in the later stages of healthcare service consumption experiences. Whereas access to clinicised self-knowledge is identified as a necessary resource for the co-production of telehealth services due to fickle machines, personalised health literacy is conceptualised as an important operant resource in the co-creation of subjective value in multichannel healthcare services.

Illustrative cases of system knowledge will be used to highlight experiences of a system rationality that appears to explain provider behaviours and how the positive value they seek from interaction outcomes are different from determinants of positive value according to patient lifeworld. Therefore the chapter will use illustrative cases of patient experience to explain the interpretation that services are experienced according to tension between two contrasting contexts that are informed by different value systems: lifeworld and service system.

In order to explain and depict evidence of the service system as an institutional arrangement that influences patient-led value co-creation processes, we focus on the role of experiential learning through antecedent patient experiences, i.e. before they were using telehealth. Patient learning from

their experiences of wider services are shown to be knowledge of service systems, and this knowledge, as an operant resource is argued to structurally condition their intention to persist with telehealth and sets up the explanation of their ensuing actions, which will be discussed in Chapter 8.

7.1 Contexts and conditions prioritising hospital avoidance

'Everybody hates hospital.' (Howard)

We begin with evidence to show that antecedent patient experiences of hospital services strongly informs participants' use of telehealth to avoid hospitalisation.

Apart from the scary and unpleasant experience of a health crisis that precedes it, the experience of hospitalisation is also described by participants as submitting to system procedures that include a series of material and social deprivations. In particular, hospitalisation means foregoing important aspects of their usual self-care routines. For example, access to their usual medications are restricted for the duration of their stay, securely kept in bedside lockers upon admission (Julia). This procedure is frustrating and illogical for Stephen because he knows his medications are physically available as he brought them with him, yet they are withheld from him and instead he is offered different medications at the 'wrong' times, e.g. the day's pain medication all at once in the morning to suit the nurses, rather than throughout the day to manage chronic pain.

> Stephen: Every time I go into hospital, I take my medication, every single time, and yet they've never got it.

Apparent dissatisfaction from being deprived of usual medication is due to patients having spent the past months in a co-productive process of adjusting dosages with their nurse or doctor to achieve the right balance (Ray, Alastair, Howard, Stephen) of safety and effectiveness for the control of disease symptoms. Relatedly, patients describe being prevented from maintaining their medically restricted diets to avoid diarrhoea, stoma blockages and risk of yet another serious infection (Elizabeth, Rachel, Clive), or using the toilet with privacy and dignity (rather than being offered a commode for use in the middle of the ward) if they are experiencing digestive problems; this is because they cannot move to the toilet without help (Elizabeth, Clive) as a direct result of the treatment received, e.g. a hip operation or an IV connection:

> Ann: When [Clive's] breathing is really bad he can't walk, because he can't walk and breathe at the same time, so therefore he's got to get out of bed, and very often he's on a drip which is on a thing, which he can't do. Now he'll ring the bell for the nurse and she'll say, "I'll be with you in a minute, Clive." And an hour later he's still waiting. […] That's the most upsetting thing …

For Clive, the anxiety that his stoma bag will burst and he will have to sit in a mess until someone comes to help him clean it, is added to panic from difficulty breathing, sleeping and resting. Participants describe being kept awake at night by the noise and disruption of other people in distress, moaning through masks or even dying nearby (Clive, Phil, Peggy). Further disruptions come from the nurses and healthcare assistants who 'are always coming at you with their machines' (Rachel), 'being woke up in the night every so often: 'Oh, got to do your obs [observations], got to do your obs' (Phil). In particular participants describe being exhausted by the endless questions, which form part of the diagnostic interview and safe handover at every shift change (Peggy, Stephen, Graham). Many participants describe the experience of having to repeatedly answer the medical history questions as burdensome.

> Peggy: I'm very tired, and people keep coming and asking me questions and it really wears me out. […] People keep questioning me and questioning me. […] everybody who comes and I have to go through all the details again. Oh, goodness! [exasperated]
>
> ***
>
> Stephen: They want all of the information again […] Why can't they read the notes? […] 'Why are you here? What brought you here? And what medication are you on?'

Questioning is experienced as particularly effortful when you are tired, sore, thirsty, uncomfortable, bored, anxious, afraid, confused and unwell. The healthcare system is therefore interpreted to be effortful because it is not empathetic to their condition. This is especially irksome when they can see the use of patient charts that they assume already contains the information required.

7.1.1 Understanding patient experiences of service failures

Even when participants describe receiving life-saving treatments (Peggy, Nigel, Howard, Stacey, Julia, Graham, Alastair, Elizabeth, Russell, Stephen, Ted) which would typically lead to perception of a positive outcome from the service experience, it was common for these events to be contextualised by narratives describing a series of challenging and unpleasant experiences.

It should certainly be noted that not all aspects of patient's hospital treatment was seen as negative. Many participants praise nurses for being friendly and caring (Graham, Alastair, Robert) although several participants described interactions with a particularly unpleasant clinician in their narratives (Nigel, Elizabeth, Russell, Stephen, Colin, Phil, Stacey, Molly). It was also evident that participants depersonalise blame: rather than blaming busy nurses as uncaring, they describe neglectful treatment as a result of their work pressures or the way work is set up, thereby ascribing the problems as generally related to the hospital environment. For example, Clive's anxiety and distress from unintentional neglect of his stomal care regimen is rationalised on the basis of being in the wrong ward for stomal care. The following quote suggests that hospital care is configured according

to different clinical specialisations. Therefore, Ann reasons, they cannot expect respiratory nurses to care for his stoma, i.e. it is the work of gastroenterology nurses.

> Ann: … he dreads me coming home because **he knows his stoma will need emptying and he can't get anybody to come and help him**. I think that really is the worst […] You see even when I go in the afternoon, I'll take him to the toilet and bring him back, change his bag and things like that. That's not really anything to do with his breathing and it's not their fault, it's just his stoma bag needs changing.

In Howard's case, we can see his understanding of the important differences between what happens in hospital and what people normally consider to be appropriate care at home. His awareness is evident by his use of tactics to interrupt the normal flow of hospital functioning.

> Howard: …there's lots of little things like that that happens when you're in the hospital. I find, if I can get out of the bed **I'll go stand out in the main corridor and go, "Hello! [in a friendly accent] Where is the water?"** or something. And I'll try to — **"Yeah, forgot, you like! Where is that tablet that you were going to give me?"** or something like – **I don't want to be in the way, I just stand there because when they're buzzing up and down they're not—or I try different tricks, you know? Like when they say that they'll be back in ten minutes with something, I might say "I don't think so. I don't think you'll be back."** So that's-- well, I think it's doing some good, because a lot of times they don't come back, do they? I mean, my experience of the hospitals is that it's quite a bit now. **There's a lot of times where if it's a minor thing, they forget, they just don't come back.** I love to discuss this with nurses now, and they say, "Sometimes when they're sitting down watching television, they go 'Oh, I never got him his last water'." **So they're already at home and everything when they realize they haven't come back to you**.

This excerpt suggests that the hospital setting (i.e. architecture that makes patients visible only by entering wards, and the work practices of nurses mostly moving between wards) makes acceptable certain neglectful behaviours that would not be considered standards of good care when removed from the hospital context. In order to disrupt the momentum of the hospital's functions, he stands where he is not supposed to, talks back and gently challenges authority in order to remind nurses about needing their help to access the care he needs. In hospital settings, he says that nurses behave as if satisfying basic needs are 'minor things' that are easily forgotten. His quote suggests that nurses behave more humanely – and reflect on how much 'minor things' matter – once they are out of the pressurised hospital setting and returned to a home setting. This implies that being out of the hospital setting enables nurses to recover their humanity[10].

Howard also describes his suspicion that he may have been victimised by a bureaucratic decision rather than a clinical decision in his best interests. He describes being released in time for Christmas.

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[10] This interpretation is grounded in the medical sociology literature's critique of biomedical approaches because they treat patients as objects (Mol 2003), hence dehumanised, and this means the clinical relationships with patients are object-oriented rather than intersubjective. The findings also relate to humane and empathic care that tended to be systemically overlooked in service quality assessment until the use of patient experience data to audit services (Black & Jenkinson 2009).

He is not sure why he was discharged and suspects the decision has brought about a heart condition. Since he has been self-managing his condition with telehealth, he has been watchful of symptoms of heart failure (weight gain and ankle swelling). During the interview he retrospectively questions the decision to discharge him because he knows he was still suffering from fluid retention at the time.

> Howard: I was in the hospital […] and they let me out on Christmas eve at eight o'clock. And I didn't have any problems with my heart before that. And I came in here and I went to bed, and then I got up the next morning at half seven, by eight o'clock I was on the floor there with the blue light ambulance man. My heart just failed. I don't know why they decided they would let me out, it was probably because it was Christmas, but it's the only mistake I've ever sort of noticed. I mean, I'd got the swollen feet and things like that, and I did have water retention. […] that's why I was in the hospital, yeah.

Howard's narrative suggests either that the hospital was clearing beds in time for Christmas or that they were humanely discharging him to have a family Christmas at home. However, it is clear that he questions the clinical judgement leading to his discharge because he recognises he was still ill and it led to disastrous consequences: heart failure that ruined Christmas.

In another case, Russell describes being left on a hospital trolley for 11 hours before being advised to change his insulin titration. His displeasure at what he believes to be avoidable discomfort, cost and inconvenience are clear, and he and his daughter suggest that he was kept on a trolley rather than formally admitted and discharged so the hospital could technically avoid failing to meet reduced waiting time targets.

> Russell: I was on the trolley 11 hours. And then along came two of the diabetic nurses. [They examined my injection sites and told me to adjust my insulin]. They did that, they told me that, and sent me home. Nobody discharged me because I was never admitted into a ward. […] my daughter stayed until 4:00 AM in the morning with the car. What they did, they could have come and done that and sent me home with my daughter instead of laying me—go out there, and walk and get a taxi. […] I had to go outside in pyjamas, to get a taxi to come home, which cost me £12. And it's disgusting.

These stories highlight key aspects regarding the organisation of healthcare services that, according to the participants, can be seen to lead to maladaptive behaviours among clinical system actors, including treating patients in a way that is object-oriented rather than treating patients humanely, i.e. consistent with an empathetic, inter-subjective relationship. Consider evidence from Russell of how different organisational priorities contradict decisions about who gains access to necessary healthcare resources.

> Russell: … [the doctor] stood in the middle of the ward - no curtains around - and he shouted at me. He said, "You're being sent home." He says, "These beds are for people who are dying, not for people with blood sugar trouble." And the staff nurse said, "Oh, no, he's not. He's being kept here for the diabetic people there." And I was in 8 days. But he was going to send

> me home because those beds are for people who are dying, not for such as me. And this is why I get a bit annoyed with them at times.

Russell's case shows tension between different perspectives and priorities. The doctor was seen to act on the basis that Russell's body fails to exhibit the objective criteria necessary to determine who gets a hospital bed (i.e. poor diabetes management vs. dying). The nurse was seen to have conflicting criteria for occupancy in that ward, i.e. he needs to wait somewhere until the diabetic specialists can see him. Part of Russell's annoyance stems from the fact that according to his sense of logic, he believes he was right to seek hospital care (his opinion is validated by eight days of hospitalisation) and the doctor was suggesting he was using services inappropriately.

This case illustrates distinct lifeworld and system world rationalities in conflict. The healthcare system is the context where tensions emerge between patients a) having to assert their subjectively perceived need for healthcare and b) satisfy the system's need for objective evidence of illness sufficient for the service to consider that patient's self-presentation as appropriate. This means patients are put in the position of asking for help, and justifying their need for it. This is a difficult argument to make when the patient is unwell and underequipped to argue against the absence of objective indicators of health and illness. According to the system view, what patients typically have is access to subjective patient self-report, and as a form of anecdotal evidence, this requires clinical evidence to corroborate patient claims that treatment is necessary.

These examples illustrate evidence of different worldviews in operation: a subjective, patient lifeworld view and an objective, healthcare system view. These views often contradict and an inability to understand how one rational system relates to another results in an effortful service experience. Therefore, the doctor's and nurse's reasoning may be required for efficient system operations, from the patient perspective, they fail to prioritise humane and empathic care. Instead, what participants describe is their observation of clinicians behaving in particular ways to satisfy bureaucratic system priorities. Therefore, the perception of an unpleasant hospital experience is due to the care they receive being perceived by patients to be at odds with what they expect in their usual lifeworld interactions.

With reference to Ann's *post hoc* rationalisation that respiratory nurses will be neglectful of Clive's need for stomal care, many instances in the data show how negative hospital experiences require patients to rationalise and come to terms with the experience of harm or neglect in various ways. Recall Nigel's case, where his wife had to technically refuse to care for him so that the hospital was legally obliged to continue caring for her ill husband. These examples of coping with hospitalisation experiences show how patients must strategically inhabit the system perspective, by trying to understand it. Making sense of the system's rationality helps them to account for otherwise 'unreasonable' clinical responses and behaviours.

Without understanding their experiences in terms of the system's strengths and limitations, it is argued that they would have a hard time entrusting themselves to its care in future. It is argued, furthermore, that patients are typically left to accept the gap between expectation and experience because the normal response to receiving poor service (i.e. withdrawal or exit in order to seek alternative provision) does not apply. This is because their provider relationship is likely to be long-term, i.e. for the rest of the patient's life, and difficult to replace with alternatives due to chronic dependency on locally accessible medical expertise.

7.1.2 System knowledge and telehealth to co-produce service recovery

The following illustrative case shows how participants overcome service failures and use telehealth to participate in a personalised service recovery process in order to re-establish trust for future care.

Managing the service relationship is effortful according to Stephen, who received life-saving treatment for lung cancer. He learnt through hospital rumours that the surgeon accidentally cut his pulmonary artery, leading him to have poor health and mistrust the quality of care he received. This is because rather than hearing directly from the surgeon about the error, Stephen was left to interpret that something went wrong when the surgeon returned from holiday two weeks later.

> Stephen: He was going around the ward and he come to the end of my bed with all his cronies around him and he says to me, "What are you still doing here?" he says, "You should be dead."

Stephen was still upset about the whole incident during the interview, which took place 18 months after being discharged.

> Stephen: I got to know a bit more and I got to talking to people on the ward, the sisters on the ward, and telling them what had gone off. And they tell me to report it, to make a complaint and— […] you always think the worst, don't you? If you complain and you got to have more treatment and things like this, are you going to get the treatment you deserve?

He was encouraged to complain by the nurses but was reluctant to seek full redress due to fear of reprisals when he needed care in future. This indicates Stephen's powerlessness in the service relationship and also the inability to exercise choice by withdrawing or exiting because of future dependency.

The evidence suggests the experience of negative hospital interactions is common to complex, comorbid chronic patients. Their serious comorbidities would account for decades of extensive and multi-layered healthcare experiences (Molly, Stacey, Graham, Nigel, Howard, Julia, Brian, Phil, Rachel). It makes intuitive sense that recursive healthcare interactions would result in less satisfactory outcomes over time because their diseases are progressive and incurable. It is suggested, therefore, that diminishing returns from successive healthcare service interactions could

naturally lead to experienced tension in their relationships with healthcare providers over time. As Russell expressed it, it's like the hospital staff care less about you over time.

> Russell: I don't want to be took to the hospital if I can help it, because I know very well what's going to happen. I'm just going to lay there [on a hospital trolley] for six hours. They're going to do another blood test, and say, "Oh, you've not had a heart attack. So we're sending you home." And it just seems like-- I don't know. It just seems like a routine, you know. And I think—I'm beginning to feel that once you're over 80, then they're not bothered very much with you.

Russell's description of what happens to him every time he is brought in to A&E with a health crisis is an example of his understanding of what the service can and cannot provide for him. In analysing participants' extensive service user experiences, they provide examples of detailed system knowledge describing the structures of formal healthcare services in terms of how they are organised, where they as patients fit in, and how they are meant to access them in order to receive attention (Darren, Clive, Stacey, Elizabeth, Molly).

These stories highlight a clear awareness of *service limitations* because they suggest services are generally arranged to accommodate healthcare service system priorities rather than lifeworld standards of care and interaction. This is suggested from the way participants describe many ways that healthcare is arranged to provide certain services – but fails to provide others.

Given the presentation in the data of evidence of poor quality of care received in hospital and the preference for self-care that mimics healthcare practices in the more comfortable home environment, this is interpreted to mean that participants' appreciation of the telehealth service's value is related to its ability to enable users to obtain respite from the exhausting experience of hospital care. Self-care at home enables participants to maintain a safe distance from risk of neglect and injury that occur in the hospital setting. Therefore, telehealth was observed to provide participants with healthcare *and* respite from hospital care, but at a cost. The trade-off entailed swapping the effort needed to use telehealth machines and services with the more serious efforts needed to recover from experiencing hospital treatment with mixed outcomes.

7.2 Translating system and lifeworlds using telehealth

The previous section discussed how participants experience and reflect on negative experiences of being immersed in a system rationality. Although telehealth extends system rationality into patients' homes, it also gives them a chance to manage this intrusion, and keep it at arm's length. It was observed that through telehealth, patients could begin to manage the conflict between their lifeworld and the perceived system world.

In this section we use illustrative cases to show how developing clinicised self-knowledge through telehealth use helps participants to bridge the gap between lifeworld and system world rationalities

toward improving interactions and outcomes. Through their service experiences they develop a perspective of hospital system functions and an understanding about their relationships with healthcare providers. Their experiences are understood through *post hoc* rationalisation processes that develop theories of causality, i.e. they are able to predict what the interaction will entail based on previous service experiences, and this experiential system knowledge is argued to enable them to strategically present themselves in ways that they believe will result in improved interactions and outcomes.

In order to explain how participants bridge the gap, this section explains an aggregate construct of translation, which entails processes that participants use in order to understand the system perspective as well as to make provider relationships and interactions more holistically patient-oriented, including their subjective concerns, in order to co-create different outcomes that more appropriately address subjectively perceived need. Evidence for this conceptualisation is grounded in the data describing detailed interactions between social actors in the telehealth service: users, machines, telehealth service workers, and their usual clinical carers. The conceptualisation is developed from evidence of customised use of telehealth machines discussed in Chapter 6 and how participants' private, 'invisible' practices are observed to force the integration of subjective patient self-report into the clinical decision-making process.

In order to explain how subjectively-informed customisations are strategically operationalised by users, we use two illustrative cases of participants who disclosed having atrial fibrillation (AF), or irregular heartbeats, as a condition. Their referring nurses requested that they regularly submit their pulse rate using telehealth equipment. Marion and Stephen are given two machines that could be used to measure heart rate (blood pressure monitor and pulse oximeter). However, participant demonstrations across the sample showed that these two machines tend to display conflicting pulse readings between them. Both participants choose to use the finger-mounted pulse oximeter to measure their heart rate. Marion's use was discussed in Chapter 6 showing how her customisation processes included selecting what she considered to be an 'average' in the rapidly changing range of readings for transmission to the telehealth remote server. Her customisation was focused on her ability to use the machine to transmit a single reading given a succession of changing readings on the display screen.

Stephen's case illustrates the translation process between subjective and clinical interpretation of vital signs. He shows how he integrates his self-knowledge and system knowledge to engineer his desired outcome. This is because he has learned to predict how the healthcare system will probably respond to the data he transmits, this is conceptualised as translation (Translation I) of the clinical language into the lifeworld context of his domestic understanding.

His system knowledge is evident as he decides which readings to transmit to the telehealth service because the decision requires him to consider the implications of those readings on any ensuing interactions with a network of service actors. He also considers which of these ensuing interactions would be preferable to him. Therefore, he must reflect on the possible consequences of his private, discretionary choices when deciding what kind of pulse rate result to submit.

> Stephen: Usually the most thing they ring, they try and get me for is my pulse. But as long as I say to them, "I just can't control that." One minute it could be 79 and the next minute it could be 97.
>
> INT: So what do you choose to enter?
>
> Stephen: I don't know [chuckle] this is my argu-- you know, it's so awkward.
>
> INT: Yeah. So awkward to decide because you see the figure jumping around?
>
> Stephen: Yeah. [pause] **It's so awkward to pin it down. If you pin it down to a low number, everybody thinks you're all right. And if you pin it up to a high number, everybody thinks you're not all right. So you just don't know**.
>
> INT: So in a sense, the awkwardness is, what impression should I give to the person down the line?
>
> Stephen: Yeah.
>
> […]
>
> INT: Okay. So that's interesting, so the awkwardness is not awkward for you yourself, it's awkward because--
>
> Stephen: Yeah. **Because of the people at the other end, because they don't really know what's happening. They'll ring me, and they'll say, "We're a bit worried this morning, because your pulse is a hundred and something." I say, "Well, you're all right. Don't worry too much about it, because it varies from 70-odd to 100 and something."**
>
> INT: [chuckles] I just laugh, because the roles are reversed, because you're saying to them, "It's all right. Don't you worry [laughter]."
>
> Stephen: **It's a good thing for me**, because I know basically if my heart's going -- because sometimes, when I've had problems with my heart, they took me into hospital, and it's been going at over 160 beats a minute, which is way, way over what it should be. **But if I notice that on that machine, then there's something I can do about it.**

Stephen shows concern that the reading he submits is an accurate self-portrayal that is both clinically valid and subjectively useful. Having to decide between the two highlights the difference between the two systems of meaning from different rational perspectives and it underscores the experience of hospital system rationality as non-natural because he wonders what kind of reading would be clinically valuable and would this data result in his ability to access the care that he subjectively believes would be appropriate? Stephen's case highlights how patients undertake to translate between what is meaningful to the healthcare system world and perceived need according to his lifeworld rationale.

This illustrates a process of strategically coping with an important moral dilemma. Stephen describes the process of deciding what message to convey as part of managing his doubly 'awkward' relationship with the telehealth service and regular healthcare services. This is morally *awkward for him* because he needs to figure out what kind of message to convey to them about his heart condition *to suit his objective clinical needs as well as his subjectively perceived needs*. He is aware of his position, moreover because of his familiarity with how healthcare services respond to types of information. Therefore, it is suggested that system knowledge appears to be introduced and reinforced through experiential learning processes that occur whenever he participates in service interactions.

Implicit in Stephen's description is how participants understand that they are portraying themselves through the transmission of their health data using telehealth and that the power to portray includes power to express intentionality. In other words, participants understand that they are able, by controlling the use of the equipment (i.e. agreeing to 'send' the output data to the remote server or not; choosing whether to repeat a reading and selecting between results) to either accentuate or de-emphasise certain aspects of their condition. This is an example of how the objective measurement of the patient's condition is subjectively constructed through the use of telehealth. This exercise of subjective authority also means patients are momentarily (and repeatedly) made 'responsible' for the 'validity' of the remote clinical decision-making process when they submit reports of their condition. Although these issues are emphasised in this study's findings, it is not possible to suggest that they are more pronounced with telehealth than occurs when patients report their concerns subjectively during a face-to-face appointment. What telehealth does offer, however, is the ability of users to choose privately what their measurements will be, whereas in face-to-face appointments, clinicians would be in control of the instruments for obtaining 'objective' patient measurements with less priority given to patients' subjective reports.

Coping with the moral awkwardness described is another example of how users are regularly confronted with additional work that is not scoped within what is envisaged to be an easy-to-use, task-based co-production process. Additional telehealth work therefore includes getting (to) and using the machines, doing repeated readings, and making a series of invisible moral decisions from the privacy of their homes. These instances of additional work can be understood as contextually significant because cumulative expenditure of effort for patients with compromised health can take a considerable toll on already constrained physical, cognitive and emotional resources. If considered as work to co-create value, the patient-led goal orientation of the linked series of interactions is nuanced to suggest that the outcomes reflect the goal of satisfying patient's subjective needs.

This example also raises two important and related issues: the rising importance of patient self-report in patient-led healthcare interactions, and the nuisance of 'false alarms'. We see Stephen's subjectively denying that the objective pulse measure submitted is clinically relevant although he knows it would trigger an automatic alert. This relates to a prominent theme of the growing importance of patient self-report in overriding hypersensitive telehealth algorithms, which may be due to inappropriate parameters being agreed by their referring clinicians (as discussed in the previous chapter). When Stephen suggests he is more clinically informed than telehealth workers, he is distinguishing between telehealth workers' view of his health as purely based on the computer algorithm's response to the data he transmits, and his more expert (although unqualified) ability to contextualise the information to his personal health history.

Stephen relies upon access to his cognitive resources of clinicised self-knowledge to respond to the telehealth workers and deny any need for further assistance because he knows the pulse is not that high. Access to telehealth equipment in his home enables him to be responsive to changes in his situation (i.e. if his pulse is 160 bpm), rather than being dependent on the telehealth service response. We can see, therefore, that even if the whole telehealth service is perceived to make systematically erroneous 'false alarms', users may tolerate this to a certain extent because they can derive some additional compensatory value from having access to the peripheral equipment in their homes to hone their clinicised self-knowledge for dealing with morally awkward service interactions.

Throughout the case examples, the need to do repeat readings can be perceived as effortful and even tiresome. However, it is clear that using telehealth is preferable to hospitalisation. Stephen's case also highlights a more nuanced interim benefit. Rather than being put off by routine requests for repeat readings, Stephen persists with telehealth because using it will enable him in future to precisely confirm why he is right to call for help. This is because he would be able to knowledgeably make reference to his extraordinary heart rate reaching 160 beats per minute. Being able to confirm his clinically validated need for treatment is understood to be a more persuasive and efficient form of communication than the use of daily language, whose imprecision can be a barrier to being clearly understood by healthcare providers.

This example of imagined future benefit from using telehealth relates to a cross-cutting theme: that the benefits of telehealth pertain to interactions within a wider context of previous and ongoing healthcare service experiences. This helps to clarify telehealth's role as an intermediary service within the context of multichannel healthcare services. The study therefore finds that participants do not consider telehealth as a replacement for regular healthcare services *per se* but as a method of improving the quality of non-telehealth service interactions.

It is also possible to see that with telehealth the onus of responsibility on patients is increased, not just with task-based labour, the creative labour of devising invisible practices and regularly resolving moral dilemmas, but also the co-production of service recovery to get over the experience of previous service failures. In this way, most of the work of managing provider relationships is perpetrated by patients, not because of a positive choice but because there is generally a lack of an alternative. Having complex chronic comorbidities means patients are 'loyal customers' who are long-term dependent on their healthcare providers. Therefore, when it is suggested that participants are aware that what they transmit is used to dictate the quality of care provided and, as shown in the previous section, the outcomes of services provided often differ from what is considered to be a good standard of care from the lifeworld perspective, this helps us to see the importance of the observed practice of participants deciding for themselves which readings to transmit in order to personalise the interactions as much as possible. This approach to the work involved in telehealth to manage provider relationships suggests that patients regularly try to bridge the gap between the two incompatible worldviews and value systems.

Managing the relationship is understood to be comprised of two linked translation processes. The first involves translating clinical rationality into the lifeworld for clinicised self-knowledge (Translation I) which was discussed in Chapter 6 as the result of undertaking customising and technical trouble-shooting work and beginning to see their health condition according to the clinical language of vital signs. This involves translating clinical rationality into the domestic, lifeworld rationality. The second process involves translating subjective patient self-reports of their need according to their lifeworld rationality into clinical self-portraits that are understood to be clinically meaningful in the decision-making process concerning access to more or less healthcare resources (Translation II). Both forms of translation are understood to be components of patients' work to manage service relationships which relates to the work of presenting themselves *prior to* the service interaction occurring. The next section defines the operationalisation of these concepts in context using empirical examples.

7.3 Co-creating value by integrating self-knowledge and system knowledge (Translation I and II)

This section considers how effortful use of healthcare services and mastery of healthcare service interactions is argued to occur through the use of two translation processes facilitated by telehealth services. The discussion picks up on the description of healthcare service experiences as effortful and the conceptualisation of effortful experiences as due to differences between perspectives and rational systems, i.e. healthcare services and patient lifeworlds. In this section, a further difference is discussed: the unequal relationship between patients and clinicians and how telehealth enables users to co-create value despite relative disempowerment. Structural disempowerment in the healthcare interaction relates to previous issues such as default suspicion of user error; the treatment of subjective patient self-report as inconclusive until it is clinically corroborated by objective measurement; and ceding control of the patient body to the authority of clinical decision-makers, who also control access to further healthcare resources.

Phil, 59, has cancer of the bones, COPD, asthma, osteoporosis, arthritis, and has had strokes, a heart attack and blood problems. He has been off work for ten years due to his health, and his wife, Mary, is his full-time carer. Mary describes an uneasy relationship with healthcare providers. She thinks they do not believe what they say about Phil's health and Mary describes gathering photographic and telehealth-based evidence to more accurately specify his need for treatment. They use telehealth to establish their credibility because she is used to being fobbed off by clinicians for making mistakes or treated as if they are lying.

> Mary: [We were referred onto telehealth] basically to record his blood pressure because it was in its 200s and I thought, "No, this isn't right." **So basically you can record it and then nobody can call you a fib**, if you know what I mean. […] That's how I looked at it because some of the, "Oh no, surely it's not, surely you're mistaken." You know what I mean? […] Even though nobody had never ever said that to me, it goes through your mind and **I think, "No, I'm going to do it" so they know**. **And then they'll get in touch with me in the morning**. "Oh, is Phil okay? You sent one at one o'clock in the morning," or whenever. And you either say, "Yes," or, "No," or, "He was fine this morning. It must have been a bleep in his life sort of thing" [chuckles]. […] I don't know. I just don't know. **I have took photos of it [blood pressure reading] in the past because** – with it being so high. And the matron will say, "But, why you took a photo of it, Mary?" Say, "Well, so you believe me." She said, "Well, just write it down. Why wouldn't I believe you?" Said, "Well, I don't know. I just do it [chuckles]."

Mary described using telehealth and transmitting the results at 1:00 AM to provide objective evidence of the seriousness of his condition, and to validate their subjective reports and defend against potential claims of exaggeration, fabrication or error. Interestingly, Mary's use of telehealth services to co-produce an accurate patient record of Phil's condition includes logging readings when she knows the service is unattended. This is because Mary describes the predicted telehealth service response (they will call the next morning, etc.). Therefore, she is deriving additional benefit

from the service through alternative use that is not scoped in the service protocol.

Further benefit relates to her narrative which suggests that the matron is totally unaware that their professional relationship makes Mary feel like they need to provide incontrovertible pictorial evidence as testimony for their version of events. Further probing explains why Mary uses telehealth to prove that Phil is in distress and requires pain relief. In the following excerpt, she explains that Phil's medical needs are discussed and altered without including them in the consultation process.

> Mary: I don't know. I just don't know. Because, you seem to go to the doctor's. **You tell them one thing, and then they'll say something totally different.** And I think, "Well, you never mentioned that to me, but you're saying to the matron something else." Like for instance a fortnight ago, Phil was on ten morphine of patches. So we went to the doctor's because we had to renew his epilepsy and everything [else?]. And basically, [the GP] knocked it down ... yeah - and never told us. So then I phoned up and says, "Well, he was on ten morphine but you've knocked it down to five. You haven't told us or anything." So we get a phone call off a different doctor saying, "Oh no, it's staying at five," so we said fine. But then the next morning I got a phone call off the doctor saying, "Well, I prefer him to be on five." **She sees him once every six weeks. I live with him every day. Charlene, the matron sees him more. You know what I mean?**

When Mary queried the decision to reduce his morphine patch dosage, the doctors confer with the matron and each other and don't offer Mary an explanation of their reasoning process. Therefore, when Mary, who is confident in her assessment of Phil's distress, takes photos of the extraordinary blood pressure reading, it is possible to suggest that she is attempting to 'speak' the clinical language of the healthcare providers through the medium of telehealth, although her role as a non-clinical carer typically excludes her from clinical decision-making discussions between doctors and the matron. Telehealth, and photos of telehealth results, play a part in co-creating what Mary hopes is a more accurate, and appropriate clinical decision-making by those who are empowered to help Phil. Whether Mary succeeds in co-creating an optimised and personalised service experience for their family was not captured in this study, but the fact that she is logging Phil's data formally may at least persuade their clinicians that she is not lying about his condition, which should improve the quality of interactions based on the perceived reliability of her accounts.

Participants often described the need to justify the level of care they seek (i.e. for more or less access to healthcare resources) because they do not easily understand the decisions that dictate their clinical experiences. For example, Rachel fails to understand why her terminal heart condition has not been under the care of the cardiologist.

> Rachel: I'm thinking they've given me 18 months. That's the prognosis and I'm thinking "If I've only got 18 months, surely I should be seeing the heart man more often," and I never ever used to see him when I was in the [hospital]. **If my heart's that bad I would have thought I would have been seen more often.**

Participants have difficulty working out the healthcare system and predicting what their treatment pathway will be, although it is something that they reflect upon.

Even when they try to co-produce obvious service improvements, clinicians can appear hostile to this kind of participation. For example, both Rachel and Elizabeth mention fear of hospital associated infections which 'could finish me off' (Rachel). However, despite all of the public health campaigns raising awareness about infection control, Elizabeth observes that reminding clinicians about this leads to hostility.

> Elizabeth: I mean it's going on in all the wards now: Please remember [remind] the doctor or the nurse, to wash their hands before they touch you… and they won't be offended. **You try it and they'll give you the most dirtiest look out!** […] I go up to the Haematology […] every so often I've got to get an iron transfusion. […] to save waiting time up at [hospital A], I usually nip on the bus and go down to [hospital B] and get the blood and they send it straight up. Now when I get there, they're dealing with people all of the time, in and out, right? And I sit in the chair and I watch, and I'll say to the Nurse: 'Do you mind changing your gloves?' And she'll say: 'Pardon?' I'll say: 'Do you mind changing your gloves?' 'You are the last...Miss Know-all here.' You know what I mean? And I'll say: 'I'm not Miss Know-all. I'm watching my health. You should know that.' **And they don't like it! So they all look at you as if […] you're an old trouble maker and it's not, it's wrong.** There's what all these adverts are about, isn't it?

From these examples, it is possible to see that outwardly communicating their intention to co-produce service improvements is not encouraged by clinicians judging by their previous service experiences. Patients must help themselves to ensure their own safety and anticipate how this can be done in response to the way healthcare services are arranged.

> Elizabeth: You could look across and maybe there was an elderly person, maybe a younger person that wasn't able to feed their self. Their dinner would be put in front of them and nobody'd come [to help feed them]. They'd come and pick up the tray and walk away with it. Now that person didn't have anything to eat. They didn't bother with that! That bugged me! […] But you see this is why I like, what I do which is why I get in here [points to her head], **as long as I know what happens to me, then I know what to look forward to**. The day I'm lost up here [points to her head], that I don't know, that'll worry me. **But as long as I know the procedure, then I'm safe, and if I can help somebody else next to me, I'll do it**.

Elizabeth explains how she has learned that prevention of harm from neglectful clinical care is something that she must attend to by keeping a watchful eye on services and improving her ability to self-care. These narratives help explain why attempts to introduce improvements in service interactions according to the patient perspectives are observed to be surreptitious, behind-the-scenes or otherwise invisible practices, which if exposed to clinical scrutiny risks being met with hostility.

What seems to help patients is an ability to communicate their condition by portraying it using the clinical language of vital signs, in order to convey the messages that they think will be received as

appropriate to enable them to access the right care and attention. As Stephen describes it below, communication with clinicians is rarely straightforward.

> Stephen: **Me, I can ring up the help straight away, or I can ring somebody and tell them what my heart rate is, which is quite a good thing really.** […] As long as I see it drop on the machine. As long as it drops, 80s 70s things like that, and then goes up to a 100. […] And it's-- I survive with that. […] Not happy with it, but survive with it.
>
> INT: Okay, so is this something that you've taught yourself, or is this something that you've been instructed to look out for?
>
> Stephen: Oh no, it's something which has happened over-- since I was diagnosed with AF, which was-- basically when I first started it was all hush-hush. [chuckles], would you believe? But then, as it's come out over the period of time I've had it […] **you pick things up yourself anyway**. […] **You listen, don't you? You listen to what's being said sometimes, and sometimes you can understand what these doctors are saying.** […] **A lot of the time you can't. […] Because they're talking that gibberish language they talk about, and you haven't got a clue**.

What we can see from Stephen's case is that access to the telehealth equipment can help him with his own understanding of his condition using objective clinical measurements because he says the AF (atrial fibrillation) can be asymptomatic: 'sometimes I haven't any palpitations or anything.' Furthermore, it enables him to be much more precise in his communications with paramedics or doctors because he 'can tell them what my heart rate is, which is quite a good thing really' because doctors use a closed language system perceived as 'gibberish'.

These examples highlight how participants are 'handling' clinical data and other forms of service system knowledge (what to do, whom to call, how, when) in a sophisticated way to portray themselves in the way they feel is more readily understood by their usual healthcare providers. This is not to say that participants are learning high level clinical skills through telehealth. Indeed, it was observed that users complete their telehealth routines without necessarily understanding the tasks they are functionally undertaking. One potential barrier to competent use of telehealth equipment is because telehealth machines use clinical vocabulary that was observed to require higher literacy and clinical understanding than many users possess. As mentioned previously, participants were observed to struggle with recognising what the regularly displayed terms meant and referred to, e.g. 'SpO2' (arterial blood oxygen saturation), 'oedema' (swelling), or 'fatigue' or 'relieving medications' (inhalers, nebulisers, sublingual angina spray, morphine patches, oxygen therapy). However, it was also observed that they have functionally translated clinical language into a domestic understanding sufficient to intersperse their subjective self-report of health status with vital signs readings, resulting in a more sophisticated form of personalised health literacy. This literacy pertains not only to their self-knowledge, but also system knowledge of the technical machines and the organisation of healthcare services and how they choose to use them.

Table 11 provides exemplar quotes highlighting differences between system world and lifeworld rationality from participant narratives. This helps to illustrate how the same 'event' is perceived differently. Conflicting perspectives of value lead to conditions for negative patient experiences, or perceived service failures, even if the clinical outcomes of the service interaction are otherwise positive.

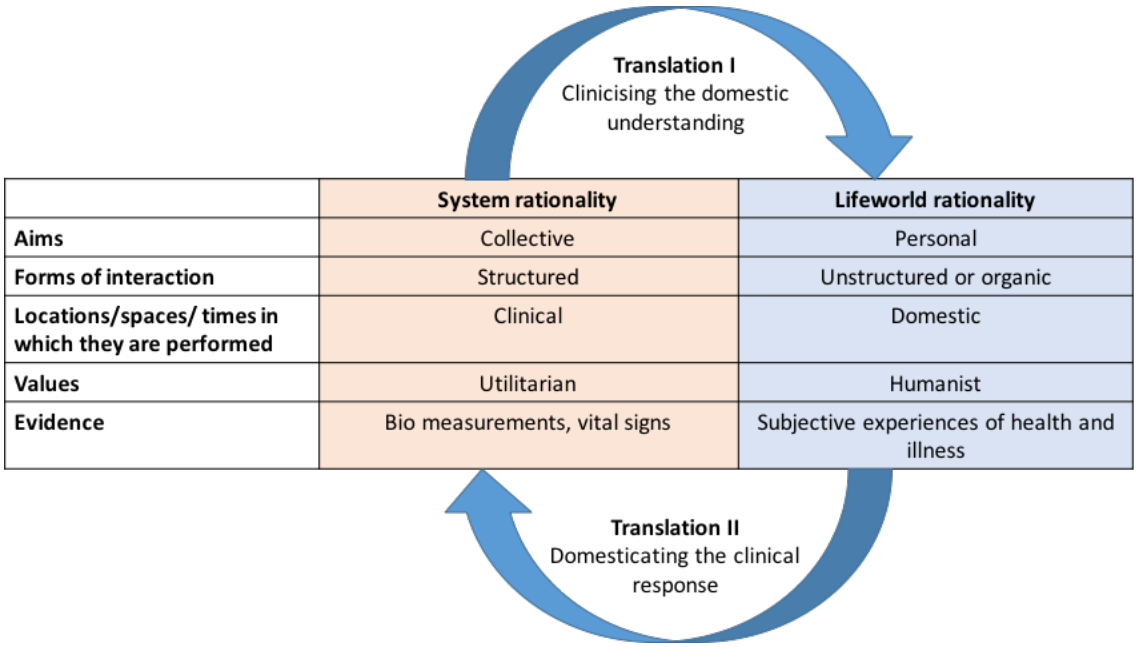
TABLE 11 EXAMPLES OF PERCEIVED SERVICE FAILURES DUE TO DIFFERENCES BETWEEN SYSTEM WORLD AND LIFEWORLD RATIONALITIES AND VALUE SYSTEMS (ORIGINAL WORK)

System value	System world rationality examples	Lifeworld rationality examples	Lifeworld value
Acute care capacity management Ambulatory diabetic care delivery	*He says, "These beds are for people who are dying, not for people with blood sugar trouble." And the staff nurse said, "Oh, no, he's not. He's been kept here for the diabetic people there."*	*And I was in 8 days. But he was going to send me home because those beds are for people who are dying, not for such as me. And this is why I get a bit annoyed with them at times. (Russell)*	Seriously ill diagnosis circumstantially judged by 8 days hospitalisation
Confirmed diagnosis of end stage heart failure – stepped down to primary care	*Then I see the heart man, Mr Smith […] on the 9th. I had a letter at the end of February for an appointment on the 9th of December. All those months. All those months. I've never seen the heart man yet. He'll see me.*	*I'm thinking they've given me 18 months. That's the prognosis and I'm thinking "If I've only got 18 months, surely I should be seeing the heart man more often" and I never ever used to see him when I was in the [hospital]. If my heart's that bad I would have thought I would have been seen more often. (Rachel)*	Heart failure requires heart specialist care
Doctors should communicate with patients Junior doctors defer to senior doctors	*Or one of the junior doctors'll say to him, "You're going home tomorrow, Clive." […] They don't know, they're young and […] The person in charge of the team, the boss, he'll say, "You're not going yet."[…] But that's where they learn isn't it?*	*And I think, "Oh no," because I know– […] she'll say that you're going tomorrow and he probably isn't going for another week and then every day he's waiting to come home. (Ann)*	Poor patient communication fosters mistrust, unease and disappointment
Patients should take medicine as directed	*Nigel: Oh forcing tablets down me and I didn't want them. I didn't want to have them.* *Sarah: He says: "You've got to have these tablets." [Nigel:] What are they? "You don't need to know that. Just take these tablets." […] And it was getting him really agitated. […]*	*I said I didn't think he was caring for you right. Because you thought that about some of the nurses. They weren't treating you right, was they? And you were very worried. […] which wasn't helping the way you was, 'cause you were poorly. So I was worried, and thought: well if he gets really agitated like that he's going to get worse. (Sarah)*	Patients have rights and must give informed consent to treatments Good care is more than administering medication
Patients cannot be discharged unless there is someone to care for them An ill patient should be diagnosed and treated until they can be discharged	*And they said, we can't understand it. We think it's just a chest infection and wanted to send him home. Debbie next door, she's a nurse, who says: If you think he's poorly, Sarah, you can refuse to have him home. So I says to the doctor: 'Where's he going to go?' He says: 'He's coming home to you.' I says: 'No he's not 'cause I'm refusing to look after him.' […] And they said, right, we'll keep him and we'll do some more tests and they found out it was his heart.*	*That was one of the hardest things I ever had to do. (Sarah)*	In order to care for her husband when he is ill, she will behave irrationally according to her values, including being prepared to refuse to care for him

With this in mind, it is, therefore argued that although telehealth use involves trade-offs (due to resource intensive interactions with machines and the network of social actors that are linked to their use), participants' preference for persisting with telehealth is explained in part by a wish to avoid experientially difficult interpersonal service failures that occur within clinical settings. These service failures are interpreted to be the result of conflicting value systems, i.e. where the clinical system is focused on narrowly defined and object-oriented outcomes of value; and subjective value in the lifeworld is focused on providing the relational and functional aspects appropriate to holistic patient need.

The evidence suggests that participants, who are not in a position to self-care and cannot avoid hospitalisation due to declining health and exacerbated conditions, would prefer their hospital interaction experiences to be more like lifeworld interactions, i.e. humane and empathic. Lifeworld interactions are conceptualised as intersubjective in orientation, and diametrically opposed to a predominantly object-oriented and dehumanised interaction following a biomedical approach to care (see Figure 15).

Participants describe experiences of friction within interactions with the healthcare system due to dissimilar language, forms of evidence and modes of communication and a value system that is driven by administrative rather than humane priorities. In order to improve the quality of interactions, participants are argued to learn the clinical language and the probable responses of system functions through reflecting upon and interpreting their experiences until they make sense, and then resolving to clinicise their lifeworld understanding (Translation I). By becoming conversant with clinical system language and perspectives, they can suffuse their communications with their subjectively perceived needs and concerns, thereby domesticating the clinical perspective by transmitting the readings that they think will garner the response they seek in ensuing service interactions (Translation II).



	System rationality	Lifeworld rationality
Aims	Collective	Personal
Forms of interaction	Structured	Unstructured or organic
Locations/spaces/ times in which they are performed	Clinical	Domestic
Values	Utilitarian	Humanist
Evidence	Bio measurements, vital signs	Subjective experiences of health and illness

FIGURE 15 HOW EFFORTFUL PATIENT EXPERIENCE INFLUENCES STRATEGIC TRANSLATION BETWEEN DIVERGENT RATIONALITIES (ORIGINAL WORK)

7.4 Conclusion

This chapter discusses the role of contexts and conditions in value co-creation processes with telehealth services. It focuses on evidence that telehealth is influenced by antecedent service experiences.

The role of patient experience in telehealth service consumption was explained to show that it provides a context, or the structural conditioning, that informs the approach and purposeful use of telehealth. From this chapter's findings, we can conceptualise a generic process, where previous service experiences (input) inform and influence current telehealth use and future planned service interactions (process) with expectations of improved outcomes (output). The intentionality that is implied in the generation of expected outcomes makes it clear that this process relates to patients assuming control of the telehealth and multichannel service interactions. Control implies agentic action, where the participant is in control of the inputs to the process, which is evident through customisation practices that contextualise the construction of the inputs (patient data for transmission). Contextualisation relates to their understanding of causality (how it will be interpreted for clinical decision-making) according to their lifeworld perspective's experience-based theories of causality.

The identification of this generic process was inductively abstracted from highly heterogeneous examples of memorable positive and negative experiences and how diverse participants with access to highly differentiated resources were understood to reflect upon and make sense of their

experiences in their own way. Their reflections and translation processes as a result of experiencing different lifeworld and system rationalities were evident as they reflected on events leading to their current health status. Furthermore, it became clear that telehealth use is informed by this reflective process highlighting the centrality of clinical language in systems perspectives of their condition and need for healthcare resources.

How this generic process works is clarified by further investigation of customisation and theories of causality as underpinned by two types of translation activities. The first is translation of clinical signs into the domestic lifeworld (Translation I). This is an interpretative process which is observed to influence their decisions about what their readings might mean from a clinical system perspective and experientially learning through telehealth alerts the extent that their condition would be perceived to merit additional help. When the participants customise the construction of their data in the knowledge that it will be likely to trigger a particular outcome that they seek, this is conceptualised as a complementary form of translation from the lifeworld to the system world (Translation II). These findings highlight key processes where a growing familiarity with clinical language is combined with subjective assessment of well-being and signs of illness. This combines to show how users' personalised health literacy relates not only to clinicised self-knowledge, but also knowledge of how the system will respond to their self-presentation through a clinical lens. This system knowledge is important for users to derive a working understanding to make sense of the limitations of hospital-based services, and helps them to evaluate negative outcomes against the relative costs of preventative self-care in the lifeworld setting with telehealth. This is interpreted as showing how the cost of using resource-intensive telehealth machines is subjectively determined against the value that it brings from personalising ensuing healthcare interactions.

The chapter also discusses the implications of the experiential learning processes that are observed in terms of growing awareness of distinct rationalities that operate in each context and how to bridge that gap for improved service experience. Evidence of this awareness emerging from the data is interpreted to suggest that participants distinguish between the lifeworld and the healthcare service system world in terms of value systems and what type of value can be co-created in each setting. Connections are drawn to effortful co-production of formal healthcare systems that are oriented toward provider-led priorities of care. These processes of translation imply patients' interest in exerting change in service interactions. Recovering from negative service experiences can be particularly effortful because patients are not typically empowered to assert their preferences and substantively alter the structure of their interactions with healthcare providers. If they are inclined to communicate critical feedback, they do so at a cost because their efforts to engage in a humane and empathic way are met with hostility or discouraged because they challenge expert authority. Patients may be shy about initiating corrective forms of feedback as a result of service failures due to fear of reprisals affecting their future care.

The findings suggest that focal operant resources (e.g. key cultural-cognitive resources of clinicised self-knowledge and system knowledge) are integrated with other salient resources (physical, social, operand). These are conceptualised as translational capabilities.

Translational capabilities are integrated in order to achieve personal goals and life projects through integrating professional care in healthcare interactions. Specifically translation is aimed at making clinical interactions more responsive to subjectively perceived need.

Participants' system knowledge is integrated into their lifeworld theories of causality about what kind of data is persuasive to clinical decision-making and appears to enable them to expect that the now-patient-led telehealth-facilitated future interactions will result in the co-creation of subjective value. The findings are interpreted to suggest that participants use telehealth as an intermediary service, or communicative resource, and their customised use is oriented toward making their interactions with multichannel healthcare services more responsive to their subjectively perceived need.

Chapter 8 Four approaches to value co-creation

Introduction

In the previous chapter the findings highlight the importance of relational aspects of healthcare in the construction of patient experience. In this chapter, we discuss the interpretation of the data to suggest provider relationships are contexts and conditions, i.e. structures, that enable or constrain patient access to further healthcare resources, leading to their perception of being treated appropriately or inappropriately. By analytically specifying the context, it is possible to present evidence of agency that influences it through interaction.

The evidence presented in Chapter 7 suggests patient-provider relationships appear to be governed by a system rationality with system values that conflict with lifeworld rationality and values. Cases evidenced the gap between two systems being bridged by participants through focusing on the humanity of care when it is experienced (e.g. kind and friendly nurses), and through a means of confrontative coping (e.g. *post hoc* reflection) when it is absent. For some participants, coping involves capitalising on effortful experiences to learn about the way the system works and how system actors think (amounting to system knowledge) in order to understand their experiences. Others clearly progress toward adopting aspects of the clinical language (e.g. vital signs, medical terminology) into the way they see their own condition. Hence their self-knowledge becomes clinicised as a result of translating system thinking into the lifeworld (Translation I). By combining system knowledge and clinicised self-knowledge into an integrated cultural-cognitive capability (personalised health literacy) over which they have authoritative capacity, they are observed to use telehealth equipment to socially construct the collection of 'objective' patient data so that it reflects their subjectively perceived need for access to more or less care resources. This enables patients to avoid immersion in system rationality by keeping it at arm's length while maintaining an outwardly compliant relationship with their providers through regular co-production of the remote monitoring regimen. Chapter 7 provides evidence of this phenomenon generated from an aggregated cross-case analysis. In constructing this view of what the participants are doing when they use telehealth, it involved controlling for variation, and zooming out to see the bigger picture. The downside is that it loses sight of heterogeneity, and assumes a base level of homogeneity at the theoretical level, but this leaves insight addressing the *how* and the *why* questions under-explained.

That is why, in this chapter, we adopt a different lens to show commonalities and differences between cases and their distribution across the sample. This enables the phenomenon of telehealth use to be understood in relation to the conditions that enable or constrain the process of value co-creation. Consistent with an S-DL perspective, the dimensions of difference consider the person-in-context and are interaction focused. As the concept of value co-creation is a process theory, we show the contexts and conditions as necessary resource endowments in order that healthcare service

interactions are more likely to result in outcomes that are subjectively valued by patients. We will explain how access to resources affects participants' ability to co-create value with multichannel healthcare services of which telehealth services are a part. The findings from a cross-case analysis are organised to show four approaches to value co-creation in the sample. They are denoted by patients who found themselves interacting with services in the following way: *Alternative Seeking*, *Boundary Spanning*, *Care Seeking*, and *Conserving*. The choice of labels relates to the healthcare interaction goals that were most relevant to narratives describing their relationship with healthcare providers. The distribution of approaches found in the sample and the relationships between them are depicted in an explanatory resource-based matrix (Table 13).

In this chapter, we also consider how the findings relate to the co-production of service recovery. Given the frequency of negative healthcare service experiences for this group, and their long-term dependency on providers, their efforts to bridge the gap between system and lifeworld can be seen as an extensive process of service recovery, with participants forced to resourcefully re-establish positive provider relationships due to the lack of viable alternatives. Although we know from participants' reflections on previous service experiences that they perceive frequent service failures, less is known about how they move from being 'victims' of system rationality-driven service failures to agentically realise lifeworld value from service providers that are the default choice owing to scarcity of viable alternatives. In order to explain this, we look at how they salvage provider relationships and institute service recovery processes within a healthcare service that structurally disempowers them.

Although the following sections describe four separate domains to describe the approaches to value co-creation in the sample, the domains should not be assumed to be mutually exclusive. Indeed, it will be explained that patients are observed to find themselves within contexts that require these approaches which affects their dynamic access to resources. Their access to salient resources are assumed to help them to move between the domains by themselves.

8.1 Alternative Seeking

The first of four approaches to value co-creation with telehealth is Alternative Seeking. The participants in this group express dissatisfaction with their previous healthcare experiences and perceive their access to appropriate care from their usual healthcare providers is low. During the study they were not currently experiencing exacerbated illness effects that would otherwise make them highly dependent on healthcare services, and they were observed to focus their resources on self-care. These participants were most critical of services, highlighting their perception of a gap between the services provided and what they think is appropriate to their needs. Their experience of healthcare services as wasteful, harmful and unpleasant yet indispensable means their narratives are characterised by plaintive outrage and bewilderment at multiple service failures (Stephen,

Elizabeth, Colin, Robert, Clive). They are frustrated by their powerlessness to improve their experiences of healthcare service interactions, although they have tried to bring these issues to the attention of providers (Elizabeth, Molly). They often experience healthcare systems as incomprehensible, sometimes describing 'stupid' or illogical processes that are taken for granted yet defy belief because they lack common sense from a lifeworld perspective (Russell, Colin). When participants try to make changes to improve healthcare, they are faced with insuperable bureaucratic barriers. For example, when Russell was ill on holiday in the West of England, he was treated with a medicated chest patch which effectively treated his angina. When he tried to get the same patches at home, he was told they only make available his usual but less effective sublingual spray. He is fed up and would consider swapping local services for the other one if he could.

Russell's case illustrates how Alternative Seeking involves identifying system processes that are impossible to change, and this notion seems to be exacerbated by patients lacking the resources, both personally and situationally, to secure effective alternative provision, either from other providers or through self-care. Practical barriers to alternatives involve personal factors, e.g. susceptibility to acute infections, breathlessness, uncontrolled diabetes, or similar forms of declining health which bounces them from one health crisis to another and doesn't give them the time and space to increase their independence from unreliable providers or to change the structure of interactions to improve the value they create. Unlike Boundary Spanners, Alternative Seekers lack sufficient system knowledge to understand or empathise with the provider perspective. They find themselves vocalising their opposition to their treatment: communicating reasons for displeasure and expressing their wish to change providers (Molly, Russell), issuing complaints (Stephen), being argumentative or self-defensive (Nigel, Colin, Elizabeth) – actions which increase the risk that they will become known and treated as 'difficult' patients by their regular providers (Julia). This undermines the therapeutic relationship with healthcare providers that is supposed to be built on trust and compliance.

The case of Colin, is a good example. He is of West Indian descent and believes in osteopathy, traditional herbalism ('bush' which is 'good against cancer') and religion ('Christ's blood protects me') rather than Western medicine. His hospital experiences include harrowing tales of being harmed either purposefully due to perceived malice or female doctors' sheer ignorance. He describes his impotence after catheterization ('they castrate me'); being virtually quarantined with suspected MRSA ('I didn't have it') so the doctors and nurses talked to him, and pushed his food to him, from the doorway of the ward; and fighting off intubation with his arms because the 'woman doctor' was trying 'to strangle me' like 'they kill my Bishop'. He denies his Type II diabetes diagnosis although he finally decided to take a partial dose of Metformin medication because he was 'feeling low' and it made him feel better. When he took the full dose, he felt chest pains. Although the A&E doctor showed him a printed heart trace to say he had a mild heart attack, Colin

insisted it was a side effect of the medication, and 'I did not have a heart attack' because he would know from the sensation: 'I would feel it inside' rather than the way he was experiencing the pain on the surface muscles of his chest. Despite this animosity and distrust of the healthcare system in general, it is interesting to note that Colin describes telehealth in largely positive terms. It is seen as allowing him to maintain a safe distance from harm while knowing that his male GP will help him if needed.

> Colin: Yes, because I think it to myself if —if anything go wrong there they will ring me up and ask if I want to see the Doctor. Also 'cause one time they take the finger test and them say it was low. Take the finger test and it was low and they ask me take it again. Then take it again, and they say, "Oh I'm still 42." It's alright, so you see sometimes I think it help. […] So that means, if [I need] anything just ring them, don't ring the ambulance services. So I don't need to ring the ambulance, or the paramedicals. Ring the doctor, they will come out. That's what Doctor R__ told me.

He is observed to have a mostly task-based engagement with the machines. This is because he does not seek to interpret the vital signs (i.e. the significance of 42) to gain a clinicised self-knowledge. His only interest is his bodyweight.

Alternative Seeking tends to result from service failures. When they complain or ask for more information in face-to-face encounters, they receive insufficient responses (Molly), hostility (Elizabeth, Robert) or fear reprisals affecting their future care (Stephen). Those participants who described successfully voicing concerns about negative services, were able to access social support to help them to do so, although this does not save them from experiencing a significant personal cost of engaging in a confrontational way (Nigel, Clive, Russell, Phil).

Participants whose service experiences condition their Alternative Seeking are dissatisfied because, although they are convinced they are doing their bit to co-produce service interactions (e.g. complying with prescribed regimens, organising themselves and transport, attending regular appointments, providing information, and seeking professional help when they are unwell), their experiences are not as beneficiaries. In fact, they describe poor and worsening levels of care during face-to-face interactions.

Like Conserving, Alternative Seeking evidences an interest in helping the healthcare service by cutting back on unnecessary interactions, as long as it does not involve sacrificing their own access to care when they perceive it to be necessary. Therefore, both Conserving and Alternative Seeking suggest a conviction that access to services is an entitlement based on justified need, and this is mixed with a wish to minimise waste (e.g. wasted prescriptions, trips and appointments). Hence they are upset when they are made to feel incapable of doing their bit to conserve resources. Below, Russell explains his struggle to cancel a duplicate heart scan appointment.

> Russell: …my daughter was with me, and when I'm not very well, I go very flushed. And she said to the doctor, she said, "Would you mind taking my dad's blood pressure," she said. "Because to me, he doesn't look very well." "**Well, you'll have to make an appointment for that to be done," she said. And she wouldn't take my blood pressure**. And then the next thing I get is a paper [to] come along to phone up to get an appointment for a heart scan. I'd already told her I got one coming. And I phoned them, and I said, "Look, why is that?" I said, "I've already got one booked." And I said, "**Could you cancel it? Because it's no use me having two**." "Oh, we can't do that. You'll have phone your doctor up and get them to do it, because they've ordered it." So I phoned up and the receptionist said, "Well, actually, she's ordered one for you." I said, "But I don't need one. I've already got one on the 20th." And she says, "Well, we can't really cancel it because--" And I said, "**Well, don't you think that's going to waste somebody's time and money? When I've already got one?**"

In addition to the Receptionist highlighting his powerlessness to cancel an unnecessary appointment, Russell's quote also shows that in his experience, the healthcare system is set up to serve other interests rather than his needs or his convenience. He suggests this is the case when he was already exhibiting what he understands to be remarkable symptoms of illness (high colour) when sat in front of the doctor, who insisted he book another appointment to have his blood pressure taken.

Russell's example is common to all participants who feel a need to manage their relationship with their regular carers by complying with the needs of the healthcare system, in addition to managing the perception of their needs by the healthcare providers (e.g. wanting to appear reasonable when requesting the duplicate appointment cancellation).

Alternative Seeking and Conserving behaviours include acceptance of telehealth services because it allows these participants to inhabit a safe haven of respite from formal, face-to-face and immersive interaction with healthcare services, which is exhausting to experience. At the same time, they realise their complex comorbidities mean they will inevitably need to find a way back into that formal healthcare setting in the future. Alternative Seeking and Conserving involves co-production of telehealth rather than more obvious forms of co-creation exhibited in Boundary Spanning or Care Seeking approaches. This is suggested to be because although these participants are observed to desire change in their service interactions, they lack the resources to make it happen without suffering further hardship. For example, when Molly was kept waiting in the GP surgery to have her blood test, she tried to express her dissatisfaction by asking the Receptionist for a form to change doctors. When she was told she needed to get the form from the new doctor's surgery, she had to take a taxi to the other part of town, which was less convenient for her. Although Alternative Seekers like Molly are observed to initiate actions to change interactions and outcomes, they fail to get the outcomes they seek.

Therefore, their limited ability to use telehealth to clinicise their self-knowledge to combine with adequate system knowledge means they are most likely to reproduce the relationship structure,

dominated by system rationality, continuing as co-producers of provider-led services. All they are empowered to do with their current resources is to put some distance between themselves and the system world by trying to self-care with telehealth while keeping the service at arm's length. This can be interpreted as co-creating some subjective value, although this is also structurally conditioned because exit or withdrawal is not a viable alternative.

8.2 Boundary Spanning

Boundary Spanning participants are broadly satisfied with their current arrangement of telehealth-enabled self-care with the support of regular at-home healthcare visitors. They perceive their access to appropriate care currently is high and this is described as the result of their active participation. Their present state of health means they have a low level dependency on healthcare services. Having learnt from previous experience that total dependency on hospital care can leave them vulnerable to harm and upset, they are actively interested in making healthcare interactions 'work' to help them achieve their personal goals, including self-care to minimise need for hospitalisation.

Participants adopting this behaviour can be characterised by their instrumental use of high levels of clinicised self-knowledge and system knowledge which are used to co-create subjective value by transforming service interactions. Specifically, their approach to the orchestration of various interactions involving telehealth and wider healthcare services integrates various resources to gain control over how and when they submit to clinical authority. This is distinct from the usual role of patients passively presenting themselves for treatment as objects by agentic clinicians who dictate the terms (i.e. when, where, what, how, why) of their care to them.

Graham's case illustrates how Boundary Spanning can make interactions patient-led. His knowledge of his condition, including his life circumstances, and specific system knowledge relates to anticipating how he can use the services to help him when he needs it. Although he describes how kind the respiratory ward nurses are, and how one gives him a hug and says hello whenever he's readmitted, he is still keen to avoid hospitalisation. In the excerpt below he and his wife, Esther, explain how telehealth can increase his autonomy regarding decisions about whether and when he needs assistance. Autonomy is important because his conditions have robbed him of many activities of daily life, describing hours every day confined to his armchair. Graham describes knowing about his condition by registering readings to telehealth in the mornings and then independently using the equipment to monitor his condition throughout the day. This helps him to choose the terms of his subsequent interactions: this is typically to delay calls for help in order to wait and see if his condition progresses toward an acute exacerbation. He slides into uncertainty as the day and his symptoms progress. When night falls, he agrees that his condition warrants relinquishing autonomy to control what will happen to him.

INT: Particularly when you're having problems like when you were coughing blood and stuff, did you find having the telehealth more useful then?

Graham: Yes, because they ask me and I tell them what they done and they usually say, "Do you want us to call a doctor?", "Do you want us to call an ambulance?" They go through… and **if I feel unreasonably unwell I think, "Well I'll leave it a bit longer and if I've got a problem I just pick the phone up and the paramedics are at the door in ten minutes**."

INT: Wasn't that the same before you had telehealth? You could always ring the paramedics.

Graham: You could always ring the paramedics but we're being more watched with these, aren't we? They're monitoring us better.

Esther: He'll tell them, "No, I'll be all right." but as the day goes on he's not all right. He's going downhill.

Graham: Deterioration. Then we get in touch with somebody.

Esther: It'll get to night and I'll say to him, "You can't go through the night like this." and I said, "We'll get a paramedic out and we'll see what he says." They come and they'll say, [inaudible]

Graham: [quoting the paramedics] **'No way, you're going...**' [crosstalk]

Esther: Never wants to go in. I can't blame him.

Graham: I don't like bed and breakfast up there. It's no good. [laughter]

Esther: **He never wants to go in** but I can't see to him all right but he gets to such a state and I think, "What am I going to do?"

Graham: Getting in and out of bed is a problem when it gets to that stage.

Esther: I think well, it's about time we fetch somebody. I say, "We'll go with what they say."

Graham: **Leave them to decide**.

Graham clearly relies on Esther to help him, but when her capabilities to provide social care support become insufficient, then he knows he must reach out to access professional services. Their narrative suggests that paramedics typically override his personal reluctance to be admitted due to their interpretation of his vital signs, therefore Graham's desire to delay handing over control of what will happen to him is an articulation of his preference, which he enacts through choice. He is guided by his own subjective self-report when he tells the telehealth support worker that he is still fine to wait and see if his condition improves rather than agreeing to help when the telehealth service prompts him to consider it. Graham's narrative highlights participants' awareness of how the locus of control over what happens to them differs depending on whether they are at home or are subject to the authority of healthcare services to dictate the terms of his care.

Boundary Spanning involves the ability to 'force' healthcare services to be patient-led and suit their individual preferences through the exertion of choice. This was apparent through more sophisticated use of telehealth in order to optimise the healthcare that is available. In the following

excerpt we see how Howard works together with his team of regular clinicians to get the balance of symptoms and medications right.

> Howard: I'm prescribed four—it's a high-dose of water tablets. it's 160, 40, 50, yeah, it's 160 milligrams, I only take them to four. And that's what I normally have, **but I try to reduce it**, and I rang them up and I said, "Can I try three?" And they said, "Yeah, but if anything happens go back on four." And then once I said, "Can I try two of them?" -- trying to cut it down. And they said, "You can't get any lower than that. You can try two, but immediately if you see anything just go on the next ones." So I basically ring them for whatever advice I think I need. […] because of my breath, the mobility from here that door is—It's reduced a helluva lot because I used to be able to make it through the door really easy enough. […] So what they're trying to work on now is they're altering my medication. I was on a tablet called Phyllocontin, and they doubled it a while back, for breathing. And that increased my heart-rate. I was sitting there and it's 116 […] So what they done is they reduced the Phyllocontin by one. And I take Allopurinol for gout, and they reduced that per one too, they're always balancing my medication. **And since they've done that, my heart-rate has gone down quite a lot. It jumps all over the place, even when I've got the thing on my finger it goes from 80 to 96 to a 100 set. But it's usually in and around about 89 or 90 at the moment, which it hasn't gone up to back when it was consistently 116**, which was high. So we think that since they reduced the Phyllocontin it's made me more stable, it's reduced it.

We can see how Howard is able to give detailed and highly personalised clinical feedback to his clinical team based on additional self-monitoring. This allows him to judge the adequacy and appropriateness of the healthcare he is receiving while he is at home. Howard's use of telehealth equipment empowers him to be a more active part of medical titration decisions through guided self-experimentation. As evidence of his personalised health literacy, his familiarity with clinical language (system knowledge) is combined with personal measurements appropriate to his lifeworld (clinicised self-knowledge). For example, he uses the ease with which he can walk the distance of his living room to his front door to monitor changes to his breathlessness and mobility. By the same token, his subjective assessments of his health or illness are qualified and made more credible because he is able to report the clinical difference that his experiments make on his fluid retention, heart rate and breathlessness. This collaborative self-care practice also allows Howard *to lead* in decisions about the consequences of treatment on his quality of life assessment, which is focused on minding his grandchildren together with his wife.

> Howard: Because when I'm on the four [water] tablets a day there's not many places you can go all day because you need visits to the toilet all the time. […] And we do the general monitoring of the grandchildren normally when they're off-school […] When we go to the parks I just get out and hobble over to a bench and watch them play. And then we get back in and we might take them to McDonalds. We spend a lot of time with the kids really.

Howard's case is a good example of how telehealth can be used to optimise healthcare interactions by increasing the level of access he has to clinical information, which makes his subjectively perceived need intelligible to the team of healthcare providers he consults. Getting clinicians to

provide precise and helpful feedback and guidance in response to his more clinically specific questions is better suited to the achievement of personal goals that matter to people who have complex chronic comorbidities. This is an example of the Translation I and II process (Figure 15) which is argued to be important for co-creating value from healthcare service interactions. Because Graham and Howard are agentically controlling their access to healthcare resources to suit their needs (e.g. to stay at home as long as possible and to reduce medication), they are changing the locus of control in clinical decision-making, which is transforming provider-led healthcare interactions for their benefit.

8.3 Care Seeking

Participants evidencing Care Seeking behaviours have high levels of subjectively perceived need. They are feeling unwell and need support from healthcare resources although they describe trouble accessing appropriate care. They are generally resource-poor due to prolonged illness, and they struggle to integrate the necessary resources to attain their life goals. The resources they seek include medical expertise to increase their ability to regain basic functionality to achieve a basic level of well-being or an improved prognosis, and therefore, this group is situated in a more physiologically demanding phase of their illness experience. Frequently bouncing in and out of hospital, these users are in a cycle of dependency on face-to-face healthcare resources and their narratives describe a succession of negative experiences that show accessing appropriate care can be a struggle. These telehealth users are more positively disposed toward healthcare service providers (compared to Alternative Seeking) because they see no viable alternatives such as effective relief from symptoms through self-care at home. Unlike Boundary Spanning, which more successfully taps into medical expertise as participants deem fit, Care Seeking increasingly views medical experts as barriers to appropriate care, withholding reasonable access to additional medical resources that they perceive are clearly needed. Generally, this group is motivated to seek more specific diagnostic or better treatment relief from the symptoms of illness which prevent them from engaging in personal projects that are precious to them.

For example, Robert has had COPD for more than 20 years leading to trouble communicating due to shortness of breath. Recently he has been under the nearly constant care of the hospital (23 hospitalisations in the past 12 months, with each stay lasting 2-3 weeks). When in hospital he gets access to rest and relief through intravenous medication.

> Robert: [At home] You're sitting there on the end of your bed, the early hours of the morning or whatever, and you're trying to breathe, and you can't and you want to take a lungful and it won't happen. And you start panicking because you think, you know, your body's telling you, 'I need more oxygen, I need more oxygen' and stuff like that. And you get scared. But when you're [hospitalised] straight away they'll be like [unclear] with antibiotics as soon as you get in there, and then you're getting intravenous drips and stuff like that, they [unclear] me feeling okay [unclear].

Through telehealth use Robert explains how he has learned to relate his vital signs with the way he subjectively feels to the extent that he can almost predict what they will be. He estimates that his understanding of his vital signs is 90 percent accurate because this is how often he can anticipate when the telehealth support worker will ring him about abnormal readings. Although he is reasonably confident about his knowledge of vital signs, he is not willing to act independently (e.g. deciding for himself that he needs to use oxygen therapy when he sees a suboptimal reading), preferring to wait for the telehealth service to tell him what to do. This is interpreted to be due to structural conditioning, becoming habitually dependent on medical expertise from his frequent hospitalisations.

> Robert: I'm waiting for them to call back because I know they're going to call back […] instead of messing about, you might as well do as you're told, like. Rather than doing anything off your own bat. Cause you don't know if you're doing right or wrong. […] Nine times out of ten [I'm] right […] what I want to do is get these [taps on his post-it notepad where he writes down his vital signs] statistics up to the […] a safe level and then I can [unclear] I know in myself, if these levels are okay, I'm going to feel okay. I can tell right now […] If I do one, I can see what the results are. That's how I can tell, by the way I feel, whether they're going to be high or low. […] I can tell that. And then when I do it, I'm usually correct. […] A couple of times, I've got up, scattered around, doing this, doing that, coming downstairs, messing about, [go] straight on [the telehealth], and my body's ... [unclear] all that exertion, I'm using, and I thought, 'Uh oh, this is the wrong reading, because if I was at rest it wouldn't be looking like that.'

His goal is to get stable vital signs, and he describes how his actions (e.g. rushing or resting) can affect them. He does not do multiple readings, and like others (Brian, Ted), experiences alerts positively as someone is calling to ask him how he is feeling on a regular basis. A positive attitude to frequent care relates to a prevalent theme, the fear of being ignored or invisible (Alastair) to the healthcare system because they are old with a chronic disease (Russell, Robert). Having access to the vital signs and telehealth calls are useful for Robert to view his body using a clinical lens, which helps him 'stay on top of things'. Robert suggests that monitoring his health helps him judge the appropriateness of the provider's responsiveness to his need, like a quality control compensating for loss of trust.

Although telehealth calls serve to remind him to use his oxygen therapy, he is not convinced that this kind of self-care, combined with nebulisers and tablets, is an adequate replacement for hospital care he needs, although the doctors try to tell him that treatment at home is appropriate for his case.

> Robert: The last time I came out [of hospital], ten days ago, I felt just as bad coming out as when I went in. They called me in an ambulance the day after I'd come out and [the paramedics] sent me back [to the hospital]. […] the doctor said I'd get the same treatment at home as I'd got here […] I don't think you do get that same treatment at home. […] There are hundreds of tablets I have to take, it's unbelievable […] There's no relief. […] The only thing

> that helps me, I've got a nebuliser by the side of my bed […] and if it weren't for that, I don't think I'd manage.

Robert's quote exemplifies a common theme in the data: the experience of conflicting clinical opinions about their care. In this case the conflict is between his opinion based on how he feels, the doctors who discharged him, the paramedics who brought him back in, and the Respiratory Ward doctors who readmit him. This theme relates to system knowledge, and how participants can be aware that trained clinicians disagree over how to interpret vital signs to decide about hospital care or access to other healthcare resources. From this observation, it is possible to see how participants could be empowered through their use of telehealth to believe that they are right to argue their case based on their interpretation of vital signs for more or less healthcare even if the vital signs provide objective contrary evidence.

For example, Robert explains how a good telehealth reading is not a predictor of whether he will need emergency hospitalisation. He, like Graham, describes a practical shortcoming of the telehealth design because it monitors trends based on a snapshot of his condition in the morning. However, because the illness is experienced as deteriorating over the course of the day, Robert describes moving from the telehealth service on to full-service channels like ambulances and hospitals in the same day.

> Robert: …everything's been alright [on telehealth]. After that, I mean -- I only take that once in the morning -- so I've got all the rest of the day to get ill again, like, so to speak, and if [unclear] you know, I started off with an infection, and it gradually gets worse during the day and very usually they phone me an ambulance at midnight or something like that. Because that's when I'm facing the floor and I'm trying to breathe and that was it. And, I say to the wife, 'Don't bother.' And she says to me, 'I'm not going to sit here and see you suffer like that.' So she phones the ambulance…

However, unlike the relief he expects to get based on previous hospitalisations, rather than being admitted, expertly treated and released after he responds to treatment, he is disappointed to experience the intervention of 'non-clinical' experts in his care. In his opinion, he is experiencing more barriers to receiving the expert care he seeks. This is an example of what seems to be a search for consistency between subjectively perceived health status and professional opinion.

> Robert: I'm disappointed, when I was in last time. Because I think, [unclear] and at the time, I had got a load of phlegm on my chest and I couldn't get rid of it. And [the doctor] said, 'Well, we'll get a physiotherapist.' So he came and examined me, and trying this and trying that exercise, and he said: 'Oh, it's tight, isn't it tight!' and he went away. And I never saw him again. So then, [unclear] this doctor said, 'Are you seeing a physio?' I said 'Yes. Hardly worth it.' And so what he decided was, 'Let's see if he can walk up those stairs.' So the same physio come, and took me to the stairway in the hospital, on one of the wards. And he was [at] the side of me and said, 'I want you to walk up these stairs.' So I walked, and I got up, you know, stopping a bit for breath, and then walked down. And he said, 'There's nothing wrong with you. There's no reason why you shouldn't go home.' And I thought, 'Well, who

> are you to know? I mean you're not even a qualified doctor, or anything like that!' And he told the doctor that, and the doctor on his recommendation sent me home. I was a bit disappointed, because I knew, I was nowhere near... I said to the wife, I said: 'I feel just as bad as when I went in.' And you know, what can you say?

Whereas Graham accepts that entering the clinical environment entails ceding control, Robert fights to maintain some control in that environment, and feels his disempowered status in the hierarchical system by trying to stand up for himself. Whereas Boundary Spanners succeed in maintaining control by staying in the context of the lifeworld, or knowing how to disrupt the flow of the system functions to make himself heard (recall Howard standing in the hospital corridors), Robert's system knowledge is based on identifying a hierarchy of expertise between physiotherapists and doctors, and trying to pull rank from the bottom rung resulting in poor outcomes.

This excerpt highlights how chronic disease patients can experience diminishing returns from their healthcare service interactions over time. This may be because their condition is already diagnosed and treatment to control symptoms already prescribed. Recall Rachel's case, despite an end-of-life prognosis for heart failure, the fact she has not been physically examined by a cardiac consultant confuses her because the care does not seem appropriate in her eyes. According to the hospital system, organised to provide timely diagnosis and treatment for acute illness, therefore Robert's chronic care needs conflict with the rational management of the hospital system. This seems 'reasonable' when we consider there are different structural arrangements organised to provide chronic care, i.e. hospices for terminally ill patients. Therefore, we can understand why Robert's interaction with the hospital's structural arrangement leads to his perception of barriers to appropriate care.

Robert's case explains why Care Seeking is observed to involve strategic use of telehealth. As illustrated by Phil's case (Chapter 7), their usage is focused upon the co-production of an evidence base that persuasively and objectively shows their need for further medical care. However, because they do not understand the implications of structural arrangements for different types of care, their intentions and expectations are not always met. This explains how the lack of sufficient system knowledge can lead to poor ability to anticipate how their patient data will be interpreted by clinicians to decide about access to further healthcare resources.

One tragic case precisely illustrates this issue, showing how Care Seeking undertakes co-production of a convincing portrait of need using telehealth, which can unwittingly lead to experiencing higher barriers to accessing care because they do not consider the implications of system rationality in the dynamic context of the resource-constrained healthcare service system.

David was hospitalised days before the scheduled interview and died after two months of recurring emergency hospitalisation and discharge home. His wife explains how his health had been

deteriorating and she had been using the telehealth regularly on him, making sure to jot down the readings on a spiral pad (see Figure 16), in addition to noting the improvement to his oxygen saturation levels after oxygen therapy, and listing adverse events over the past few days, like falling off the sofa. David eventually died forty days later, and it is clear from his case that the use of telehealth can bewilder users especially when the results of the vital signs tests and the way they are interpreted by various clinicians do not seem to confirm their subjectively perceived need for urgent care.

> *I had spoken with David on the phone to arrange the interview a few days before. He sounded breathless but positive. When I arrived there was commotion visible behind the net curtains in the council bungalow. They explained that he'd been admitted to hospital on Sunday. His wife, Pat, was worried, and seemed relieved to tell me what happened. She invited me to sit on the sofa at the foot of his hospital bed which occupies the corner of the living room. David has COPD and has a pink card*[11] *from Hospital A. He has oxygen therapy, telecare and telehealth. At some point on Sunday he'd felt very ill and unbeknownst to her, had pressed his pendant alarm, and so when she was assisting him, she heard the voice from the Telecare [box] that an ambulance was on its way. When the paramedics came (may have been First Responders?), followed by the ambulance,* ***they checked his vital signs and they were registering as 'normal' despite being doubled over facing the floor and unable to breathe, however the hospital was refusing to admit him to the Respiratory Ward because his vital signs were 'normal'.*** *There was confusion about what to do, so the paramedic said: 'Well, what they'd do in hospital is administer cortisone, and I can do that here', so they did that and he continued to be unwell. Finally, it was decided that he be brought to A&E at the other hospital. He was admitted and was, on Tuesday, still in the acute general ward 57. The family were told that he is in quite a state and they were unable to put the oxygen mask on him.* [Field notes]

David's experience makes it clear that there can be a real gulf in understanding between various interpretations of vital signs for clinical decision-making, and how they are imagined to be a reliable way to read a person's need for care. Recall from previous cases showing how telehealth alerts in response to transmitted clinical data can be overridden by patient self-report (e.g. Stephen, whose fast pulse due to atrial fibrillation regularly triggered the alarm although he said he was fine). In David's case, however, neither his self-report nor the more qualified observations of trained paramedics, relaying David's condition by telephone to the Respiratory Ward's admitting nurse,

[11] Patients under the care of the Respiratory Ward of the Main Hospital are issued with a pink card. Before it is laminated, the name, NHS ID number, and range of oxygen saturation percentages that are 'normal' for that patient are handwritten by someone in the hospital. Respiratory patients are advised to keep this pink card handy to expedite them through the system to the appropriate medical specialists.

held sway over the decision not to admit him to hospital based on the objective 'fact' of his blood oxygen saturation level reading.

These examples show that Care Seeking uses telehealth in order to co-produce effective care interactions and aim to co-create value by making service interactions more responsive to their perceived need. However, in Care Seeking, the co-production process that enables participants to glean a more clinicised view of their condition also makes them susceptible to service failure because they lack insightful system knowledge.

The cases of David and Robert show how confusing system rationality can be, since clinicians interpret vital signs differently in order to triage dynamic demand for care according to the availability of resources in hospital at the time. This can be understood according to the key differentiators between system and lifeworld rationality which suggest system decisions have collective aims and seek utilitarian value and lifeworld aims are personal and value is humanist (Figure 15).

Care Seeking occurs when participants experience the gap between system and lifeworld rationalities affecting their care but they lack the insight into the conditions or mechanisms that influence clinical decisions (unlike Boundary Spanning). They assume that their current dissatisfaction may be due to their clinicians lacking sufficient information, hence their aim to provide a more detailed patient record. Therefore, Care Seeking activities are primarily focused on co-producing a more complete evidence base by logging vital signs evidence for clinicians in the hope that their care will be more responsive to their subjectively perceived need. It is suggested, therefore, that because they maintain a relatively passive patient role despite the increased level of co-production activity, this group lacks the necessary resources to co-create value in terms of transforming provider-led services to more empathically respond to their subjectively perceived needs.

Care Seeking is not observed to critically frame the shortcomings of their service experience due to structural influences. They are focused upon remedially addressing small-scale components of interactions in a piecemeal fashion rather than aiming to transform interactions more radically. In terms of agency, the service interactions show some exertion of choice, which is to help themselves by using telehealth, which shows them as cooperative, collaborative and co-productive of self-care, such as responding to reminders to use relieving medications and therapies.

8.4 Conserving

Conserving participants are generally satisfied with the high level of care they experience, but feel it is appropriate to have less frequent interactions. Typically recovering from receiving life-saving treatment after a health crisis, they express gratitude and positivity about their care. As they are

regaining stability in their condition, they prefer to self-care as much as possible and the frequent monitoring via telehealth in their homes allows them to reduce the intensity and frequency of full-service care. Conserving participants recognise that they must enact regular self-care practices, including regularly being checked or monitored by their healthcare providers. Given the complex cases in the sample, and the high proportion of elderly and frail participants, the frequency of service interactions is often high. This context of high service utilisation explains one aspect of the most commonly expressed reasons for using telehealth, which was the wish to 'give back' to the NHS (Julia, Peggy, Aziz, Ted), primarily through task-sharing and being conservative users of scarce shared healthcare resources. Conserving, therefore, suggests the participant is in a position to relate personal value to collective value and enact citizenship behaviours.

Although nearly all participants consistently praised the friendly and caring manner in which telehealth support workers undertook their duties, it was clear the interactions with their usual clinical carers seemed to be more important than the relationship they had with telehealth support workers. Telehealth provided participants with an opportunity to share the work involved in their care, and this was frequently linked to a wish to reduce the workload of busy and time-pressed community-based nurses, particularly during phases of the illness experience when patients feel their condition does not require face-to-face care and seem happy to replace some of this with telehealth support.

Participants describe various ways of task-sharing in order to help their usual carers. Examples include following instructions (Ruth, George), having written records to hand to answer questions quickly, and having learnt how to answer clinical questions succinctly. For example, Peggy regularly jots her readings on a scrap of paper and hands it to the nurse to copy into her notes when she visits. This helpfulness and willingness to do the telehealth readings is intended to save their nurses some work (Aziz, Stacey, Julia). This was a commonly expressed reason for additional record-making (Figure 16) and *ad hoc* record-sharing.

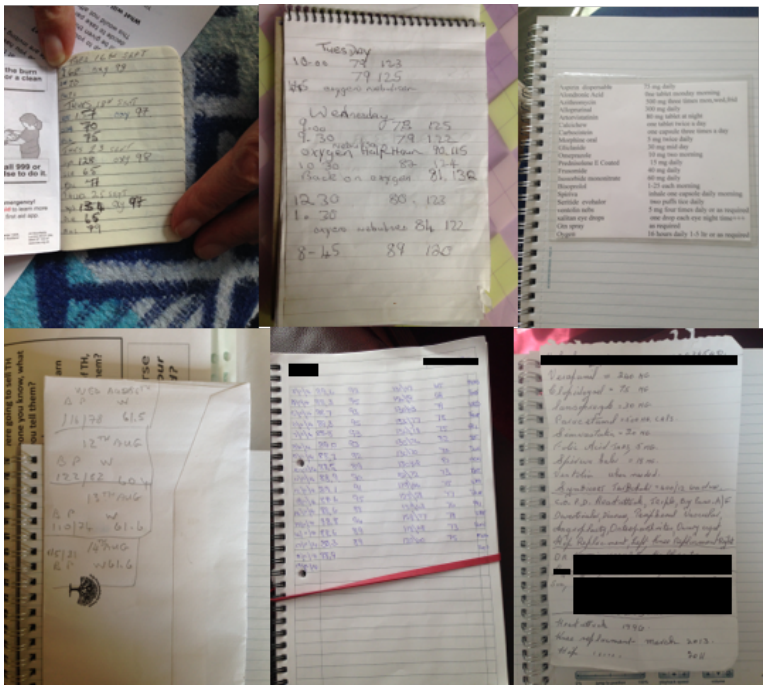


FIGURE 16 EXAMPLES OF PARTICIPANTS' OWN PERSONAL HEALTH RECORD KEEPING

These photos include examples of patients own health records (including medications, dosages, dates and causes of health events, hospitalisations, and treatments). Participants maintain the practice of handing over notes in response to questions because it is appreciated by clinicians, and this type of collaboration is seen to have a positive effect for the management of the therapeutic relationship.

> Graham: Usually when we go into the hospital and I produce this to a doctor they say, "That's going to save me a lot of work." Because they've got to write all that lot out. They're ever so pleased because I've done it. I'm passing my time on as well. Keeps me up to date.

Conserving participants are interested in saving time for themselves and their carers. Keeping and sharing written records is faster than using the telehealth machines again while the nurse is present. This was interesting as it contradicts the presumption of increased efficiency from automatic digital recording of patient data to the telehealth server, especially as many participants seemed to believe their usual clinicians use this data regularly to keep a watchful eye on them, which is their reason for submitting them as directed (Colin, Phil).

Conserving is based on 'giving back' out of a sense of mutuality, as participants describe ways in which they try to balance their high levels of healthcare utilisation with efforts to cut back, and to use healthcare resources responsibly. They expressed concern that their actions could influence equity of access for others in need.

> Stacey: For people that can't get out much, [telehealth is] ideal for them, and it saves having to rely on the medical services coming, especially if it's just for something silly like mine with blood pressure. It'd mean a nurse having to come and do my blood pressure, whereas someone really ill could have that slot.

Undertaking their own regular telehealth monitoring is a way of 'doing my bit' (Julia) for the NHS by conserving scarce resources for someone who needs to be physically seen by the nurse more than she does. Effective self-care therefore is clearly linked to notions of collective resource conservation.

> Julia: I'd sooner the bed goes to somebody that needs it.

Telehealth services, therefore, are frequently experienced in terms of mutual benefit.

> Peggy: … the heart failure nurse suggested it. She thought I would be suitable for it. […] Well because Stephanie suggested it, and I thought that I'd try anything that would help. Me and her.

Interestingly, when suggesting that they are helping their healthcare providers, participants did not seem to worry that the way they use the equipment might be a cause for concern while replacing the need for nurses to do the tests themselves. For example, George describes never being called to redo his telehealth readings because 'I follow it to the letter' although he was observed to remain standing when taking his blood pressure.

It is suggested that reasons for using telehealth are not altruistic because it enables patients to keep a safe distance from healthcare services that were frequently experienced as harmful, neglectful or otherwise challenging and upsetting, while maintaining and managing an outwardly positive relationship with providers.

> **Julia**: Plus, well, I hear it helps them as well because at least they're not having to – 'Ugh, I've got to go see that woman again,' sort of thing, you know, […] 'cause I can understand, it must be as monotonous for them as it is for anyone else, you know. If you know that, okay, if you've got a very poorly person, like sometimes my nurses will come at me and say, 'Do you really mind if we cut the thing [short]? Are you alright? Can I check this blah blah?' I says, 'Yeah, fine.' Or they'll ring me and say, 'Look, I've got an urgent… a patient's gone very poorly, do you mind if I put you on the Last List?' I says, 'Oh, while I'm feeling fine, you can put those emergency patients first.' I said, 'I'm alright.'

Managing relationships with carers is important because, as Julia explains, there is awareness that chronic comorbid patients like her run the risk of being perceived by busy nurses as too demanding,

so making a show of reasonably reducing their dependence on healthcare services, and being seen to do their bit to recover (cf. Parsons' (1951) 'sick role') includes complying with the needs of a provider-led service such as prioritising patients by urgency.

However, there is evidence that personal and collective benefit need to be balanced, otherwise participants are observed to be more protective of their scarce personal resources. For example, Conserving, like Alternative Seeking, can find telehealth to create negative personal value when it simply increases their work load by repeating tasks already being done by a nurse on the same day. Both Cleo and her non-residential carer became fed up with doing telehealth as scheduled when it coincided with the checks that a visiting nurse would do a couple of hours later the same day. By repeating the work, they save the nurse time if he or she comes *after* they've registered their readings because they can hand over the information from their written records, although this adds to their own inconvenience. If they try to avoid the overlap by skipping their scheduled telehealth use, they will get a reminder phone call to do the readings anyway, which is tantamount to satisfying system requirements rather than the needs of the patient (Clive, Russell, Ray). The extent that this imbalance is acceptable depends on the patient's access to personal resources (e.g. patience, energy, focus, coordination).

8.5 An explanatory matrix of resource-based patient agency for value co-creation

The four approaches reflect patterns in the data. Figure 17 maps the distribution of cases in the sample. The participants are clustered according to the dimensions of the organising conditions, i.e. high or low level patient need; high or low level access to appropriate healthcare to meet need. This describes the relationship between types, including a sense of how common the types are in proportion to the whole sample, with most participants occupying the NE quadrant (Conserving). The main differentiator between quadrants is argued to be relative access to appropriate resources. These resources may be those required for self-care and/or those required to access formal care. The approaches are not mutually exclusive, indeed characteristic activities were observed to be shared between certain types, but the influence of dynamic access to resources due to changeable health conditions highlights the way patients find themselves in a particular quadrant according to changing interactions within service and lifeworld contexts.

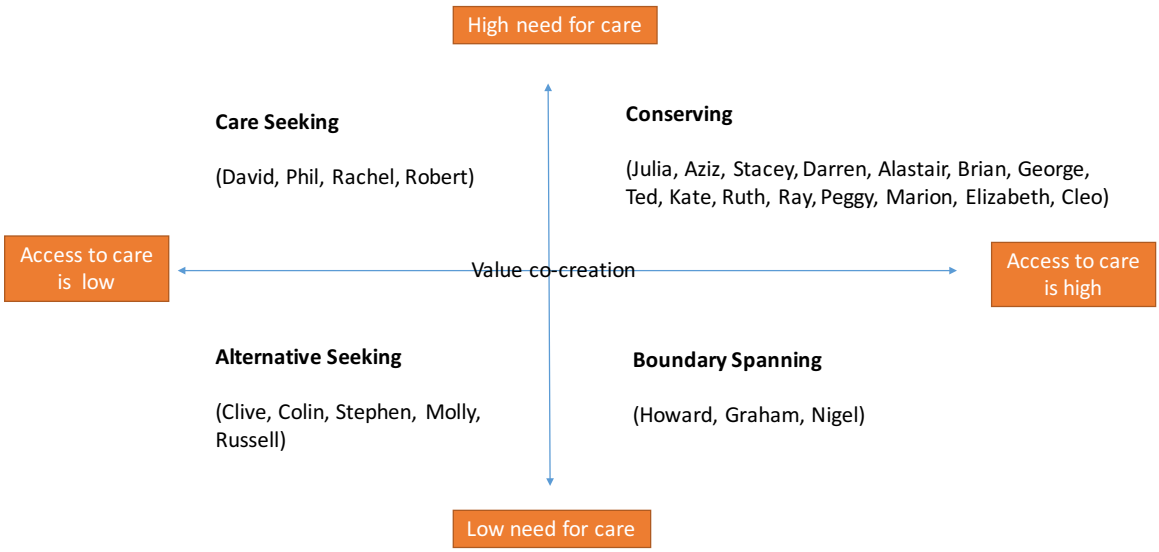


FIGURE 17 THE DISTRIBUTION OF PARTICIPANTS ACCORDING TO THE CONDITIONS STRUCTURING THEIR CURRENT APPROACHES TO HEALTHCARE SERVICE INTERACTIONS (ORIGINAL WORK)

We will now relate these findings to the concept of patient agency, and begin by defining the nature of the context in which agency occurs. During coding Schütz and Luckmann's (1973) phenomenological term 'lifeworld' was used to define the patient's perspective in terms of their phenomenological understanding of the world through interactions that foster personal and socially constructed theories of causality as reality. A distinction between the lifeworld and healthcare system setting is analytically useful to describe patterns emerging from the data, however, for the purposes of this section, we collapse them to clarify that the patient's lifeworld includes experience of the healthcare service setting and therefore system world is part of lifeworld. Developing the discussion in Chapter 7, we may consider this hybrid context of lifeworld and system experiences as the patient experience. By doing so, we suggest that based on the data, patient experience results from reflections on service experiences. These reflections appear to evaluate service experiences on the basis that they met subjectively perceived need resulting in lifeworld value being generated.

This relationship is expressed parsimoniously in Figure 18 to show patient experience as evaluation of previous and current healthcare service consumption experiences, resulting in their subjective opinion about their level of access to appropriate care resources (*x axis*). The second determinant of patient experience is reflected in their illness experience influencing their subjectively perceived need for care, and relates to dependency on formal healthcare service resources (*y axis*). They are both determined from the patient perspective and assume agency in the assessment of service value and subjectively perceived need.

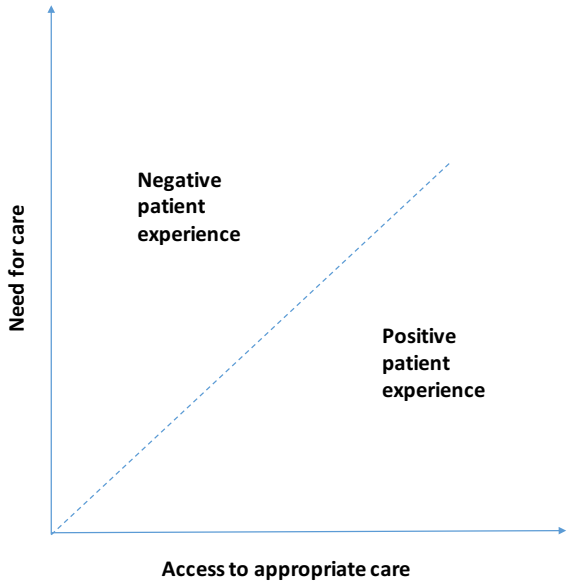


FIGURE 18 FACTORS OF PATIENT EXPERIENCE OF HEALTHCARE SERVICES (ORIGINAL WORK)

The relationship between the four approaches to value co-creation according to the determinants of patient experience are shown in Table 12 to provide an explanatory matrix that describes what was observed during the study. It is argued that patient experience has structured the context in which participants found themselves at the time of the study, (i.e. participants were observed to be interacting using Alternative Seeking, Boundary Spanning, etc. approaches as a result of these two factors).

TABLE 12 APPROACHES TO VALUE CO-CREATION: GOALS, RESOURCES AND ACTIVITIES (ORIGINAL WORK)

	Access to appropriate care (low)	Access to appropriate care (high)
Need for care (high)	**Care Seeking** • Disempowered and under-resourced • Investing scarce resources to co-produce 'accurate' and compelling clinical evidence base • Seeking improvements in access to further resources to improve outcomes	**Conserving** • Moderately well-resourced • Seeking to minimise impact of interactions on lifeworld • Giving back through task-sharing • Patient-led relationship management
Need for care (low)	**Alternative Seeking** • Structurally disempowered to change • Wanting to change interactions but under-resourced • Arm's length relationship management	**Boundary Spanning** • Well-resourced to change interactions and outcomes • Assertively optimising healthcare interactions to suit personal goal achievement

As the four approaches are structured by participants' experience of the healthcare service configuration, and the extent that it meets their perceived needs, the approaches reflect the personal goals that are most immediately relevant to that person in the context of their access to appropriate care. Therefore, their perceived access to care orientates their efforts when interacting with services to co-create value. The approaches also indicate how patients may determine value furthermore according to their capability to access and integrate the resources required to achieve the value sought. The matrix provides information about the observed activities and their resource implications.

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We will now explain the implications of patient experience resulting from the conjunction between need and access to care, as they structurally condition strategies for ensuing action influencing subsequent service interactions. We focus here on the interaction of patient agency to orientate the use of telehealth to take control over service interactions, conceptualised here as evidence of structural elaboration processes.

We have described individual (need) and structural factors (access to care resources) of patient experience determining the dynamic conditions affecting access to resources that are necessary for

value to be co-created. As service is defined for service-for-service exchange, it is suggested that the resulting interaction affects structural elaboration, i.e. how the patient and provider as social actors simultaneously produce and consume the service will structurate the service interaction. Structuration of the service will reflect reproduction of provider-led interactions (morphostasis), or transformation to patient-led interactions (morphogenesis). According to the S-DL perspective, either will result in the co-creation of value in the service-for-service exchange, but what matters more to the patient perspective is the realisation of patient value. Hence, transformation to patient-led interactions are argued to have a higher probability meeting patient value determinants.

It is suggested that depending on changes to resource availability (e.g. recovering from health crisis) and strategic use of patient experience as a guide for ensuing action (e.g. evaluating previous experiences in order to choose between self-care and formal healthcare services), patients are understood to move between these four approaches by themselves. These moves are conceptualised as agentic and are enabled and constrained by access to resources, which are symbolic of structural factors (personal and situational). Therefore, access to relevant resources is assumed to affect their agentic ability to co-create value by asserting a form of controlled independence, which is signalled by their ability to influence the quality of their healthcare interactions.

A resource-based model of patient agency for co-creation relates to the conceptual framework that informs this study (Figure 9) in the following way. As discussed in Chapter 4, Archer's theory of agency describes the link between reflections and ensuing action. Reflections are also understood to be related to the construction of personal theories of causality in the lifeworld (Schütz & Luckmann 1973). Reflections lead to 'stores' of accessible knowledge used as operant resources in service interactions and influence patients' capability to integrate resources for effective value co-creation through service for service exchange (Vargo & Lusch 2008). Therefore, reflections and resources can be understood to influence purposive, rather than passive, engagement in ensuing interactions. The perception of healthcare service experience outcomes as positive or negative, in relation to the perception that expenditure of resources in order to cope with effortful experiences is worthwhile, may be considered the necessary condition that primes ensuing action, such as motivating an interest to change the service interactions to better suit changing needs. These interactions are the conditions that may or may not trigger emergence of subjective and clinical value (i.e. patient value). Whether or not value is realised as an outcome is contingent upon the resources inputted and the relationship between goals and activities that characterise interaction processes.

8.6 Realist retroduction

This section uses realist retroduction to explain the resource-dependent movement between the four domains where patients find themselves, and how telehealth plays a role in this movement by influencing access to key resources.

Previous chapters defined the construct of personalised health literacy as the combination of clinicised self-knowledge and system knowledge. Personalised health literacy as a cultural-cognitive resource, or capability, is argued to affect patients' ability to engage in a morphostatic- or morphogenetic-oriented interaction with full-service healthcare service providers. From an S-DL perspective, the co-creation of value is described as an ability to convert key resources (personalised health literacy) into subjectively perceived value (appropriate care). The data suggests that this value is *not* limited to the co-production of telehealth services because they are experienced as an intermediary service to influence interactions with full-service healthcare. In other words, the value that is co-created through the use of telehealth is determined by the experience of care primarily as an outcome of full-service healthcare interactions. The telehealth experience, therefore, is conceptualised according to a *context-mechanism-outcome* understanding (see 4.3.6 Retroduction) in order to theorise about the emergence of patient agency and how it relates to structuration of the relational dynamics of the healthcare service interaction using Archer's theory of morphogenesis in three temporal stages (T1-T3) (Archer 1995; 1998a). It is suggested that reflections about previous experiences (*context* or T1 structural conditioning) steer their ensuing actions to persist in their co-production of telehealth services in order to affect the structure of their interactions (*mechanism* or T2 interaction) so that they better reflect subjectively perceived need to which providers can respond in order to co-create value in the wider healthcare services (*outcome* or T3 structural elaboration).

This proposition depends upon telehealth's role in developing personalised health literacy and its integration with other resources. Access to resources is enabled or constrained by the patient experience context, which affects patients' ability to engage in actions that will lead to an ability to reproduce or transform the structure of those interactions (Table 13).

TABLE 13 AN EXPLANATORY MATRIX OF CONTROLLED INDEPENDENCE: HOW USE OF TELEHEALTH TO CO-CREATE SUBJECTIVE VALUE IS EXPRESSED AS AGENCY TO REPRODUCE OR TRANSFORM THE STRUCTURE OF HEALTHCARE INTERACTIONS (ORIGINAL WORK)

	Access to care (low)	**Access to care (high)**
Need for care (high)	CARE SEEKING Potentially morphogenetic value co-creation	CONSERVING Morphostatic value co-creation
Need for care (low)	ALTERNATIVE SEEKING Morphostatic value co-creation	BOUNDARY SPANNING Morphogenetic value co-creation

In suggesting that patient-led interactions are mechanisms for the co-creation of subjective patient value, this is not to suggest that provider value is forgone. Consistent with the earlier clarification regarding the inclusion of system experience within the lifeworld, we also assume that lifeworld value includes objective clinical outcomes valued by healthcare providers and co-produced by patients, and which we assume to be instances of value that is socially constructed and taken for granted until they are empirically challenged, e.g. upon reflection.

From the data we see that subjective value is distinct because it is highly relational (e.g. choosing whether to cede or regain control over interactions), while functional outcomes (effective treatment and safety) are less controllable by patients. Therefore, all outcomes of value are relative to a context of seriously compromised physical health. Hence, although a telehealth user may *de facto* be highly dependent on healthcare services, they may yet derive benefit from less frequent access to healthcare interventions.

The following sections explain the types of agency evident in the four approaches to value co-creation.

8.6.1 Morphostatic agency

Alternative Seeking and Conserving approaches exhibit morphostatic agency. Alternative Seeking desires change in healthcare interactions to obtain better outcomes but their agency is constrained to only reproduce social structures (morphostasis). Resource constraints mean they cannot leverage their reflections into ensuing actions for structural change. Alternative Seeking (unlike Boundary Spanning) patients lack the specific system knowledge that enables them to exert system change, which would be valuable service-for-service exchange. Lack of access to resources increases their dependency on system resources so they are forced to reproduce the role of passive patient according to system rationality and are consigned to co-producing provider value over patient value.

Conserving participants are observed to use telehealth to help them recover and recuperate from effortful full-service interaction experiences, while obtaining respite from further harm or upset by maintaining distance yet keeping access to services within virtual reach. Their patient experiences are more positive although they show awareness of the limitations of healthcare system rationality, hence their goal is to stay at home. Conserving participants are observed to prioritise finding their feet, and regain strength and stability, therefore, they integrate resources including telehealth to facilitate staying at home. Their telehealth use is observd to be for relationship management with busy community-based carers through task-based labour sharing and willingness to increase self-care. Conserving participants therefore maintain and reproduce a morphostatic relationship, outwardly pleasing and complying with the recommendations of their community-based clinical carers. Compared to Alternative Seeking patients, Conserving involves a greater proportion of patient value co-creation although it also primarily involves co-production of provider value.

8.6.2 Morphogenetic agency

Care Seeking participants are observed to experience telehealth as a useful tool that helps communicate their subjectively perceived needs to clinicians, who they believe to be interested in controlling their access to care based on their interpretations of vital signs. Within this group there are varying levels of personalised health literacy, and the balance between access to self-knowledge and system-knowledge, is critical for their ability to translate their clinicised self-knowledge (developed through Translation I) for integration into the clinical decision-making process (using Translation II). These participants seem to temporarily suspend their mistrust of clinicians that result from experiencing effortful or upsetting service interactions in the hope that they can appeal to clinicians to respond to them intersubjectively, even if it means maintaining the object-oriented structures of interactions through basic co-production of telehealth processes. Care Seeking users of telehealth evidence morphostatic agency because their activities maintain and reproduce the hierarchical relationship between powerful clinicians and disempowered patients. Although they increase their self-knowledge using the language system of biomedical rationality, there is no implication that this leads them to an increase in their knowledge of how the system operates. This

combination of available self-knowledge and lack of system knowledge as cultural-cognitive resources are not likely to result in transformative change to their care. By transformative change is meant being treated humanely i.e. inter-subjectively, rather than maintaining object-oriented interactions, which entail patients being dismissed or deprioritised for care predominantly on the basis of triage processes that are over-reliant on clinical vital signs. Therefore, although Care Seeking may be considered evidence of morphostatic agency, a major differentiator is their intention to transform the structure of the interactions to be more humane and considerate of their subjectively perceived needs, which highlights the *potential for morphogenetic agency* if they succeed in obtaining more subjective value from ensuing service interactions because they are patient-led.

In contrast, Boundary Spanning participants evidence that they are already co-creating outcomes that deliver subjective value through their telehealth use. The healthcare interaction, furthermore is shown to be transformative from the bottom-up, as users show how they are exerting control over how, when and what kind of full-service interactions they experience. It is argued that Boundary Spanning involves the use of telehealth to increase their self- and system knowledge resources in order to successfully exert morphogenetic agency that transforms the social structure of interactions they experience. As a group, the potential for transformation is founded on the unusual role of controlling patient access to healthcare resources; this is more usually determined by clinical experts.

8.7 Conclusion

This chapter presents findings from cross-case thematic analysis. Simple pattern identification between cases led to four distinguishable approaches to value co-creation differentiated by access to salient resources to meet subjectively perceived need.

Using illustrative cases to evidence that patient experience structures participants' relationships with their healthcare providers, suggests that experience structures their ensuing actions with telehealth as its usage is oriented toward provoking particular types of responses to increase or decrease access to care from their providers. The extent that access appropriately meets need results in the co-creation of subjective value. Patient experience of wider healthcare services is therefore presented as a social structure that enables and constrains participants' agency to co-create subjective value. This means patient experience is said to affect goal formation, access to resources, and agency. Therefore, experience of provider relationships positions patients on the explanatory matrix according to the patient's approach to accessing necessary care, or value co-creation.

Because the thesis applies a process rather than variance model of causality, value co-creation is shown to be the contingent outcome that depends upon certain antecedent conditions being met (i.e. access to resources that are understood as constrained or enabled by personal and situational

factors). Antecedent conditions, or the context of value co-creation is conceptualised as patient experience. This was further defined according to two determinants of patient experience: assessment of service interactions and subjectively perceived need.

The findings evidence that value is subjectively determined, multi-dimensional, and may be observed as a process rather than an end state. Value as an outcome is also resource-dependent and availability of salient resources as inputs to the co-creation process are shown in an explanatory matrix. The matrix shows the relationship between patients, contextualised by their antecedent experiences and current need, finding themselves at the time of the study interacting with telehealth according to the four approaches to value co-creation. Patients can move between the approaches by themselves although their agency is enabled and constrained by their access to resources. Access is affected by various structural arrangements that may be personal and/or situational. The availability of salient resources is interpreted as necessary conditions that affect the ways participants agentically influence wider service interactions.

Agency is therefore interpreted to be resource-dependent because the value that emerges from patient experience depends on the patient's access to resources that enable them to strive for goals to change or maintain their existing relationships with providers, hence structure affects agency at the level of individual resource endowment. For example, agency is evidenced by patients' evident reflection and ensuing actions as they resolve to integrate their available resources toward achieving personal goals. Their actions are structurally influenced as the quality of their resource-dependent reflexivity about their experiences influences the extent that they understand their position in relation to the service system.

Their understanding of their position in the relationship is shown to structure their value co-creation behaviours and the emergence of their agency as morphostatic or morphogenetic. Agency is adduced from their resource integration in pursuit of personal goals from ensuing service interactions, and these goal-oriented actions can be viewed as structural elaboration of the patient-provider relationship (Archer 1998b; 2003). Therefore, in changing the ontology of the patient from passive recipient to social actor, the analysis suggests that because participants find the outcomes of interactions to be out of sync with their expectations, they are observed to integrate resources to influence interactions with healthcare providers for improved outcomes. This is seen to involve agentic interplay between telehealth and multichannel services.

Chapter 9 Discussion

Introduction

This chapter synthesises the key findings summarised in Table 14 and discusses their significance in light of the SST literature (Table 15) using key concepts from the S-DL literature in order to theorise about customer participation in healthcare (Bitner et al. 1997; McColl-Kennedy et al. 2012) with telehealth services.

The discussion will focus on two main contributions. The first changes the typical framing of SST from the retail context, and explores the distinctive nature of the healthcare context. This contributes a theoretical perspective on the use of SST relevant to other high involvement and highly institutionalised service contexts, like education, e.g. where university students who are tied into the institution are forced to use the technology provided as part of a broader service system.

The second concerns the advantages of advancing a sociology-based theoretical perspective of patient 'experience' of SST as an alternative to the predominant psychology-based models to explain SST 'use' and how this can inform management theory about the strategic benefits of consolidating patient experience and patient value co-creation for service system change.

The discussion will also relate the study's contribution to two key debates: firstly, about consumer empowerment as partial and unevenly distributed in professional services (Newholm et al. 2006), and secondly, the ability of disadvantaged consumers to knowledgeably and advantageously choose between healthcare providers (Sirgy et al. 2011; Fotaki 2014; Anderson et al. 2016). It does this by considering the findings to show that when choice is conceptually restricted to three service channel options in a multichannel service (SST, full-service or exit/withdrawal), the study highlights the importance of autonomy to choose between service channels as part of value co-creation directed at accessing resources that are relevant to subjectively perceived need.

TABLE 14 SUMMARY OF KEY FINDINGS (ORIGINAL WORK)

Self-Service Technology (SST) & Multichannel Service Interactions

1. Effortful use requires access to resources to develop mastery to co-produce service
2. Resource integration is based on interactive experiential learning to access requisite resources
3. SST, social and physical resources underpin development of cultural-cognitive resources for strategic value co-creation with multichannel services
4. Value co-creation with SST is oriented toward interaction specific outcomes ('clinicised' self-knowledge, self-efficacy, relational value from outwardly evidencing compliance and responsibility)
5. Value co-creation integrating SST is oriented toward multichannel service relationships and interactions
    a. SST offers specific benefits as a private, patient-led, pre-service, virtual staging area
    b. SST is an endogenous service environment within exogenous multichannel services and sociohistorical institutional arrangements in the service ecosystem

Patient Experience and Provider Relationships

1. SST evaluation is determined by access to resources to co-produce and compensate for systematic deficit in relational outcomes during provider-led hospital experiences
    a. SST enables patients to regain control of interaction processes (who, what, when, how)
    b. System value emphasises object-oriented clinical outcomes
    c. Patient value emphasises relational and functional outcomes oriented to lifeworld
2. SST to co-produce service recovery and manage relationship with multichannel service
    a. Creative customisation to make co-production process suit their preferences
    b. Relational value from overt show of compliant co-production and covert resistance to ceding control
3. Structural configuration effects:
    a. Full-service immersion in system rationality leads to relational service failures and value co-destruction
    b. Looser relationship through SST maintains patient-led context of interactions and value co-creation through service recovery because there are no viable alternatives

Patient Agency and Value Co-creation

1. Four resource-dependent approaches to value co-creation with telehealth
2. Personal goal achievement influenced by resource constraints: especially physical and cultural-cognitive
3. Resource constraints constructed by structure of service interactions focusing on system value co-creation
4. Value co-creation necessary to achieve lifeworld value
    a. Links between patient and provider value – sometimes convergent and sometimes divergent, but always oriented toward patient value
    b. Fully realised value (Boundary Spanning & Conserving)
    c. Partially realised value (Alternative Seeking & Care Seeking) patient-led but under-resourced
5. Patient agency is intrinsic to patient experience in different consumption stages
    a. System value creation through morphostatic agency in interaction (co-producing provider-led interactions)
    b. Lifeworld value co-creation through morphogenetic agency in later consumption stage (reflection, ensuing action, influencing interactions using telehealth)

9.1 The distinctive nature of the healthcare service context

We begin by discussing the contribution to SST knowledge as a result of changing its typical retail context to healthcare services. It is widely accepted that healthcare is a distinctive service context because consumers are unwell, providers are stressed, and although valued, it is rarely used, due to an assumption that there is conflict between what patients want and what they need (Berry & Bendapudi 2007). This conceptualisation is based on descriptions of healthcare as a 'negative service' because people hope they never will need to use them, the rarity of use makes it difficult for patients to establish expectations (Morgan & Rao 2006; Spanjol et al. 2015), and that evaluation of service outcomes tends to be overshadowed by a focus upon service processes that entail emotional experience of stress (Gelfand Miller et al. 2008; 2009). The literature suggests patients are ill-qualified to judge quality of clinical outcomes, instead judging service quality on affective qualities like clinicians' bedside manner (Berry & Bendapudi 2007). Citing a chronic disease example of diabetes care, the literature argues that negative services become 'neutral' through routine use (Morgan & Rao 2006) although Spanjol et al. (2015) suggest co-production of chronic disease care regimens becomes more difficult over time.

Firstly, as argued in the conceptualisation (Chapter 3.1) the ontology of healthcare services in the healthcare literature could reasonably be revised to reflect theoretical developments from marketing like the S-DL. Here we emphasise that aforementioned nomological definitions of healthcare services in the marketing literature also require updating to reflect changing emphasis in chronic disease care policy and as a result of this study. This is because the findings suggest that chronic disease patients' desire for preventative support in order to avoid hospitalisation nuances the assumed binary opposing what patients want with what they need from healthcare services. The findings suggest, as will be discussed in Section 9.2.2, the broad definitions of 'negative', 'neutral' and positive services require further specification in light of patient preference and the discrete experiences of a multichannel service.

Secondly, chronic disease patients evidence frequent use of healthcare services, leading to extensive service user experience and detailed expectations about the interactions, leading to development of heuristic tools which participants are observed to use when deciding between care options. This is noted to be decided according to the perceived appropriateness, not only of relational outcomes (Berry & Bendapudi 2007) which are described as pertaining to the interactions in the service environment, but also functional outcomes because they are shown to be important to regaining control over their interactions in lifeworld environments that otherwise prevent them from achieving their lifeworld goals and projects.

Thirdly, the literature discusses the influence of institutional arrangements affecting value co-creation processes in all services (Vargo & Lusch 2016) and suggests that in healthcare these may account for different determinants of value used by healthcare providers (calculated) and patients (experiential) (Helkkula et al. 2013). The findings evidence that outcomes from patient-provider

interactions are not only dictated by different value determinations to identify desirable outcomes (e.g. clinical *or* relational/affective), but that these outcomes shape patients' lifeworlds in an iterative, continuous fashion determining the relationship that patients have with providers. This is evident in later stages of consumption experiences when they reflect on the interaction event, as well as influencing the resource endowment with which they make decisions about future service consumption. The findings therefore evidence that previous experiences structure the patients' scope of access to resources that comprise current resource endowment and this affects their ability to more effectively co-create value. Hence, the findings show that based upon their experiences they are positioned to use telehealth to interact using Alternative Seeking, Boundary Spanning, Care Seeking or Conserving approaches in order to improve their access to appropriate care.

9.2 Value Co-creation using SST in Multichannel Services

Table 15 shows the aspects of the SST literature that will be covered in this section. The findings confirm that telehealth conforms to a definition of SST as specifying the scope of interactions that users have to make their demands known (Dabholkar & Bagozzi 2002). This is because telehealth use is shown to help providers to achieve their strategic aims by introducing service constraints. However, the findings also evidence that the shared strategic goal of reducing emergency hospital admissions is achieved through patients diverging from provider-led service processes in order to achieve this outcome.

TABLE 15 CONTRIBUTION TO THE SST LITERATURE (ORIGINAL WORK)

Assumptions in the SST literature	**Thesis Contribution**
SST introduces service constraints by specifying scope of interactions (Dabholkar & Bagozzi 2002)	YES
User benefits: convenience, more focused service responses, avoidance of interpersonal interaction, personal benefit, lower prices (Meuter et al. 2000; Weijters et al. 2007; Beatson et al. 2007), reduced waiting time, perceived level of customisation, fun, enjoyment (Dabholkar & Bagozzi 2002), flexibility, delight and extraordinary benefit (Ostrom et al. 2014)	YES
Provider benefits: increased speed of delivery and customisation, reduced labour costs, increased productivity, improved competitiveness, differentiation (Beatson et al. 2007)	N/A
User risks: negative reaction, discomfort, anxiety, intimidation, may foresee recovery issues from potential service failure and no staff support (Bitner et al. 1998), loss of interaction with service employees (Zeithaml & Gilly 1987 in Beatson et al. 2007)	YES
Provider Risks: Loss of interpersonal contact may lead to problems establishing service recovery strategies, loss of social bonds, loss of upselling opportunities, negative effects on staff (Bitner 2001; Curran et al. 2003 in Beatson et al. 2007)	YES

Therefore, the understanding that SST is designed to constrain service interactions by offering few opportunities for patients to deviate from the relatively rigid user-machine interface, is contradicted by observing telehealth to be the site of much purposeful and accidental customisation.

In this study, when participants were questioned about their deliberate and accidental customisation their responses suggest that they were not self-conscious about implementing customisation processes. In fact, they often justified why they 'need' to introduce workarounds. Their comfort and confidence to use the equipment and service in unexpected ways can be interpreted to suggest that purposive customisation is due to the influence of ideologies, or socially accepted ideas about technology consumption (Kozinets 2008), reinforced by their nurses referring them as suitable and telehealth installers encouraging them to believe they can get used to the equipment quickly. It could also be due to habit as adept technology consumers. Evidence of orchestration and customisation resulting in creatively customising solutions in response to emergent problems are consistent with user-based studies that show divergence between expected and actual use (Schwartz Cowan 1985; Mick et al. 1998; Kozinets 2008; Pinch & Oudshoorn 2003; Greenhalgh et al. 2013).

The technology consumption literature suggests that a person may be taken by the idea of telehealth, but its failure to meet expectations may lead to disillusionment and subsequent avoidance (Kozinets 2008). Although the sample's experience of activities as effortful might be normalised by life with chronic conditions making all activities effortful, drawing on Mick et al.'s (1998) explanation that disappointed technology consumers either resolve to engage confrontative coping or avoidance strategies, it was important to understand why users were observed to engage confrontative coping when avoidance is relatively cost-free because using telehealth is voluntary. Despite evidence of effortful user experiences, we find they continue to integrate resources until they achieve a level of technical mastery. Therefore, contradicting the literature suggesting SST adoption is dependent on perceived ease of use, and that telehealth is convenient, findings about actual use suggest that participants are choosing to put up with regularly effortful experiences.

In order to consider the significance of this deviation from the literature focusing on psychological factors explaining SST 'use', we will discuss the findings according to the socio-cultural experiential perspective of telehealth consumption. We begin by articulating the study's contribution to the understudied role of physical resources. Participant use of telehealth was largely dependent on their access to physical resources in value co-creation (Arnould et al. 2006). For these users, it is unsurprising that physical resources influenced their access to cultural-cognitive and social resources. Illness and frailty may affect coordination, emotional control, energy, patience, persistence, and physical and physiological traits may also affect their ability to use equipment designed for mainstream users (e.g. calloused fingers, atrial fibrillation, impaired vision, poor mobility). Ability to concentrate and cognitive clarity relate to both physical and cultural-cognitive

resources. Inability to use equipment due to physical or cognitive deficits, means the support of human and machine-based carers were observed to compensate for patients' lack of physical and cultural-cognitive resources. Cultural-cognitive resources include access to knowledge and technical skills (e.g. sufficient literacy and numeracy for health literacy) to understand how to self-care from experiencing healthcare services, including learning how to use equipment and interpret clinical language sufficiently to know their use conforms to expected machine functioning. Access to social support is especially important for new users getting to know the machines, when services fail or when fulfilling the user role is difficult. Social support helps users who feel confused, or that they are being blamed for making errors because the default response of the service is to trust in the machines and blame the users or their bodies for breaching normal parameters.

Applying Arnould et al.'s (2006) consumer resource integration framework is helpful not only for elucidating the role of resources and their interaction in co-producing the service, it also provides a plausible explanation for adoption of confrontative coping strategies, which is that telehealth is perceived to be instrumental for personal goal achievement. This explanation is supported by the observation that participants are adept users of a suite of assistive technologies, including increased dependence on consumer services, to meet their changing need for help with everyday activities.

Therefore, for resource constrained users to persist in effortful telehealth use, this suggests that they perceive trade-offs from using it as more beneficial than not using it, and that expending the required resources helps them to achieve personal goals that matter to them. This is borne out by the study findings showing that users of telehealth are goal oriented such that they aim to influence their access to further healthcare resources. Furthermore, this finding supports the interpretation that the trade-off involved in dealing with effortful telehealth experiences is acceptable because they were in exchange for avoidance of more effortful experiences, i.e. immersion in full-service healthcare contexts, where there are no available alternatives apart from exit/withdrawal. It is suggested that this explanation is consistent with the literature that suggests value from SST is related to extraordinary benefits not otherwise accessed by full-service alternatives (Ostrom et al. 2014). The thesis suggests that the search for sociocultural value integrating the assessment of trade-offs in resource intensive experiences are a more compelling explanation for SST 'use' than the determining factors identified through applying psychological approaches, which may explain why the findings contradict this literature's assumptions regarding ease of use and convenience as important adoption drivers (see Table 15).

9.2.1 Integrating resources to regain control

How do we understand these extraordinary benefits to materialise and what is the nature of these benefits? These questions are especially important for patients who are personally and situationally disadvantaged, as well as sociohistorically disempowered by healthcare structures. The findings

suggest that through engaging in intermediary telehealth processes, users gain value from confrontatively coping and learning to work through emergent problems. These processes confirm the literature suggesting that users engage in self-directed learning processes resulting in useful outcomes from regularly interacting with machines and service responses (Hibbert et al. 2012). The findings suggest that sufficient access to resources (including opportunities for learning experientially and applying understanding and accessing social support and feedback from experts) enables users to achieve sufficient technical mastery to overcome emergent machine-based problems. Through self-directed learning users learn tolerance for machine fallibility, and this technical mastery appears to enable users to become less dependent on machines as authorities on their condition, thereby avoiding anxiety from unpredictable results. This machine scepticism is argued to foster greater competence and assertiveness in their ability to self-assess their well-being, as well as to diagnose machine functions over time in order to know when they are playing up. The mastery of these skills seems to be critical for their ability to co-produce the service by successfully transmitting data as instructed. Being able to demonstrate competent use of machines was observed to be important to participants. These demonstrate various types of patient value that emerge from telehealth use.

Participants who learn how to identify problems and resolve them by themselves, e.g. through asserting that what they know about their bodies is more reliable than the machines, are able to assert their relative independence, which is argued to be reflective of their choice based on application of clinicised self-knowledge. Therefore, a by-product (clinicised self-knowledge) that emerges from these unscripted patient-led interactions with telehealth as a result of misbehaving machines, can be understood as an outcome of early value co-creation which enhances their capability for more effective value co-creation later, i.e. when integrating their clinicised preferences into their full-service interactions. The findings confirm a staged process with (1) pre-service resource integration for customer learning occurring before (2) effective value co-creation (Hibbert et al. 2012). However, whereas the literature implies that value co-creation only occurs in the joint sphere of interaction and other consumption stages (i.e. pre- and post-interaction) are where value creation occur (Grönroos & Voima 2013), our findings suggest that patients are constantly in the process of co-creating value in both stages. The first stage involves integrating resources for two aims: to learn to use SST so they can co-produce shared value related to SST service outcomes for mutual benefit, as well as co-creating subjective value as a by-product for their own use. This by-product is conceptualised as self-confidence from perceived competence, which is the aforementioned cultural-cognitive capability that facilitates their regaining control over their condition in lifeworld contexts. The findings suggest that cultural-cognitive resources are a necessary input for improving interactions with actors in healthcare system contexts in the second stage of co-creation, which we showed to be more or less successful probabilistically depending on

the approach to value co-creation they were in a position to enact (i.e. Alternative Seeking, Boundary Spanning, Care Seeking or Conserving). We reiterate here that patients' positioning relates to their capability to fulfil the four processes of co-creating subjective value across both stages, which is argued to be resource-dependent, where access to relevant resources is determined by personal and situational (i.e. structurally influenced) factors. Therefore, the findings suggest that when patients have access to the necessary resources, they are observed to pursue behaviours that attempt to maximise benefit from choosing between three alternatives: an SST, a full-service option, and exit/withdrawal.

Choice is argued to be beneficial because it is related to patients' quest to maintain or regain a sense of control in their interactions with healthcare services, including avoidance of harm or upset as a positive individual benefit, and opportunities to scale back their consumption for collective benefit. The findings suggest that for the sampled cases, even temporary experiences of autonomy are valued by patients whose personal context entails iterative experiences of losing control because of their illnesses as well as from participating in successive healthcare provider-led interactions where negative consumption experiences are compounded by diminishing returns over time due to disease progression.

This kind of resource-dependent autonomy and dependency resonates with critiques of paternalistic or provider-led medical practice accused of only paying lip-service to patient autonomy, e.g. through relatively meaningless informed consent processes (O'Neill 2001). This literature suggests that an allowance 'for the variable and partial character of actual human autonomy' which recognises 'that all human capacities for autonomous action are limited', is preferable to imposing 'an idealised picture of unlimited autonomy' (O'Neill 1984, p.173). The thesis provides evidence to corroborate a conception of partial and variable autonomy as it is contextualised by dynamically shifting resource-dependency. This suggests that although we evidence that disadvantaged patients' desire for control can be interpreted from evidence that they exert choice between service channel options; and that these choices can enable them to be more agentic, involving service interactions that more effectively target patient benefit (compared to paternalistic service interactions systematically designed to denigrate parts of it), it would be unsound to over-emphasise the role of patient choice without making explicit reference to the influence of contexts of resource-dependency that are *not conducive* to patients' effective value co-creation. Evidence of patients seeking and sometimes failing to benefit through agentic value co-creation include participants using Alternative Seeking and Care Seeking behaviours.

9.2.2 Exploiting structural affordances in multichannel services

Although healthcare is understood to be a typically high involvement service (Zeithaml & Bitner 2003), the findings suggest that complex chronic comorbid patients welcome the opportunity to influence and contribute to decisions about the frequency of their exposure to healthcare service interactions by shifting a proportion of their care to a less involving, partially automated series of machine-led service interactions. This is interpreted as gaining respite by avoiding face-to-face interactions.

Additional value that patients derive from telehealth is due to their ability to socially construct their system-readable prompts for care from the privacy of their homes so that they can focus service responses upon their subjectively perceived need. This suggests that the context of SST is perceived by patients to be structured by a different organisational culture to hospital-based channels. This is evident from participants' praise for humane and caring interactions with non-clinical telehealth support workers, and that personal interaction with installers encourages progression from acceptance and intention to use (Liljander et al. 2006; Meuter et al. 2003). The findings also suggest that having access to full-service channels as a fall-back to provide speedy recovery in case of SST service failure (Reinders et al. 2008; Wang et al. 2012) is important toward building more realistic expectations of machines as needing some tolerance from their users, and helping to avoid technology anxiety (Meuter et al. 2003) from unpredictable results. Hence the findings confirm the literature advocating multichannel options so that perceived availability of alternatives ensures patients do not feel forced to adopt SST which can lead to negative attitudes (Reinders et al. 2008). This is further evidence that choice is important for consumers faced with SST.

The findings contradict the literature in several ways. The literature suggests that perceived ease of use, reliability and reduced waiting times are determinants of use (Weijters et al. 2007) and help overcome technology anxiety as a barrier to SST adoption (Meuter et al. 2003). Yet, as aforementioned, evidence that SST adoption, conceptualised as persistence to use telehealth, occurs despite evidence of effortful equipment use. Whereas customer perceptions of SST are often derived from assessing past experiences of SST (Wang et al. 2012), our findings show that despite participant recall of multiple service failures, most participants in the sample are undeterred from using telehealth.

This literature also tends to compare assessment of SST experience to past experience of full-service counterparts, in order to show that preference for SST is related to personal preference, situational factors, and the ability to realise extraordinary benefit not available through full-service channels (Ostrom et al. 2014; Wang et al. 2012), and this is where the significance of the study's findings seem to benefit most from framing telehealth as an SST. This is because the literature automatically relates SST to the context of alternative service channels. This means that the study's

empirical finding that patients prefer using telehealth to avoid hospital-based care is theoretically grounded in the finding that SST is preferable due to strategic avoidance of full-service interpersonal interactions (depending on personal and situational factors). Therefore, the finding that telehealth can deliver extraordinary benefit, such as avoidance of incidental harm and upset from immersion in the clinical context, is supported by the literature, and emphasises the importance of understanding patient 'experience' in providing insight over and above observations of SST 'use'.

9.2.2.1 Breaking free from managed patient experiences

When considering SST from the perspective of the multichannel service management literature, it is suggested that the thesis contributes a much needed service user perspective. This literature assumes that there is a linear relationship between process design and the customer experience of those processes (Payne & Frow 2004), although customer experience management is acknowledged to be difficult and multidimensional (Verhoef et al. 2009). The linear model of user experience management is challenged by the study's findings confirming user-centred studies in the science and technology studies highlighting unexpected use (Pinch & Oudshoorn 2003; Oudshoorn & Pinch 2006; Kozinets 2008; Schwartz Cowan 1985). For example, Banerjee's (2014) multisite case study suggests that misalignment from poor service channel integration leads to customer disappointment and potential for withdrawal and draws on literature suggesting that integrated system processes may be a route to seamless positive experiences and optimised customer relationships (Payne & Frow 2004; Patricio et al. 2008). Firstly, within healthcare services complex comorbid patients are put on integrated multispecialist care pathways that were observed to be effortful to manage and unpleasant to experience. These negative experiences are interpreted as influenced by provider actions focused upon deriving system value through object-oriented efficiency (recall Russell's description of doctors deciding which cases merit a hospital bed). Secondly, although participants are observed to take for granted that integration between the telehealth services and their usual healthcare providers exists (this is based on their referral onto the service by their usual carers, as well as the frequency that they suggest that their doctors and nurses are keeping an eye on them through telehealth), it seems that the subjective value that participants seek is not from seamless alignment of service channels continuing the object-oriented healthcare system experience *per se*. In fact, it appears the value from telehealth relates to delivering respite from exposure to provider-led healthcare system interactions.

It is suggested, therefore, that patients take most advantage of the cracks in the service system culture and context, wherein such affordances created by dissimilar channel contexts enable patients to instigate acts of resistance to provider control without overtly committing to a full, formal break from the compliant provider relationship, i.e. through choosing exit/withdrawal. We may consider SST use as a pre-service staging area for patients to access information in order to

decide whether or not to seek formal assistance through full-service (Ingram et al. 2013). The importance of patients actively experiencing service interactions, reflecting on them and deciding whether they want to interact with them or not highlights the connections between patient experience, patient agency and the experience of the provider-led structure of provider-patient relationships as systematically delivering negative lifeworld value due to its focus on provider value.

9.2.2.2 Channel mis-alignment for co-creating relational value

Thus far, we have discussed SST and multichannel services as complementary as well as conflicting, as a result of the interpretation of patient experience as informed by tension between lifeworld and system rationality emanating from their non-aligned value systems (Figure 15). This was followed by the suggestion that loosely integrated channels may offer distinctive user experiences.

We now consider these explanations against the S-DL literature, where value misalignment between providers and service users is often conceptualised as leading to value co-destruction (Echeverri & Skålén 2011; Plé & Cáceres 2010). More recently, value misalignment has been developed to show potential for realignment and improved market orientation (Skålén, Pace, et al. 2015). This constructive view of misalignment was also considered at the service system level, where the metaphor of strategic action fields to interpret evidence of contention between value systems and service configurations was used to frame conflict between incumbents and challengers clashing in the market. This frictional interaction, signalling service system failure, is observed to resolve ultimately as organisations coalesce around emerging market needs, transforming service systems and privileging the co-creation of different types of value (Skålén, Aal, et al. 2015).

When considered in this light, the findings lead us to question whether multichannel management should strategically aim for tightly aligned service channels that would reinforce intrinsic, organisational values, rather than viewing misalignment as an opportunity for realigning provider values to better accommodate the value that customers place on variety in services to meet heterogeneous needs. Recognising that different channels offer different, extrinsically valuable experiences – especially those that are contrary to full-service experiences – is argued to be necessary in order for services to be customer-led thereby catering to changing personal needs.

With reference to provider relationships, and the assumed conflict between want and need for healthcare services (Berry & Bendapudi 2007), it is suggested that being able to choose between service channels may help to manage this tension. It is suggested moreover that cultural affordances between service channel contexts enable SST users to co-produce service recovery and relationship management in their terms. Our findings show that telehealth use is part of participants' active

relationship management, maintaining outward passive compliance and cloaking their resistance to provider control as they task-share and collaborate in between-patient triage.

9.3 Patient Agency and Service Structures

Although SST use is shown to be resource intensive for this user group, the findings suggest that the machinic and humanic flaws and faults are much less significant than those that pertain to the socio-technical system that is the hospital-based healthcare context. Studies show that chronic disease patients frequently have lower satisfaction than acute care patients in hospital and GP settings (Hewitson et al. 2014). Therefore, resource expenditure in effortful use processes can be assessed in terms of system-level trade-offs, including the cost of accessing available alternatives. Subjective or experiential value determinations (Helkkula et al. 2013) from telehealth use is therefore highly contextualised to system experiences and the extent that they are perceived to systematically deliver negative lifeworld value in terms of functional and relational outcomes, whereas the service configuration of the SST offers benefit of distance and protection from exposure to and immersion in the dehumanising system context, which is replaced by caring and humane service support interactions by non-clinical telehealth support workers.

By considering these issues through S-DL as a system level perspective, we can see that social actors are endowed with resources as a result of being embedded in cultural-contexts (Akaka, Schau, et al. 2013). For example, when patients were observed to depersonalise their negative patient experiences, they often praised otherwise friendly clinicians who behaved badly and were perceived to be uncaring, which was interpreted to result from clinicians inhabiting pressurised work contexts and bureaucratic systems that drive them to behave in ways that are contrary to positive intersubjective empathic interactions expected in the patient lifeworld (recall Howard's story about the nurse who forgot to get him a drink of water). Therefore, in making explicit the different contexts inhabited by patients at the lifeworld and system level, the findings show that one system experience is affected by another.

In the SST service system, patients' access to resources is structurally constrained by their interactions with multichannel services (e.g. patients who are positioned to use Alternative Seeking and Care Seeking approaches). Continuing the discussion from the previous section, the findings suggest moreover that the structural affordance provided by SST enables patients to exploit the endogenous service environment (Lusch & Vargo 2006; Baron & Harris 2008) of the telehealth service as a resource for exogenous service system transformation (Skålén, Aal, et al. 2015), and they are typically not empowered to exert structural changes at this level.

At the micro level of service interaction, however, the at-home delivery of telehealth is critical because it affords paradoxical 'invisibility' that enables customisation practices to be hidden from view – and evade external governance – at the same time that telehealth enables the controlling

clinical gaze to monitor their physical bodies and keep them out of the formal clinical setting using system rationality in ways that patients are not trained to fully understand. Although such 'remote control' is designed to enable providers to govern against patients' maladaptive behaviours (e.g. being habitually 'over-demanding' in their expectations of care), in many ways this theoretical understanding of external control over patients is overturned by the practices observed in this study. Agency is inherent in participants' actions leveraging patient self-report ('denigrated as merely anecdotal' and the lowest form of clinical evidence (Morse 2011) from the system perspective) to regularly gainsay the algorithmic interpretation of their vital signs grounded in system rationality. This is observed to be part of patients' iterative process of regaining control over decisions regarding how and when to cede personal control to clinical authority.

It is suggested that the role of interactions within the endogenous environment of telehealth services is potentially exerting transformative pressure on the highly structured exogenous environment of healthcare services, where control over clinical decisions to enable or constrain access to further healthcare resources is normally reserved for trained clinicians. The findings suggest that agentic use of telehealth may be enabling the structuration of new institutions, and this is consistent with evidence of SST's disruptive capability in other service environments, and is interpreted here as a lever of social change. Through realist retroduction, the study suggests that under certain conditions, the exertion of patient agency through telehealth use can trigger either morphostatically reproducing or morphogenetically transforming relationships that structure provider control over resources in clinical interactions.

9.3.1 Joint spheres and discrete channels structuring co-created value

The patient experience of multichannel services suggests that transformation toward patient-led interactions is necessary for subjective value to emerge. Whereas providers may think that complex chronic disease patients *seek solace in* medical care, patients show that they *require solace from* medical care in the home environment, i.e. using Alternative Seeking and Conserving approaches in order to recover from effortful healthcare interactions. It is observed that the subjectively perceived inaccessibility of appropriate care resources creates the conditions for, or motivates the use of telehealth specifically to support personal decisions about when and how to cede control over themselves to the healthcare system. Therefore, the study finds that at the macro level, there is convergence between providers and patients about the value of avoiding emergency hospital admission, but the routes toward arriving at the recognition of this goal as valuable are highly divergent and the end goal of transformation is also suspected to be divergent from the provider aim to maintain control over decisions regarding access to healthcare resources.

Although the patient home is conceptualised as the lifeworld throughout the thesis, patients' familiarity with the hospital system world as determined by the experience of its administrative

bureaucracy is shown to form part of their lifeworld, too. Hence the development of personalised health literacy as a resource, is comprised of clinicised self-knowledge, as well as system knowledge from their perspective as an extensively experienced service user. By focusing on differentiated provider and lifeworld contexts, the findings contribute to theory relating to the study of value co-creation occurring in different interaction spheres (Grönroos & Voima 2013).

This study suggests that the telehealth joint sphere is occupied by lifeworld and system world values in contestation because it incorporates both context-based rationalities, and maintains opposing criteria for what is real (e.g. what is a clinically valid input), and what is good (e.g. objective or subjective value). Patients are observed to maintain heterogeneity in the lifeworld without necessarily creating a cohesive whole (Arnould & Thompson 2015).

Telehealth is shown to be influenced by normal healthcare experiences, where the joint sphere of full-service interaction is provider-led, and the joint sphere of SST interactions are paradoxically patient-led despite a highly constrained service interface. Therefore, this case study suggests that when integrating the spheres metaphor to consider the management of value creative processes using multiple service channels, their different interaction spheres may be conducive to the co-creation of predominantly provider *or* patient value, and moreover that they may be mutually exclusive because they enable and constrain each other.

This suggests that when the patient interacts in one service channel or another, the ontology of the patient and their agency is constructed by the structure of the service channel and patient and agency mutate by changing spheres of interaction. This is significant when considering the role and effects of institutional arrangements (Edvardsson, Tronvoll, et al. 2011; Edvardsson et al. 2014; Vargo & Lusch 2016) on the ontological demands that services make on service users. In the healthcare context, provider-led interaction is both sociohistorically embedded in the biomedical approach to healthcare (Engel 1977) influencing organisational values, and upheld in wider society's evaluation of what good healthcare services do (Parsons 1951) as objectively evidence-based (Dopson et al. 2008; Greenhalgh 2014), thereby influencing the perception of what responsible patients are expected to do for themselves (Askegaard & Linnet 2011; Earley 2013; Giesler & Veresiu 2014). These factors highlight the considerable social barriers to patients co-creating subjective value with relatively scarce resources. The study suggests that patients as social actors are shown to flex ontologically in response to their institutional environments. The act of flexing their structurally determined identities with respect to enactment of services has resource implications such as being able to understand the institutional structure in which the interactions are embedded in order to rationalise the patient experience (conceptualised as developing system knowledge in this study) without having the option of quitting the provider relationship because it is so socially diffuse.

When considering evidence of resource-based patient mutability – sometimes passively reproducing, sometimes agentically transforming – it is possible to suggest that the socially constructed pretense of institutionalised provider-based control, or paternalism that is always in tension with autonomous patients (O'Neill 1984), is not always applicable and therefore this opens the possibility that provider-control may not flourish in contexts and interactions that occur outside of the organisational context, i.e. the lifeworld. Therefore, services that occur in the lifeworld context are more naturally suited to the emergence of lifeworld value in which the co-production of provider value is ancillary. As our findings show, provider-control is applicable in some interactions but not all. And this may explain why most participants appear to be relatively un-self-conscious about the introduction of customisations when using telehealth. Through this framing, the findings show how the provider-patient relationship is an unnatural one that would not necessarily flourish without the exercise of purposive managerial control evident in cultural-cognitive, regulatory and normative institutional arrangements that predominate in the healthcare service's organisational settings (Scott 2008; Edvardsson et al. 2014).

The unnatural circumstance of ceding control over the self to others (cf. Adler 1930 in Burger 1992) in the lifeworld, is acceptable when illness occurs (Parsons 1951) because the 'sick role' means patients are structurally conditioned to share certain aspects of provider value, including the expectation that they will cede control over themselves to professionals, comply in the face of uncertainty, and valorise collective benefit. This would explain why participants are observed to derive value from actively contributing to mutual benefit when they are able. So, although the majority of findings are interpreted to show divergent underlying value systems (Figure 15) pertaining to lifeworld and system contexts, we can interpret the evidence of commonalities including waste avoidance and need-based access to resources consistently while suggesting the lifeworld and system contexts are held in tension.

Commonalities may indicate that the link between resource availability and need for care is related to social identity and group membership (Champniss et al. 2016), where patients are observed to shift between empathising with healthcare providers and other patients, and thinking like consumers and citizens. Such an interpretation of the findings speaks to a turn in customer experience literature away from psychology-based explanations of customer decision making toward suggesting that social-psychology and sociology-based approaches, like social identity theory (Tajfel & Turner 1986), can provide explanations for why it is that 'when it comes to purchase, the group you identify with at the time of transaction is a very important function in your decision' (Champniss et al. 2015). In this way, the study shows that individual behaviours emerge from generative structural mechanisms, whereby consideration of institutional arrangements contributes a sociology-based explanation for the chronic disease patient's behaviours. This is argued to be due to the temporal context of chronic disease as life-long and the situational context of home-based care dominated by

the lifeworld determinants of value. This explains why patients would be constantly engaged in asserting their control over situations and environments as they are able, and which is normal to their usual activities in the lifeworld. This search for control often puts them in conflict with provider-led control of interactions and explains evidence of resistance to provider-led interactions through the introduction of customisation.

9.4 Conclusion

This chapter discussed patient-centred value co-creation by disadvantaged healthcare consumers mixing use of SST and multichannel healthcare services. It explains the distinctive context of healthcare services particularly as it relates to chronic disease. A full discussion of the implications of value co-creation processes in light of institutional arrangements takes place in order that disadvantaged patients with limited choice and resource-endowments use SST to manage their relationships with healthcare providers.

By showing cases of interdependency of values and resources, the study showed how very ill patients in dynamic circumstances of illness and recovery are able to co-create personalised alternative service experiences, and can exert choice with some efficacy, without having to choose permanent exit. These findings relate to the role of SST in the co-production of service failure and service recovery (Ostrom et al. 2014). Although these concepts are not central to the current scope of the thesis, they highlight avenues for further research.

What the study implies is that the theoretically contradicting values between objective and subjective positions are perhaps not in conflict all of the time but that patient experience involves focusing on occasions when there is friction, especially when there is a suspicion of clinical or functional error or suboptimal outcomes as a result of the interaction (treatment event(s)) and that these instances seem to be both front-of-mind and long-lasting for patients when they reflect on their healthcare options. This may suggest that patients who are asked about satisfaction with a specific treatment event may be taking the opportunity to feed back about their general experience as patients. This may be interpreted as highlighting the extent that the interview situation is a moment during which patients are situationally more reflective about their experiences, and provides opportunities to articulate their hopes for ensuing action if they are endowed with access to the relevant resources to act autonomously.

The conflict of values emerging in the data can be understood as determined by structurally embedded networks of interactions, which may spark more active resource integration in order to assert subjective values over system values, but also show that subjective values are always engaged as a meaning-making interpretive reference with which to understand service experiences, even when patients are most resource-depleted. Hence, although access to physical resources are important because they affect cultural-cognitive and social resource endowments, it is argued that

access to the cultural-cognitive resource that enables value judgements is the most important 'necessary condition' for engagement in the process of value co-creation – even if little actual value is co-created, i.e. the patient does not feel they receive appropriate care. Telehealth is shown to enable patients to enhance their cultural-cognitive resources, by improving their personalised health literacy to understand their experiences and assess what is required for ensuing action in their relationship with providers. By exploiting the available technological resources, telehealth enables disadvantaged patients to exert more control over their care in the endogenous environment of SST in order to regain some control within the exogenous environment of full-service interactions.

The findings suggest that patients' shift between contextualised identities occurs regularly as a result of illness experiences, how they are evaluated, and what access to available resources affects the evaluation of the experience and their ensuing action in the short-term and long term relationship. 'Seamless' patient experience is abrogated by the 'movement' between the service environments in which interactions occur under the influence of institutional arrangements. We may consider the four approaches to value co-creation with telehealth as evidence of patients' strategic forward planning in order to cope with discontinuity of care experiences, and the situational influence making a 'loyal' customer relationship (even with service providers who evidently co-destroy patient value at the same time as they co-produce provider value) the best option for subjective value co-creation in the absence of viable alternatives.

The patient-provider relationship is complicated further by the inevitably diminishing returns in the long-term value that a chronic disease patient is probabilistically going to experience. Patients are not structurally enabled to control decisions regarding further access to scarce healthcare resources due to the hierarchical relationship with providers, which is sustained on clinical information asymmetries. This clinical knowledge is highly valued by the healthcare system; it can be argued that it is the core of the bureaucratic system that sustains healthcare as an expert service. What chronic comorbid patients 'know' experientially is that clinical knowledge, and clinically valued outcomes are object-oriented, objectively determined, and regularly may attempt to reject subjective input unless it is used to validate the object-oriented diagnostic process (Doyle et al. 2013). This means that choice to comply or resist, to accept or deny, is constrained because there are few real alternative providers that these patients can access especially while they inhabit the clinical setting. However, where they can exert their preferences to regain autonomy is through the use of telehealth in the lifeworld, especially when using customisation processes. It seems that access to telehealth as an intermediary service channel better enables users to exert control over the timing and outcome of responses to their subjectively perceived need compared to not having access to telehealth.

Chapter 10 Conclusion

This chapter reflects on and draws together the key contributions of the core thesis of the PhD, and summarises its contribution to theory, methods and practice. This is followed by a discussion of areas for future research and ends the chapter with closing remarks.

10.1 Thesis summary

The study set out to investigate patient experience of telehealth among complex comorbid patients. The core thesis of the PhD argues that telehealth is valued as a resource to influence an iterative patient experience of illness and recovery involving healthcare service interactions. Telehealth is a resource that is contextualised to this iterative experience which structurally conditions patients' access to resources as well as orienting their goals. Patient experience is therefore a key determinant of value. Figure 19 depicts the patient-centred process describing the way experience structurally conditions structural interactions both before, during and after effortful resource integration processes determining the value of outcomes.

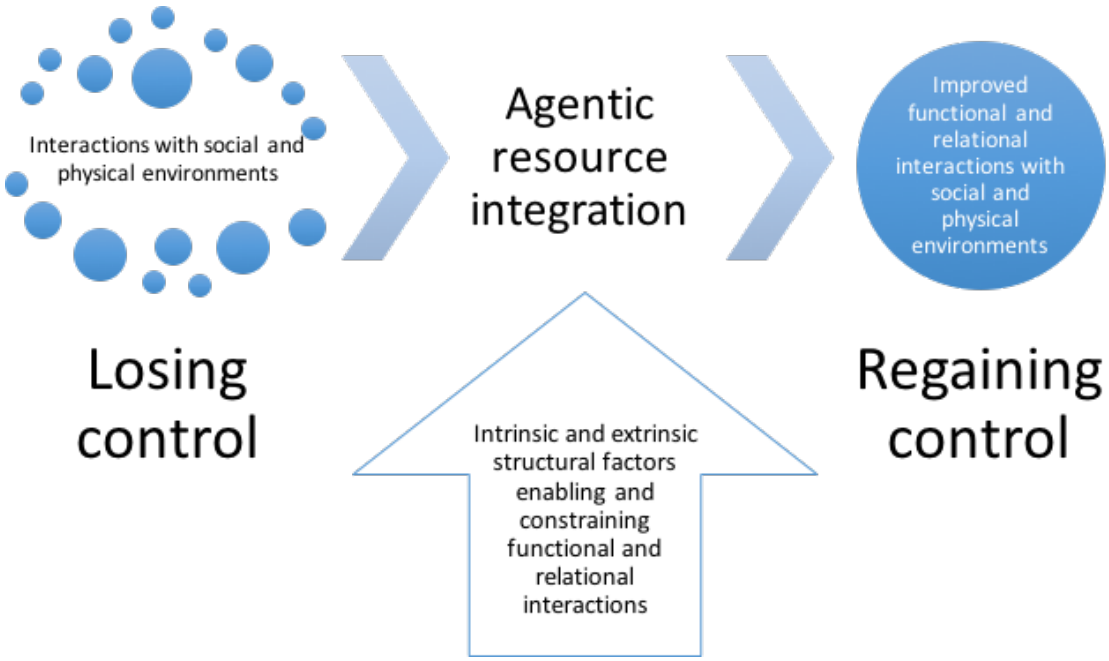


FIGURE 19 PATIENT EXPERIENCE AND ACTIONS TOWARD ACHIEVING OUTCOMES OF VALUE (ORIGINAL WORK)

In evidencing participants' preoccupation with minimising experiences of losing control, the study shows the experience of losing control to be linked to an inability to function in familiar physical and social environments. Perception of poor functioning is contextualised to their previous interactions with familiar environments and situations, making them aware of a deficit of capability

and requirement for assistance, conceptualised as perceived need. Thus patients are confronted with the emergence of unfamiliar problems that surface and make their intention to achieve life projects and obligations that matter to them difficult to fulfil. Furthermore, the thesis suggests that based on observations that participants are adept consumers of health-related assistive technologies it is argued that technology consumption is highly contextualised to a personal purpose: to help them regain control over potential harm posed by their physical and social environments and recover normal functioning (Section 6.2.1).

The thesis therefore suggests that telehealth is normalised by their typical technology consumption experiences, and thus it is posited that telehealth is similarly contextualised to the patient's efforts to regain control. As previously explained, control is not a concept limited to a psychological understanding (e.g. Adler 1930 in Burger 1992), it also relates to sociopolitical power over constituents, thus it has a sociological association that is consistent with the concept of determination and governance, which is relevant to technological architecture controlling users through designed interfaces (Pinch & Oudshoorn 2003). Thus, as the thesis focuses on the unit of analysis at the micro level investigating user-machine interactions, incorporating sometimes directly observed but always indirectly provided through narratives detailing aspects of their interactions with human elements of the service, it is prudent to clarify that the thesis does not claim to find sufficient evidence that patients achieve control over situations beyond what is supported by the findings, i.e. that they do evidence a certain level of technical mastery over fickle machines whereby, problematic usage due to unpredictable machines showed patients regularly establish a limited situational control through customisation sufficient to co-produce the telehealth service protocol.

When considering evidence that telehealth use is oriented toward influencing their healthcare providers' responses and providing data which they understand will be used as decision-making criteria, an empirically grounded retroductive analysis posits that telehealth's role as a resource for value co-creation suggests that patient value is oriented toward assuming a degree of relational control at the meso level. Hence, the thesis suggests that social acts of telehealth and other healthcare services consumption can be classified as social acts by social actors structurally elaborating new forms of patient-led service interactions (Chapters 7 and 8). Control over social and physical environments as an issue and a priority is evidenced to be highly pertinent to healthcare service interactions and colours their relationships with healthcare providers (Chapters 6 and 7).

The exploratory study findings evidence that multiply resource-constrained consumers make agentic use of SST in multichannel services in processes that are transgressive of institutionally deterministic (strong form) and directive or provider-led (weak form) service interaction designs (Chapters 6 and 8). This is interpreted as showing signs of structurally disruptive tendencies if the

enabling conditions are met and supported to be maintained. Drawing on the value alignment literature employing the strategic action fields metaphor (Skålén, Aal, et al. 2015), theory suggests that the service system may be transformed by consumers constructing new market opportunities for alternative providers to cater to emergent demands (Venkatesh & Peñaloza 2010). Speculating from the findings points to a future prospect where prevention efforts can tip the balance from overdependence on paternalistic full-service designs only paying lip-service to patient choice but providing few endogenous service channel affordances for its exercise. Multiple service channels are shown to provide affordances where patients coalesce to exert their autonomy to suit their preferences.

10.2 Theoretical contributions

The overarching aim of the thesis was to contribute to theory on the management issue of unsustainable demand for chronic disease care services. This task involved conducting a case study focusing on user experiences of telehealth to improve preventative self-care. By framing the study to investigate patient experience of telehealth in order to understand the factors that encourage or impede their use, the thesis explains the structural conditions determining agentic use and benefit from the understudied patient perspective and forms the basis of managerial and policy recommendations.

The thesis considers issues characterising an understudied consumer segment to study innovative technology-based service designs. This enabled consideration of the applicability of theories of behaviour and interaction that tend to assume abilities and capabilities of mainstream population segments. Although it may appear that the thesis addresses a niche market addressing the intrinsic value of capturing the neglected patient voice, with the chronic disease epidemic forecast to grow with implications on population well-being, the findings from this research are relevant for the majority.

The thesis contributes by providing novel empirical and theoretical insights about complex, chronic comorbid patients. This is important for two reasons. Telehealth is unusual for its level of patient participation in the co-production of the service processes and outcomes than is usual in full-service, face-to-face healthcare designs, and the user groups targeted are characterised by physical and functional disability. Therefore, the thesis addresses research gaps because vulnerable and disadvantaged user groups are under-studied consumer segments (Rosenbaum et al. 2015) and there has been little theoretical development to progress a long-held sociological understanding of chronic conditions (Rogers 2011).

The thesis relates to broad debates in management theory establishing the benefits of co-opting customers into the process of customising the goods and services offered, arguing that these create firm benefits in terms of competitiveness and sustainability (Sections 3.2, 3.3, and 3.5). The

management literature also advances the normative view that making customers endogenous to firm processes improves firm performance, by assuming this is enabled by close alignment between firm value and customer value, often described as increasing a firm's market orientation (Section 3.5). These management assumptions are known to be complicated further by being contextualised to the healthcare service sector. Distinguishing characteristics of the healthcare context include patients being ill, providers being stressed, and that provider and patient value alignment is potentially problematised by the perception of healthcare as a negative service, therefore, what the patient wants is not always commensurate with what the patient needs (Chapters 7 and 9). This means heterogeneous perspectives of value potentially split the patient-provider dyad (Chapter 7) undermining normative alignment as a driver of 'loyalty' and occasioning the search for market alternatives.

Firstly, although claims to heterogeneity are often countered by professional factors that unify provider and patient interests around the ideal of patient benefit, many fields of study into this relationship have long argued that conflicting interests regularly introduce tensions that prevent the realisation of patient benefit through collaborative, co-productive interactions (Sections 2.2, 9.1). Secondly, there are few viable alternatives for healthcare services, and this is exacerbated by the relative homogeneity of organisational culture among medical care providers (discounting complementary and alternative medicine providers) that guides and authorises them according to standard regulatory frameworks resulting in little actual variation in the biomedically established approach to service provision. Therefore, patient choice as an analog of consumer choice requires close investigation and the thesis contributes evidence of patients' choice to continue collaborating with their providers using telehealth despite effortful and resource intensive user experiences and as articulation of preference between multichannel service options and exit/withdrawal to improve their care for better functional outcomes (Chapters 6, 8 and 9).

10.2.1 Healthcare management literature

The thesis 'speaks to' the healthcare literature by addressing debates between epistemological approaches. By developing an alternative philosophical, methodological and epistemological approach combining marketing and critical realist perspectives, the thesis is able to integrate extant knowledge and address the fundamental research questions that hold them in tension.

As transformation of healthcare systems to meet growing demand for chronic disease care is likely to be a gradual process, the practical need to support more and better quality patient participation in their self-care is inevitable. Thus, we have much to learn from patients who are in the vanguard of managing their own transition from treatment to prevention approaches by availing themselves of SST to play a part in safely reducing overall demand for full-service healthcare. Important lessons can be gleaned from the study's findings about the interplay between service experiences in multichannel services, and how a highly institutionalised provider-led service can be customised by socioculturally and physiologically disempowered service users by studying how they integrate various provider resources to co-create a greater proportion of subjective patient value from their clinical interactions. Through customising the user-service interaction, home-based SST enables patients to assume limited amounts of control within an otherwise constraining healthcare service structure.

By carefully conceptualising the research problem through the integrated literature review, the research was designed to link glimpses of participants' narrative interpretations of their observed actions, enabling evidence of theoretically-grounded patient agency to surface. This was framed as an active experiencing process, suggesting that experience of service interactions is both a value process and a value outcome or resource for further onward integration in continuous, related processes of value co-creation. The thesis suggests that the extent that the participants are able to effectively co-create their sought after outcome or goal, which characteristically involves regaining controlled independence through experiencing autonomy in their interactions with their environments – whether lifeworld or healthcare service orientated – is observable. Although it may be of short duration due to the complex illness experience, it is critical for patients' ability to cope with chronic illness effectively.

The particular study context makes it important for the thesis to acknowledge both the limits of this agentic view of patient-led control in an otherwise highly structured interaction – whether that be through designed technology interface or the designed service encounter as it is informed by a biomedical approach (Engel 1977). This accounts for patients being positioned by service structures to deny, delay, deflect and defend themselves from various negative implications of treatments and interactions. These actions underpin the four approaches to value co-creation that mean patients are attempting to control access to healthcare system processes. They engage in these processes because

they lack alternatives. This is because previous life events have structurally conditioned them to expect that they will be in a situation of need for formal healthcare services even though it involves ceding control and immersion in a system rationality that is unpleasant and disorientating according to the lifeworld rationality. This is conceptualised as negative patient value.

10.2.2 Marketing literature

The thesis makes incremental theoretical contributions to marketing thought in the still nascent research area of SST. It does this by integrating contextual issues from its use in the healthcare sector and contributing insights from sociology-based literature to encourage a focus on experience rather than use to explain adoption behaviours. By drawing on the key concepts of the S-DL, the thesis is able to add to key debates that emerge from that area of scholarship and apply it to contribute insight regarding resource implications and institutional arrangements affecting SST in multichannel services.

The thesis contributes to SST research by drawing upon the literature on technology consumption describing coping behaviours resulting from divergence between expected and actual use. Expectations about interactions and benefits of technology use are socially constructed (Kozinets 2008), and divergent consumption experiences trigger adaptations and plans for ensuing action to avoid or confrontatively cope so that subsequent experiences improve (Mick et al. 1998). Not only does the thesis confirm that it is wrong to assume a linear relationship between design and user experience (Schwartz Cowan 1985; Pinch & Oudshoorn 2003), it underscores the importance of patient perspectives and actual user experiences in order to understand invisible processes and non-economic cost implications of using SST.

In suggesting that actual use of SST can result in satisfaction, delight or disappointment from expectations (Ostrom et al. 2014), the thesis shows that these cognitive and affective responses partially influence ensuing consumption decisions. Although avoidance may be a strong affective response to poor functional and relational outcomes from service interactions, high probability of urgent care needs in the future maintain their relative dependency on the healthcare service as their condition worsens, hampering their access to resources for self-care. Manifold structural constraints do affect patient agency, which the thesis suggests may be morphostatic, reproducing the provider-dominant relationship when there is no viable alternative other than ceding control[12] over their bodies in order to co-create patient value. Therefore, SST are shown to play a part not only in

[12] In this sense control has an extrinsic political dimension, as in the exercise of control over another constituent in an organisational arrangement, although it is often understood as a social psychological (Adler (1930) in Burger 1992) construct, where humans respond well to having control in one's own environment, suggesting control is intrinsically necessary. In mentioning both examples, we refer to its salience to a person in context, which is consistent with the thesis' sociological approach focusing on structure-agency interactions.

service recovery but patient-led relationship management through maintaining a safe distance from immersive experiences that detract from patient value co-creation.

Despite the aforementioned structural constraints, the thesis suggests participants come to accrue resources upon which they draw for value co-creation with telehealth and wider services. The study finds that these are related to actions domesticating fickle machines and stabilising health conditions (e.g. to combat anxiety about interpreting vital signs) as they recover from a health crisis or treatment. These processes result in topping up physical (including emotional, as indicated by Arnould et al.'s (2006) framework, as well as physiologically-influenced mood, concentration, cognitive clarity and focus) and social (patience, ability to communicate) resources in order that cultural-cognitive resources can be deployed in 'clinicised' self-care routines with telehealth. Construction of these resources are argued to emerge from latter stages of experiencing in the 'post-consumption' stage of reflecting and understanding 'what happens to them' and 'what happens when', which suggests growing knowledge of the system rationality, (e.g. adopting a clinicised view of their bodies through Translation I), thereby accepting and domesticating the diagnostic clinical lens as an outcome of learning through consumption experiences (Hibbert et al. 2012), which helps them regain control over their lives in masterful ways through creative labour (Huws 2010). In recognising their customising actions in a positive light, rather than seeing them, for example, as risky, maladaptive behaviours from the misuse of telehealth equipment and manipulation of objective patient data to get services to respond to their subjectively perceived need, it is possible to suggest that in co-creating the overall strategic aim of reducing demand for emergency hospital admissions, these unexpected routes to achieving a convergent form of patient and provider value can be encouraged, improved and supported. The thesis provides the germ for further research, in order to consider whether patient-centred outcomes clash with provider-valued outcomes in a way that is complementary or more fundamentally challenging to incumbents in strategic action fields (Skålén, Aal, et al. 2015) leading to potentially transforming service systems from the bottom up.

In addition to revising passive perspectives of patient experience and recognising patient agency at different stages of service consumption (pre-, during and post-interaction), the thesis contributes a nuanced view to the debate showing particular conditions when patient autonomy is emergent in SST, and still pays heed to warnings about the negative connotations of 'responsibilization' in the governmentality and marketing literature (Giesler & Veresiu 2014; Anderson et al. 2016), by arguing that choice and autonomy are beneficial to patients precisely because extrinsic pressures on healthcare systems force full-service designs to defend and sustain institutionalised self-interest (provider value) at the expense of providing holistic patient value.

If external forces further entrench provider-led object-oriented service interactions, the thesis suggests patient value may be better served by a mix of SST and full-service use at the discretion of patients. This view suggests moreover that tight multichannel integration needs to be considered as potentially co-destroying value, especially when organisational culture systematically denigrates customer value as a negative service. The thesis suggests that micro-institutional affordances (van Dijk et al. 2011) in organisational culture are found within self-service channels that can be exploited by users to suit their preferences and enhance their experiences, especially when they exceed the benefit that can be derived from full-service (Ostrom et al. 2014).

With reference to S-DL, the thesis provides empirical evidence that even disadvantaged consumers always co-create value as beneficiaries in a highly institutionalised service structure, even with services that may be understood to systematically destroy aspects of patient value due to different priorities and value systems. Patients are seen to use SST for prolonged service recovery processes where there is no viable alternative. Patient value relates to managing provider relationships by spanning the distance between non-aligned value determined by service and lifeworld rationalities.

10.3 Contribution 1 : Determinants of patient value

Patient experience is frequently linked to the concept of patient value in the healthcare literature using health economist approaches underpinned by rational choice assumptions about the pursuit of individual value or psychological accounts of satisfaction. The thesis contributes a novel conceptualisation of patient value as limited autonomy regained through the exercise of choice. Choice is constrained and enabled by their personal and situational resource endowments. Personal is conceptualised as primarily cultural-cognitive understanding (but also includes access to physical, social and operand resources), and situational includes the access to appropriate care provided by healthcare services in order that they may be integrated to achieve personal goals and life projects. Goals are not only and always observed to be directed toward individual value, as there is empirical evidence of mutuality of benefit, or collective benefit in the cases studied.

10.4 Contribution 2: Evidence of patient agency

In arguing against the ontology of patients as passive, it was important to provide robust evidence of patient agency, which has implications for wider debates about interventions to support chronic disease self-care and/or addressing care needs by focusing on amplifying the ability of providers to deliver good quality patient care in pressurised healthcare services for sustainable healthcare systems. This is relevant to the fields of healthcare and marketing, where the thesis contributes to debates about customer participation (Bitner et al. 1997), the difficulty of experience management (Palmer 2010), and the illusion of choice among disadvantaged consumers (Sirgy et al. 2011; Mol 2008). It is also highly relevant to the current context of economic austerity shrinking public services and increasing governmentality among citizens to expect self-improvement (Rose &

Wickham 1993), where politics saturated with consumerist ideologies advocate for the importance of individual choice in all areas of life, including healthcare (Sulkunen 2009).

The thesis contributes to these debates by evidencing that when complex chronic comorbid patients are given a choice of three options: STS, full-service, or exit/withdrawal, they make decisions on the basis of their understanding of their condition in the context of their lifeworld and the healthcare service system, thus their decisions are not only driven by affect but are argued to have a cultural-cognitive dimension because telehealth is an instrumentally valuable resource for users. The concept of positive patient value from using telehealth is derived from exerting their autonomy, which is natural to the lifeworld, and is implied in their decision to accept trade-offs of effortful resource integration with telehealth compared to more intensive resource integration and less lifeworld value co-created with full-service channel options. This suggests that choice between service channel options to evince patient autonomy is highly relevant to patient value.

It also highlights the important role of providing support to patients to access the necessary resources to exert agency in order to achieve the goals that are important to them – which are shown to include the shared strategic aim to reduce need for emergency hospitalisation, as well as co-creating mutual and collective benefit when they are able. By showing that disadvantaged patients exhibit choice between service channels to suit their context-driven priorities, and that these contexts determine the value from the service consumption experience, the thesis is able to suggest that despite high barriers of institutionalised information asymmetry, participants are able to choose the channel (or combinations thereof) that has greater probability of suiting their holistic needs. The thesis' evidence is not suggested to support a rational choice theory, however, as there is evidence that patients sometimes seek to co-create mutual benefit as a goal. Neither should the evidence be construed to suggest that providing poor service automatically results in motivation and focus to improve self-care, as evidence of participants finding themselves adopting Alternative Seeking and Care Seeking behaviours show that under-resourced patients expend their limited resources trying to address their current care arrangements's failure to meet subjectively perceived need.

Overwhelmingly, the story that emerges from the data is of a person in context, where patient narratives and actions are interpreted as actors and environments interacting. The context of telehealth use is a lifeworld where patients are experienced technology consumers adept at customising to regain control over the environment in the way they perceive is necessary. Necessity and goal formation is determined by context which is conceptualised as the individual's resource endowment, and that is structured by their experiences. Context is also the environment in and with which they interact.

Service channels are shown to contextualise each other, where preference for one is argued to relate to the perceived extent that the relevant socio-technical system's value is adequately aligned with

the patient's lifeworld values. Value alignment shifts with patients' perceived need, as participants are shown occasionally to forgo lifeworld value as they cede control over their bodies and their autonomy in order to co-create predominantly provider value in full-service interactions.

Telehealth provides an opportunity to choose between three options, whereas hypothetically there were two: comply or exit. The first option is full-service immersion in provider control which pays lip-service to patient autonomy (O'Neill 2001). The second is SST that enables the pretense of provider control to be upheld as users manage their provider relationships by appearing outwardly compliant, while enacting resistance through customisation. This is an expression of user autonomy to dictate terms of their interaction with healthcare services (e.g. what data to send, when, how and if the purpose is for more or less help). The third option is exit/withdrawal, which is the ultimate expression of autonomy but likely to result in subjectively and objectively poorer outcomes.

10.5 Contribution 3: Value co-creation with SST in multichannel services

In redefining patient experience to assume patient agency, the thesis engages with debates among marketing scholars analysing structural implications on consumption decisions in order to clarify the relationship between structure and agency for value co-creation (Edvardsson, Tronvoll, et al. 2011; Edvardsson et al. 2014; Vargo & Lusch 2016). It does this by comprehensively arguing for a more nuanced, resource-based explanation for the emergence of patient agency toward increased autonomy in dynamic personal and situational conditions that trigger different perceived needs leading to highly personalised determinants of value. The thesis suggests that interactions are structured by socio-historically embedded provider-led relationship dynamics, and that patients may exert resistance to the relationship without rejecting it entirely through telehealth, thereby maintaining heterogeneity without necessarily creating a cohesive whole (Arnould & Thompson 2015).

Agency is assumed in value co-creation as explained by CCT's experiential perspective of consumption (Arnould et al. 2006; Peñaloza & Venkatesh 2006). Agency is a necessary condition for interaction and also structures the process of experiencing as culturally embedded meaning making and value determining, which is used to explain how consumers are constructed by and construct markets (Penaloza & Venkatesh 2006). Patient experience of healthcare service consumption, therefore, is shown to be a condition that contextualises the use and individual determination of phenomenological value from using telehealth services. Telehealth use in certain circumstances provides the necessary and sufficient conditions to trigger co-creation of subjective value by making the ensuing telehealth and full-service interactions subjectively oriented. Value co-creation is constrained by resource availability that describes circumstances or conditions where patient experience has not resulted in the emergence of subjectively perceived value, e.g. when patients fail to gain understanding about their own condition or the structure of healthcare service

interactions. Thus customer-learning to improve self-knowledge and system knowledge are enhanced capabilities necessary for more effective value co-creation (Hibbert et al. 2012).

More effective value co-creation occurs within the endogenous service environment of telehealth, and then aimed at influencing the exogenous structure of healthcare interactions in multichannel services, as well as in the social superstructure that upholds system rationality, by legitimising clinically valuable outcomes as evidence, and only latterly subjective patient reports of functional outcomes to the extent that they are validated by other forms of objective evidence. The thesis suggests that through telehealth and the observed influence on wider healthcare interactions, patients agentically engage in structural elaboration. It is reasonable to argue that this is reflective of bottom-up transformation of healthcare services at the micro level of patient-provider interactions. Such evidence suggests attempts to transform service structures should not only consider top-down approaches to restructuring the provider's organisational culture or other social networks. Indeed, given the tendency for user customisation evidenced in the study, engaging patients more directly to use service channels in order to customise experiences may be a more effective way to trigger market orientation, by inviting users to deviate from expected interactions with highly structured services as necessary, creating market pull for system transformation.

10.6 Methodological implications

From inception, the purpose of the PhD was to study the patient perspective of innovative technologies to improve self-care in a way that alleviated the burden of managing life with chronic disease. Focusing on patient experience as an approach helped to anchor the qualitative study using language commonly valued by healthcare management audiences.

In order to contribute rigorously to the patient experience literature, it was necessary to build interdisciplinary 'bridges' to transport theoretical frameworks and perspectives, treating healthcare as more than a research context, but an area of the academy with a significant epistemological tradition and ontological assumptions. Doing the philosophical underlabouring using immanent critique enabled identification of a central paradox that, given the provider bias structuring the disciplinary research culture, could not be addressed through continuing to take for granted disciplinary assumptions about the ontology of patient agency and the underlying logic of the healthcare service. In attempting to improve the construct validity of patient experience research as respectful of the intrinsic value of obtaining patient perspectives, it was possible to build an alternative conceptual framework for patient-centred patient experience founded upon marketing theoretical perspectives on the structural influences on individual acts and agency through telehealth use. Thus, by considering the concept of experience as a verb rather than an event, the framework draws on realist understanding of patient agency in context to address assumptions

about patients being passive according to a biomedical approach to healthcare, where clinicians are assumed to have agency.

Integrating a S-DL perspective of healthcare services as involving actors and always including beneficiaries (Vargo & Lusch 2016), complements the widely accepted biopsychosocial theory of health and illness (Engel 1978), as patients are assumed to collaborate in healthcare outcomes, co-creating services and the value that results together with providers through intersubjective interactions (Löbler 2011). In order to pay heed to literature on professional power that resists a strong form of individualist patient agency, and favours holist structurationist theories, it seemed reasonable to occupy the middle ground by integrating socio-cultural perspectives of consumption and value from CCT scholarship, to provide scope to consider the interplay between agency and structure equitably. Following a commitment to trialling the marketing perspective enabled the conceptualisation of telehealth as a SST, the purpose was not to draw similarities between telehealth and a grocery self-checkout, for example, but in order to substantiate the provider and user perspectives as differentiatable. By underscoring the importance of intended use and actual use, it outlines the relationship between providers and patients as potentially influencing each others' value generation, and also adds contextual depth to actors' interactions through use.

This series of linked philosophical, methodological, and epistemological shifts enabled the multiple case study within a single case study research design to successfully achieve the research aim and deliver the research objectives identified through the literature review. The outcome is empirically-grounded insights built upon a foundation of internally valid patient-centred constructs. Internal and construct validity is ensured through integrating analytical methods that iteratively and systematically checked data for reliability and validity through robust systematic comparison between multiple cases, and interview and observation data, the novel conceptualisation contributes novel findings that explicitly question prevailing assumptions in several literatures. The benefits of adding participant observation to the research design improved the validity of the data immeasurably because it highlighted how participant narratives only told part of the story of their use experiences.

10.7 Limitations and future research

10.7.1 Limitations

By considering the consumption literature describing a resource integration process (Baron & Harris 2008; Hibbert et al. 2012), the thesis integrates a resource-based view of value generation (Vargo & Lusch 2004; 2008; Arnould et al. 2006), and a process orientation that assumes a temporally ordered assembly of inputs that condition the mechanisms of interaction, which are the determinants of outcomes (Section 4.3.6). As process theories are not variance based models, the contribution to knowledge that emerges from this empirical investigation and theorisation does not purport to explain causal relationships for prediction, adding to key debates about what theory is and how it evolves. Process theory suggests that the study evidences the relationships between some of the 'discrete states' and 'events' where 'the process at issue is a probabilistic conjunction of two or more specified phenomena' (Mohr 1982, p.50). This meant the conceptual framework was equipped to consider telehealth use as involving accessing and integrating relevant resources with a view to investigating the value that emerges (Chapter 8) and also to conjecture about the role of patient agency and experience of telehealth in structural change and healthcare system transformation described in the CCM (Figure 1). This suggests that future research to develop a testable hypothesis, for example trialling different forms of guidance or training intervention (e.g. in-person or virtual) to evalute which supports effective value co-creation through service channel selection, would need to develop a variance theoretical model with predictive capability developing upon the theoretical stance elaborated in this thesis.

Typically studies of the influence of an intervention on existing service relationships employ longitudinal research designs to establish a baseline or use extended exposure case studies to evaluate impact during the study and adduce causality. This was not possible due to practical constraints of the PhD and vulnerable participant characteristics. Instead, using a narrative strategy for process analysis enabled the consideration of temporal ordering of interactions. Through logical and systematic retroduction the thesis was able to explain how processes suggest that subjective value could be achieved – although it was not directly observed – based on the cross-case analysis. This was because participants were interpreted as being constantly mid-process of co-creating value at many levels simultaneously depending on the context of interaction. We discussed two such contexts: the telehealth SST and the full-service provider relationships that surrounds it, and signposted other contextual (f)actors influencing the telehealth service ecosystem, such as social support networks, commercial services, assistive technologies etc. that were being 'consumed' in order to meet subjectively perceived needs. The validity of the thesis findings about the realisation of patient benefit through SST would benefit from replication using longitudinal research designs in order to gain specificity about changes in certain user characteristics.

The validity of the findings is subject to self-selection bias although this was controlled to the extent possible by ensuring heterogeneity of sample demographics and experience, including participants expressing dissatisfaction and intention to withdraw from the service. As a small scale exploratory study, the findings do not claim statistical generalizability to populations. Sampling adequacy to address the research questions was achieved and 38% response rate is argued to reflect experiences among current users in the case study. Given the positivist bias in healthcare research, the validity and impact of the findings on practice could be strengthened through integrating the thesis' theoretical stance using an experimental randomised controlled trial design.

Participant validation of findings was not part of the research design due to sensitivity about burdening vulnerable patients and this is a weakness of the study. Future research needs to address this issue more creatively by making use of alternative methods (like patient and public involvement and engagement groups) to systematically access feedback.

10.7.2 Future research

The thesis generates new questions about how to generate impact from this research. For example, how can the conceptual framework from this exploratory study be elaborated into testable hypotheses to enable experimental designs whose findings are more easily translatable to healthcare practice? In order to make measuring instruments more patient-centric, co-design of the questionnaires from concepts and language for clarity and specificity, for example to distinguish experience as event and experience as action when evaluating fulfilment of expectation and adaptations required, could help to prompt for patient-centred issues relevant to complex chronic comorbid patients. Further research could attempt purposive integration of patient-centred value determinants, such as clinical, functional and relational value, together with current approaches to patient experience and informal care measurement development.

The thesis provides insight for managers and health economists about the flow of non-economic costs and perceived health benefits to patients when using telehealth services. How can this research inform new valuation methods and move the framing of value from focusing on provider value toward more equitable distribution of dyadic value? What would be the effects on system rationality of translating identified non-economic costs and benefits into economic equivalents? Are objectively calculated clinical and monetary and subjectively experiential non-monetary value determinations integratable? Further research could explore the extent that increased patient autonomy and reduced secondary care utilisation through telehealth use results in better patient outcomes when measured using clinical value determinants. This could help determine the implications of identified divergence between patient and provider value on patients' outcomes.

The theoretical perspective can be applied to any contexts where there is a problem of unsustainable consumption by disempowered service users with few viable alternatives but opportunities to

choose among multichannel options. In education, for example, students are tied into using the technological systems provided by universities which have institutionalised outcomes of value driving interactions. How do they co-create subjective value?

Further research to test the applicability of the findings in a different context of telehealth use for a different type of user group facing different resource and service structure constraints on agency are needed. Examples include parents of sick children trying to get diagnostics or antibiotics prescriptions, or uptake of consumer-driven mobile health apps in order to get instant access doctor appointments, diagnostic tests, e-prescriptions or second opinions.

10.8 Practical implications

Managerial implications are discussed in three subsections addressing customisation, multichannel services, and strategic market orientation through cultural change.

10.8.1 Embrace customisation

Telehealth providers must recognise that easy-to-use machines and services can be effortful to co-produce and experience. Patients find telehealth services to be beneficial for communicating their care needs more specifically but this comes at a personal cost. The thesis acknowledges that mass produced machines will never be perfectly suitable for the dynamic context of their use by patients with different skills and capabilities and with bodies that are unpredictable. Because telehealth equipment is vulnerable to misuse and it is important for users to integrate their subjective self-reports into healthcare service interactions, customisation is important to user experience and value co-creation, even if self-reports regularly contradict the expectation of objective evidence gathering from clinical monitoring.

Use is influenced by the personal, as presented by the user's physiology, and situational factors, i.e. positioning within a household which may introduce unwanted effects when obtaining vital signs. Some patient practices and their interpretations of vital signs could raise concerns among policy makers that telehealth equipment is being operated and used in ways that are not standardised, however patients succeed in transmitting 'sensible' readings, which shows that the machines and the service can tolerate a high degree of variation. As there are few opportunities for clinicians to observe how patients interact with telehealth in practice, this points to a need for service protocols to regularly obtain feedback on how the equipment is being used and providing additional training where necessary. Suggestions for specific training of telehealth installers to engage users more when responding to reported faults might present opportunities for observing practice as well as checking and refreshing user skills. Improving skills should address use of Any Time Tests, how the diagnostic questions guide clinical decision-making, how to measure pulse manually for patients with atrial fibrillation, and what to do when the blood pressure reading is high.

When the study's findings were reported to telehealth service commissioners, the risk of deviation from expected use triggered concerns and impetus to provide more specific user training to avoid repeat readings. They also resolved to discuss the reliability issues particularly around Bluetooth connectivity with the equipment manufacturers. The service provider response, therefore, was to reassert control over equipment characteristics and patient usage processes and practices in order to avoid any need for patient coping strategies as a precursor to customisation. Yet, the study finds that customisation is a key factor of patient value co-creation, and that optimising the co-production process will be difficult given the experience of fickle machines is partly to do with the equipment but also to do with user characteristics and situational factors, including the wish to avoid hospital experiences due to significant trade-offs.

Patient goals to avoid hospitalisation and improve service interactions by making them more responsive to their needs align with provider goals although they use different routes to achieving them, of which customisation is a major part. Telehealth services are shown to play a part in achieving these goals through patient-led change in service interactions. Telehealth services provide affordances for patient agency to gain some control over decisions about their care by choosing the service channel with which they prefer to interact. Telehealth enables patients to privately customise telehealth processes to reflect their beliefs and concerns about their care without being openly confrontational.

Patients seek control and telehealth helps them to regain control through subtle and invisible means. Regaining control is a highly valued patient experience, especially as they frequently experience losing control and disorientation that changes familiar people, things and spaces into potentially harmful interactions. Provider institutions are challenged to consider how professionals can share control with patients. The extent that patients are dependent on professional expertise means they are prepared to relinquish control when necessary, but that they do this with strong reservations when they distrust that they will be medically treated as objects rather than humanely and empathically.

10.8.2 Provide multichannel service options

Users definitely benefit from a mix of self-service and full-service options. Options for obtaining feedback from a range of experts, including their usual healthcare providers and telehealth equipment specialists, is necessary for patients to continue developing their self-knowledge in more clinically standard ways. Although users are not 'forced' to use self-service, it can be experienced as tantamount to being forced if there are problems and no easily accessible recourse to assistance to help resolve the issues. Equally, when full-service options are experienced as negative, then complex chronic disease patients who have the option of using telehealth, are relatively speaking, forced to continue using it or else exit, which is not viewed by the majority of patients as a good

alternative, unless they are nearing end-of-life. Therefore, telehealth is valued by patients for delivering outcomes that they cannot otherwise access through full-service channels. If there were no additional benefits from self-service, then telehealth use would only be adding effortful work to already intensive self-care regimens.

10.8.3 Strive for an intersubjective organisational culture

Negative patient experience relates to healthcare service interactions when they are object-oriented, and fail to treat patients holistically and respect their humanity and personal beliefs. Providing an indictment of quality of care in hospital settings experienced by complex chronic disease patients suggests that moving patient care to community settings with telehealth can help this user group to avoid neglect and incidental harm from hospital-based care. Telehealth services are shown to help those users who have sufficient access to necessary resources to optimise their community-based care and future hospital-based care according to relational and functional dimensions. Therefore, provision of multichannel services can improve patient experience by respecting patient autonomy without having to depend upon clinicians to improve their intersubjective communication skills and introducing intersubjective processes that do more than pay lip-service to it, e.g. pretending that obtaining administrative evidence of informed consent in provider-led interactions respects patient autonomy (O'Neill 1984; 2001).

It is suggested that it may be beneficial to add relational outcomes of patient experience to the CCM's (Figure 1) clinical and functional outcomes. This could help legitimise recommendations for changing organisational cultures to recognise how the expectation of humane and empathic interactions is fundamental to the realisation of patient value. Adding this outcome to the CCM-based policy could provide the leverage to encourage providers to shift from valuing only object-oriented outcomes toward fostering intersubjective relationships with their patients as a priority. Such a structural shift would mean the organisational culture is more market orientated, holistically addressing the needs of patients as subjects.

10.9 Closing remarks

The thesis succeeded in achieving the original research aim to provide a vehicle for the understudied patient voice to influence theory and practice for their benefit and developing research skills to cope with unexpected issues throughout the research process. From ambitiously identifying significant research gaps and understanding how they frame the scope of the research, the thesis helped in developing research skills for framing, developing and conducting interdisciplinary research in open systems to investigate complex problems.

The path toward conceptualising the research as a 'patient experience study' was serendipitous owing to its designation as such by the local research collaborators. The currency of this term provides fertile ground for this research among NHS commissioners and managers used to

receiving reports on patient experience to guide service quality management (Section 3.1). In designing the research to fit the patient experience label, the thesis is positioned to demonstrate that patient-centred qualitative research is insightful, managerially relevant and potentially impactful for practice (Section 2.3.4).

Patient experience of telehealth services is a perfect context for impactful research for several reasons. Firstly because it adds to a growing a body of work studying patient-centred value co-creation in healthcare services. Secondly, it relates to a growing body of research into technology-based self-services and their relationship with multichannel services management. Thirdly, it is a very clear example of patients co-producing the healthcare service, which has long been mooted in the sociology-based healthcare literature (Stacey 1976; 1984; 1991). This type of work helps to nuance over-reliance on the conceptualisation of patients as resistant to participating in healthcare decision-making due to information asymmetries. In a time characterised by consumerism in an Information Age, it is unsurprising that both patient interest and expectations may be changing, and our ontological and epistemological assumptions must shift to address these changes.

Although it is important to remain dubious about the ethics of expecting resource-constrained patients' capability to self-care in order to justify withdrawal of access to professional full-service care capabilities (Rose & Wickham 1993), the effects of full-service on patient autonomy and the quality of healthcare services under pressure are things that researchers and practitioners must also confront. Therefore, the thesis suggests telehealth has potential to disrupt healthcare services *in a positive way* by providing patients with alternatives to directly avoiding or confronting insuperably high institutional barriers to patient-led interactions and outcomes.

Transforming service systems to provide prevention support over treatment is an ambition significantly constrained by the stark challenge of preventing complications arising from the progression of complex chronic comorbidities once they have developed. Given technological service development, including robotics, however, there is greater scope for more sophisticated technology-enabled self-care to obtain even better self-directed value co-creation, potentially enabling 'market forces' to structurally prioritise consumer-led relational and functional outcomes over clinical outcomes in the case of chronic disease.

On this basis, the thesis argues that patient use of telehealth provides structural opportunities for bottom-up social change for patient benefit. This work has implications for the integration of SST in order to increase empowerment among resource constrained consumers. SST may be considered a route to addressing highly structured service roles upheld by informational barriers, especially in contexts where unsustainable consumption trends seem impossible to reverse without swingeing top-down system transformation.

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Appendix

Additional data sources

The research incorporated sources of data providing an organisational view of the telehealth service:

- work shadow visits and non-participant observations with telehealth support workers and installation engineers
- 2 different healthcare team meetings during the recruitment stage with more than a dozen nurses
- participant observation in 3 x 2-hour assistive technology programme evaluation steering group meetings (average of 6 attendees present each time)
- e-mail exchanges and pre-study meetings with the local research collaborator
- publicly available documents (e.g. brochures and articles presenting patient stories in marketing documents and project reports).
- not-for-public-release interim findings presented by independent external consultants.

In addition, I conducted interviews with key informants (in-person and via telephone) with 9 individuals (1:1) related to healthcare service provision at the clinical delivery, training, operations management and strategic management levels. External perspectives of the service were provided by independent consultants and telehealth service stakeholders who are part of the Assistive Technology Evaluation Steering Group. This corpus of data provided information about the context of telehealth within national and local service priorities and strategies (Table 16).

TABLE 16 ADDITIONAL DATA SOURCES

Study ID / Date	Role	Method	Duration (hrs)
P1	TH Worker	Obs/Interview	2
P2	TH Installer	Obs/Interview	3
P3	TH Installer	Obs/Interview	3
P4	HTA	Obs/Interview	1
P5	HTA	Obs/Interview	1
P6	TH PM	Interview	1.5
P7	Nursing Lecturer	Interview	0.5
P8	Assistant Director Health & Social Care Integration	Interview	0.5
P9	Cardiac Nurse	Telephone calls, informal talks	0.5
02/06/2014	AT Evaluation Steering Group meeting	Participant Observation	2
21/08/2014	AT Evaluation Steering Group meeting	Participant Observation	2
03/12/2014	AT Evaluation Steering Group meeting	Participant Observation	2
2014-2016	Nursing School presentations	Guest lecturer	5
			24

Before contacting participants, a detailed understanding of how the telehealth service operates in practice was sought through work shadow visits and meetings with telehealth workers including:

- 2 x half-day work shadow visits with 2 telehealth installation engineers. This involved meeting at the telehealth and telecare service headquarters, meeting the teams, observing the detailed scheduling of twice weekly telehealth call outs, retrieving equipment from the stock room, and making a total of 10 home visits for various reasons including: collection of equipment from a withdrawn user; installing new equipment; training new clients; responding to faults; and repair and replace call-outs.
- 2 unstructured interviews with NHS Health Technology Assistants to view their use of the Honeywell LifeStream telehealth management system and to hear their account of routine telehealth service interactions and use of response protocols
- 2 unstructured interviews with Nottingham on Call telehealth support workers to view their use of the Docobo Doc@Home telehealth management system and to hear their account of routine telehealth service interactions and use of response protocols
- Telehealth service documents: evolving service protocols, marketing brochures and service reports including patient case studies as testimonials, client information packs
- Restrictions on sharing of confidential data meant contact details for potential participants could not be emailed to the researcher. Physical visits to the telehealth office to collect the completed data sharing consent forms, and occasional telephone calls for further information, provided opportunities for informal interaction with telehealth support workers on an ad hoc basis. These conversations provided an additional understanding of patient status, as well as a chance to observe how remote telehealth support can still be personally engaging and caring in practice. For example, support workers seemed to know the patient's experience of their current health condition as well as their personal situation (e.g. if they were in hospital, on holiday, out of the house early, days their carer came to help with telehealth). This knowledge seemed to enable continuity of social care through personalised remote interactions by telephone.