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THE ROLE OF THE COMMUNITY PHARMACIST IN BREAST CANCER SURVIVORSHIP SERVICES

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Abstract

Background: Breast cancer is one of the most common cancers in the UK and incidence is increasing. Efforts to promote early diagnoses along with advances in treatments mean people are surviving for longer with breast cancer. This, coupled with the long-term treatment requirements of the condition, have created increasing demand for primary care-based services to support survivors. The current role of community pharmacists in cancer services focuses largely on prevention and early diagnosis. However, as one of the most accessible healthcare providers in primary care, community pharmacists have potential scope to take on a more significant role in supporting breast cancer survivors. The aim of this study was to identify the opportunities for community pharmacists to develop their role in providing support and improving health outcomes for people living with and after breast cancer.

Methods: This mixed methods study took a sequential approach with the findings from each phase informing the design of the next. Phase 1 consisted of a retrospective cohort study. National primary care prescribing data from the Clinical Practice Research Datalink was utilised to explore prescribing patterns in current practice and identify potential healthcare needs of breast cancer survivors. Data were analysed using descriptive statistics. Phases 2 to 4 used qualitative approaches to explore the perspectives of breast cancer survivors,

community pharmacists and stakeholders respectively. Phase 2 consisted of focus groups and interviews with survivors, investigating experiences of the breast cancer care received in the community and identifying areas where community pharmacists might have scope to support. In Phase 3, online focus groups were conducted with community pharmacists to explore attitudes and feasibility of new roles or interventions. Phase 4 involved interviews with a range of stakeholders to establish their perspectives on findings and gain insight into future work. Survivor and stakeholder data were digitally audio-recorded, whilst transcripts of the typed discussions from the online community pharmacist focus groups were saved. All qualitative data were analysed using iterative thematic analysis.

Findings: National prescribing data revealed that 53% (n=3084) of adjuvant endocrine therapy users with sufficient follow-up did not complete the recommended five years of treatment as per the national guidance. Frequent switching between endocrine therapies was also a concern, with 32% (n=3930) of users switching up to five times. Both are associated with increased risk of recurrence and mortality. As experts in medicines optimisation, the role of the community pharmacist could be key to tackling this issue. Qualitative findings revealed further care needs of survivors, who reported initial information overload then feeling abandoned post-discharge. Additional information and support was required on a range of clinical, emotional and lifestyle-related issues. Early and regular contact with community pharmacists was

seen as important in improving care experiences. Community pharmacists and stakeholders noted the importance of providing the right information at the right time. Strategies included appropriate signposting, collaborating with other healthcare providers and charities, tackling public perceptions of roles, and building pharmacist confidence. Potentially feasible interventions included incorporating breast cancer into existing advanced services and healthy living pharmacy campaigns.

Conclusions and recommendations: This research has identified considerable scope for community pharmacists to take on a larger role in breast cancer survivorship services, highlighting several potential features of future interventions. Approaches to care should be holistic and person-centred. Increased awareness of survivor care needs amongst community pharmacists is required to encourage proactive conversations with survivors, networking activities and further training. Findings can inform the development of community pharmacy survivorship services and healthcare policy. A more integrated and multidisciplinary approach to care is required, and policymakers and commissioners should consider the benefits of community pharmacy involvement when designing new services and care pathways. Future research should further investigate the feasibility of proposed interventions and consider how they could be incorporated into the changing landscape of pharmacy services.

Publications and conference presentations

Lydia Tutt, Tracey Thornley, Li-Chia Chen, Claire Anderson. Survivor perspectives on the role of the community pharmacist in breast cancer services. 2018. Research in Social and Administrative Pharmacy. 14 (8): p. e31

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Presented as a poster presentation at the Royal Pharmaceutical Society Annual Conference 2016, Birmingham, United Kingdom, 4th September 2016.

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List of Abbreviations

A&E	Accident and Emergency
AHP	Allied Health Professional
AHSN	Academic Health Science Networks
AI	Aromatase Inhibitor
BC	Breast Cancer
ATLAS	Adjuvant Tamoxifen: Longer Against Shorter
BMIP	Boots Macmillan Information Pharmacist
BQUAL	Breast Cancer Quality of Care
CAQDAS	Computer Assisted Qualitative Data Analysis Software
CCG	Clinical Commissioning Group
CCR	Cancer Care Review
CNS	Cancer Nurse Specialist
COPD	Chronic Obstructive Pulmonary Disease
COREQ	COnsolidated criteria for Reporting Qualitative research
CPD	Continuing Professional Development
CPPE	Centre for Pharmacy Postgraduate Education
CPRD	Clinical Practice Research Datalink
e-HNA	Electronic Health Needs Assessment
ER	Oestrogen Receptor
ET	Endocrine Therapy
GP	General Practitioner
HEE	Health Education England

HER	Human Epidermal Growth Factor
HES	Hospital Episode Statistics
HIV	Human Immunodeficiency Virus
HLP	Healthy Living Pharmacy
HNA	Health Needs Assessment
HPV	Human Papillomavirus Virus
HRA	Health Research Authority
HRT	Hormone Replacement Therapy
ICD	International Classification of Diseases
ISAC	Independent Scientific Advisory Committee
LPC	Local Pharmaceutical Committee
MHRA	Medicines and Healthcare products Regulatory Agency
MICa	Macmillan Integrated Cancer
MOST	Multiphase Optimisation Strategy
MPharm	Master of Pharmacy (degree)
MRC	Medical Research Council
MSRG	Macmillan Survivorship Research Group
MUR	Medicines Use Review
NCSI	National Cancer Survivorship Initiative
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NMS	New Medicines Service
NRES	National Research Ethics Service

NSAID	Non-Steroidal Anti-inflammatory Drugs
OTC	Over-the-counter
PAM	Patient Activation Measure
PhD	Doctor of Philosophy (degree)
PPI	Patient and Public Involvement
PR	Progesterone Receptor
QOF	Quality and Outcomes Framework
RCGP	Royal College of General Practitioners
REC	Research Ethics Committee
RPS	Royal Pharmaceutical Society
SRQR	Standards for Reporting Qualitative Research
SSRI	Selective Serotonin Reuptake Inhibitor
SUS	Secondary Uses Service
TCAM	Transfer of Care Around Medicines
UCLH	University College London Hospitals
UK	United Kingdom
US	United States of America
WHO	World Health Organisation

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Chapter 1: Introduction and Background

1 Introduction

Cancer is a condition that affects us all in some way; at some point in their lives everyone is likely to know at least one person who has been diagnosed with cancer. It is also one of the most feared conditions.¹ However, in terms of research, cancer is one of the leading fields. Many advances in treatments and diagnosis techniques have been made over the years and things are starting to improve.² Cancer represents a key priority in terms of healthcare policies.^{3, 4} Worldwide, there is a drive to prevent cancer and improve survival.⁵ Closer to home, policies also focus on improving patient experiences and increasingly, the provision of survivorship care.²

As part of my day-to-day practice as a community pharmacist, I would regularly encounter people living with cancer, as well as cancer survivors. Often, even for those regular customers with whom I thought I had a good professional relationship, I would not realise they had cancer unless they were noticeably ill or started receiving palliative care. This would make me feel terrible and that I should be doing more to support my customers with cancer. Training to become a Boots Macmillan Information Pharmacist provided me with an opportunity to start having meaningful conversations with customers about their cancer. Although I was nervous at first, I began to enjoy the role and it

really sparked my interest in cancer services in community pharmacy. The lack of cancer support in primary care became increasingly obvious with the more time I spent in the role having conversations with survivors, their friends and families. These experiences made me feel that community pharmacists could be doing even more to support these people and this motivated me to eventually become involved in research on the subject.

When this research was conceptualised, the initial scope was very broad – simply aiming to explore cancer in the community pharmacy setting. As the background research got underway I was able to gradually refine this into the research project presented within this thesis. This first chapter sets the scene for this research; outlining the current landscape of cancer in terms of statistics, healthcare policies, current service provision and opportunities for future. It explains how the research question was refined and provides a justification for the focus on the role of the community pharmacist in breast cancer survivorship services.

2 The current picture of cancer

This section introduces the broader topic of cancer; exploring the national and global epidemiology, and United Kingdom (UK) Government strategies to improve health outcomes for cancer.

2.1 The increasing prevalence and incidence of cancer

Cancer is one of the most prevalent conditions worldwide. The World Health Organisation (WHO) reported 18.1 million new cases and 9.6 million deaths from cancer globally in 2018.⁶ Due largely to the increasing and aging global population, cancer incidence is likewise increasing.⁶ It is currently predicted that there will be a 62% increase in new cancer cases globally by 2040.⁷ Although cancer can affect any part of the body, the most common types worldwide are lung, breast and colorectal; which accounted for 11.6%, 11.6% and 10.2% of new cancer cases in 2018 respectively.⁸

In keeping with the global trend, cancer incidence in the UK is also rising, with a 13% increase seen since the early 1990s.⁹ This increase is partly due to improvements in diagnostic methods and screening programmes that result in increased diagnosis of cancer at earlier stages.¹⁰

In 2016, cancer accounted for 28% of all deaths in the UK, which amounted to around 164,000 cancer deaths a year. Meanwhile, data from 2015 reported 360,000 new cancer cases annually. The most common cancers in the UK in 2015 were breast, prostate, lung and bowel, accounting for 15%, 13%, 13% and 12% of UK cancer cases respectively.¹¹

Cancer incidence and prevalence are affected by many factors, such as age, sex and lifestyle choices. Cell repair becomes less efficient with age and this combined with an accumulation of other risk factors leads to an increased risk of cancers.⁵ Lifestyle factors associated with cancer include poor diet, lack of exercise, smoking, increased alcohol intake, obesity, exposure to certain chemicals and pollution, exposure to some cancer causing viruses and infections, and over-exposure to the sun.¹²

2.2 Cancer healthcare policies in the UK

In recent years, the UK government have published several policy documents addressing cancer. The *NHS* [National Health Service] *Cancer Plan* was published in 2000 with the aim of tackling the issue of the country having one of the lowest survival rates in Western Europe. This ten-year strategy made improvements to cancer prevention, encouraged faster referrals and improved access to screening programmes and treatment. As a result, the country's cancer survival rates began to improve.¹³

Building on this, the 2007 *Cancer Reform Strategy* aimed to make UK cancer services among the best in the world by 2012. The Strategy set out to introduce new service models and improve experiences of care throughout the cancer journey. The National Cancer Survivorship Initiative (NCSI) was introduced to improve survivorship care through developing new services and interventions to promote healthy lifestyles,

self-care and education; monitor late effects; detect recurrences; support carers and provide psychological, spiritual and financial support to meet the individual care needs of survivors.¹⁴

In 2011, a new plan for cancer - *Improving Outcomes: A strategy for Cancer* - was published to supersede the *Cancer Reform Strategy*. This new policy acknowledged that, despite the improvements made over the years, national cancer health outcomes remained poor compared to the best European countries, and therefore aimed to reduce the difference in survival figures by 50%, saving 5,000 extra lives per year by 2015.¹⁵

Alongside this, NHS structural reforms aimed to give more power to local communities, healthcare professionals and service users to shape service improvements as required. NHS England was charged with supporting the 221 local Clinical Commissioning Groups to ensure this vision was carried out. ^{14, 15}

Following their establishment in 2007, the NCSI had been working on gathering data at population, health service, and patient levels to help them assess how to better support survivors. In 2013 they released their report on the subject: *Living with and beyond cancer: taking action to improve outcomes*.¹⁶ The key message of the report was to ensure all survivors are offered a package of advice, information and support. The importance of empowering healthcare providers in primary care to

support survivors whilst also empowering survivors themselves to take on a greater role in their own care was highlighted. The document recommended some key interventions that would have a big impact on survivor experience: Structured Holistic Needs Assessments and care planning; treatment summaries, patient education and support events; healthy living and physical activity schemes. These interventions combined are referred to as the Recovery Package (see also section 3.1.4 Survivorship support).¹⁶

By the end of 2014, the fourth annual *Improving Outcomes: A strategy for cancer* report was published; providing an update on how the strategy was progressing. It confirmed that the main aim of the original policy - to save an extra 5,000 lives per year by 2015 – was well on target to be achieved and predicted that the increase in survival rates per year was more likely to be twice this amount; therefore bringing national cancer survival rates closer in line with the best in Europe.¹⁷

A second publication was also released in 2014 that would further shape the national cancer strategy: *The NHS Five Year Forward View*. Due to changing healthcare needs of the national population, including the prevalence of long-term conditions, various advances in treatments and ongoing health inequalities, it was recognised that big changes were required within the NHS to ensure the quality of care delivery and efficient use of funding. The document therefore set out the vision for the future of the NHS and introduced new models of care. In terms of

cancer, the plan called for faster access to diagnoses; care planning and uniform treatment strategies; integrated care services and greater care provision in the community setting including treatment (such as chemotherapy), aftercare and end of life care; and greater focus on cancer prevention through raising awareness of lifestyle factors that increase risk of cancer (such as obesity and smoking).¹⁸

In order to continue the progress in improving national cancer survival rates and ensure the cancer-related plans set out in the Five Year Forward View would be delivered, the Independent Cancer Taskforce was established.¹⁹ Chaired by the Chief Executive of Cancer Research UK, the taskforce comprised of various stakeholders across the healthcare and cancer fields; this included representatives from healthcare professional bodies, cancer charities, local council, various organisations within the Department of Health, and a patient representative. The group, working independently from the NHS, published their own strategy to ensure that cancer outcomes would improve over the subsequent years: *Achieving world-class cancer outcomes: a strategy for England 2015-2020*.²

Importantly, the report noted that each individual cancer patient has a different experience of the cancer journey and therefore encounters different care needs. It recognised the need to improve patient experience and quality of life at all stages of the cancer journey through providing patient-centred care. The report focused on six key areas:

prevention and public health; earlier and faster diagnosis; patient experience; living with and beyond cancer; investments to deliver modern high-quality services; and commissioning, provision and accountability processes.²

The report highlighted the importance of promoting lifestyle changes, such as regular exercise, to reduce the risk of secondary cancers. It recommended that support provided on this topic be tailored to meet the care needs of the individual and summarised in their medical records. Meanwhile, making various improvements to the existing national cancer screening services, along with exploring the potential of additional screening services and continuing to promote and expand the Be Clear on Cancer campaigns (see also section 3.1.2 Diagnosing cancer earlier), would help promote earlier diagnoses. The National Institute for Health and Care Excellence (NICE) had recently introduced new referral guidance for GPs to support with faster diagnoses²⁰. One of the recommendations in the report was therefore to ensure these guidelines were quickly and widely disseminated amongst GPs and, following this, to evaluate the implementation of the guidelines. Establishing funding for diagnostics and improving direct GP access to diagnostic tests were additionally recommended.²

In terms of improving treatment and patient experience, the report highlighted the need to address the issue of access to new cancer drugs; encouraged the future provision of chemotherapy in community

settings; and emphasised the importance of streamlining multidisciplinary processes and piloting integrated care pathways. The importance of assigning a Clinical Nurse Specialist (CNS) to each individual at the point of diagnosis was noted in order to provide support and coordinate their care. Due to the large workload of CNS's, collaborating with local cancer support services was also recommended. One suggestion to facilitate this was that hospitals compile a directory of relevant local organisations and services that patients could be signposted to as required. Another recommendation of the report was that Health Education England take steps to provide mandatory communication training to all NHS staff who interact with cancer patients. Providing opportunities for patients to be involved in research and utilising technology (for example by developing a smart phone app to help patients keep track of their medical records or providing patients with online access to their test results) were also suggested to improve patient experience. The national Cancer Patient Experience survey was noted as an important tool to provide insight into this area. Annual commissioning of the survey was recommended to measure and drive progress.²

Due to reports that survivors required more support within the community setting, the plan made several recommendations to improve survivorship care. This included developing and piloting services to effectively manage cancer treatment; tackling adherence and addressing the long-term consequences of treatment. Community

oncology nurse roles in community pharmacy services were put forward as potential solutions, requiring further exploration and evaluation as part of the new models of care. Other recommendations supported utilising the Recovery Package, particularly Health Needs Assessments (HNAs) (see also section 3.1.4 Survivorship support) to provide patient-centred care and various strategies to support survivors in returning to normal life.²

An important aspect of survivorship support is the provision of care at end of life. The report outlined the need for more patient choice in terms of the care received, along with earlier access to palliative care, which has been shown to reduce symptoms, improve quality of life, and reduce the cost of care. The utilisation of Allied Health Professions (AHPs) was a key part of this; their roles being crucial to integrating health and social care services.² The AHP workforce comprises of 14 groups of healthcare professionals, including physiotherapists, speech therapists, osteopaths, dietitians, paramedics and podiatrists.²¹ Whilst AHPs have a key role in multidisciplinary palliative care teams, their involvement in supporting survivors prior to the palliative stage is often overlooked. It was therefore recommended that new models of care be trialled that allow AHPs to be involved in care earlier in the cancer journey; providing them with the means to support survivors throughout diagnosis, treatment and recovery as well as during end of life care.²

Service commissioning was a key issue for the report. It was recommended that NHS England lay out clear expectations in terms of commissioning cancer services and integrated care pathways. A proposed structure for this was included in the report, which saw primary care services being commissioned on a regional level by NHS England or by individual Clinical Commissioning Groups (CCGs). Survivorship services, meanwhile, would likewise be commissioned locally by the CCGs as part of a strategy to support faster and more straightforward establishment. Another recommendation of the report was that the commissioning of the entire cancer pathway should be piloted in one area initially.²

Research was also a priority within the report, which recognised the importance of Patient and Public Involvement (PPI) activities and identified various topics for future studies. This included how patient experience and quality of life are affected by multimorbidities or long-term consequences of treatment; what issues are faced by survivors; secondary cancers and recurrences; new service pilots, such as those for depression care, post-treatment exercise programmes and assessing the care needs of older people; and establishing a national system to measure quality of life.²

In response to *Achieving world-class cancer outcomes: a strategy for England 2015-2020*, NHS England's National Cancer Transformation Board put together an implementation plan to ensure that the five-year

vision could be successfully achieved. This plan, published in May 2016, was entitled *Achieving world-class cancer outcomes: Taking the strategy forward*.²² Since investment formed an important aspect of the original strategy, a cancer transformation fund was also set up; this set aside an initial £200 million to support its implementation.²³ The National Cancer Transformation Board took on the role of overseeing the implementation of the strategy across the NHS and in addition to this, the National Cancer Advisory Group was established to independently monitor progress.^{19, 22}

The content of the plan was set out under the same six key priorities established in *Achieving world-class cancer outcomes: a strategy for England 2015-2020*. The plan pledged, for example, to ensure patient experience was recognised as being just as important as any other patient outcome. The introduction of the Cancer Alliances aimed to support the drive for improved patient experience at all stages of the cancer journey, through driving change and facilitating the implementation of the national cancer strategy at local level.

Investments have also been made to develop and launch a Cancer Dashboard supporting the collection of a variety of data on cancer survival, patient experience and other relevant outcomes. The data collected can then be used by CCGs and Cancer Alliances to improve local care delivery.²²

In addition to the work of the Cancer Alliances, the national Cancer Vanguard will also add to the growing pool of data on how to improve the delivery of care by exploring new models of care across the whole cancer pathway. The cancer vanguard was set up following the Five Year Forward View as a collaboration between the Christie, University College London Hospital (UCLH) and The Royal Marsden NHS Foundation Trusts, in order to pilot new models of care specific to cancer.²²

Since the publication of *Achieving world-class cancer outcomes: A strategy for England 2015-2020* and *Achieving world-class cancer outcomes: Taking the strategy forward*, progress reports on the current national cancer strategy have been published by both NHS and the Independent National Cancer Advisory Group.^{3, 24} NHS England reported excellent progress, with national survival rates being at an all-time high and feedback on patient experience being more positive. Meanwhile, to support in realising the vision of providing personalised cancer care, Health Education England had been putting together a cancer workforce strategy, which they expect to be fully implemented by 2021. Despite the obvious progress, NHS England's report also acknowledged the need for improved progress in certain areas; moving forward, the Cancer Alliances would need to focus on tackling health inequalities and improving access to care for all, along with facilitating faster diagnoses. The report pledged that by 2020, all patients should receive their diagnosis within 28 days.³

The National Cancer Advisory Group issued their most recent statement in September 2018. This called for more sustainable access to funding for Cancer Alliances, so that they may work to their full potential. Public health, workforce training and research were additional areas of suggested improvements. The group also raised the issue of health inequalities and suggested that these should be addressed through providing personalised care at all stages of the cancer pathway.²⁴

The most recent policy publication is *The NHS Long term plan*, released in early 2019. The document sets out the NHS plans for the next ten years, encompassing providing everyone with the best start in life and ensuring they live well and age well. Many of the priorities from previous policies are continued here, such as preventing ill health, reducing health inequalities, improving patient experience, creating more integrated care and investing in primary care services. The policy also outlined some major changes to the NHS model that introduce fully integrated multidisciplinary community teams, improved digital solutions and new models of care for involving urgent treatment centres for emergency care. In terms of cancer specifically, much of the focus was on earlier diagnosis and screening.²⁵

2.3 Summary

The current picture for cancer can largely be interpreted as a positive one. Despite the increase in cancer prevalence, much is being done to

prevent cancers, enhance treatments and increase survival.²⁶ Cancer is being recognised as a healthcare priority both nationally and internationally.²⁶⁻²⁸ In the UK, there is an ongoing effort to ensure that our cancer services and cancer-related health outcomes are brought in line with the best in the world.²⁹ Healthcare policies are regularly updated, implemented and independently monitored by organisations such as the National Cancer Advisory Group.²⁴

Recent strategy has called for more patient-centred care, highlighting the importance of making patient experience and health inequalities a key focus.^{24, 25} Changes to commissioning aim to facilitate the tailoring of cancer services around local needs, whilst new models of care focus on integrated and accessible services.²² As part of a drive to provide care at all stages of the cancer journey, there has been increasing call for improved services and support in the community setting.²⁴ In order to maximise opportunities to improve care, community healthcare providers must therefore consider how to develop their roles.

3 Cancer services in primary care

Primary care refers to a group of community-based healthcare services that commonly act as the first port of call for members of the public seeking access to healthcare. Often described as “*the front door to the NHS*”,³⁰ these services, (which include general practice, community pharmacy, dental and optometry), provide vital but non-urgent care and facilitate access to other relevant healthcare providers.³⁰

As cancer survival increases and national cancer priorities turn towards improving patient experience and quality of life, the role of primary care in cancer services is becoming increasingly essential. Several recent national policy recommendations aim to support the commissioning of new cancer services and, whilst progress has been made in this area, much improvement is required.^{2, 22} Continued research is needed into the opportunities for healthcare providers to make a difference to those living with and recovering from cancer; this could range from small local-level interventions to new national models of care.^{3, 24}

This section explores the provision of cancer services in the primary care setting. In order to explore the opportunities for community-based healthcare providers to develop their roles in cancer services, it is important to initially establish what services currently exist in this setting. The first part of the section describes the journey that people with cancer embark upon, outlining the various stages that they might experience. An exploration of the literature provides details on current and recently trialled cancer services or interventions; these are linked back to the cancer journey to develop a picture of the types of care provided at each stage. The second part of this section goes on to consider where potential opportunities for future services might exist, providing the rationale for the selected focus of this research.

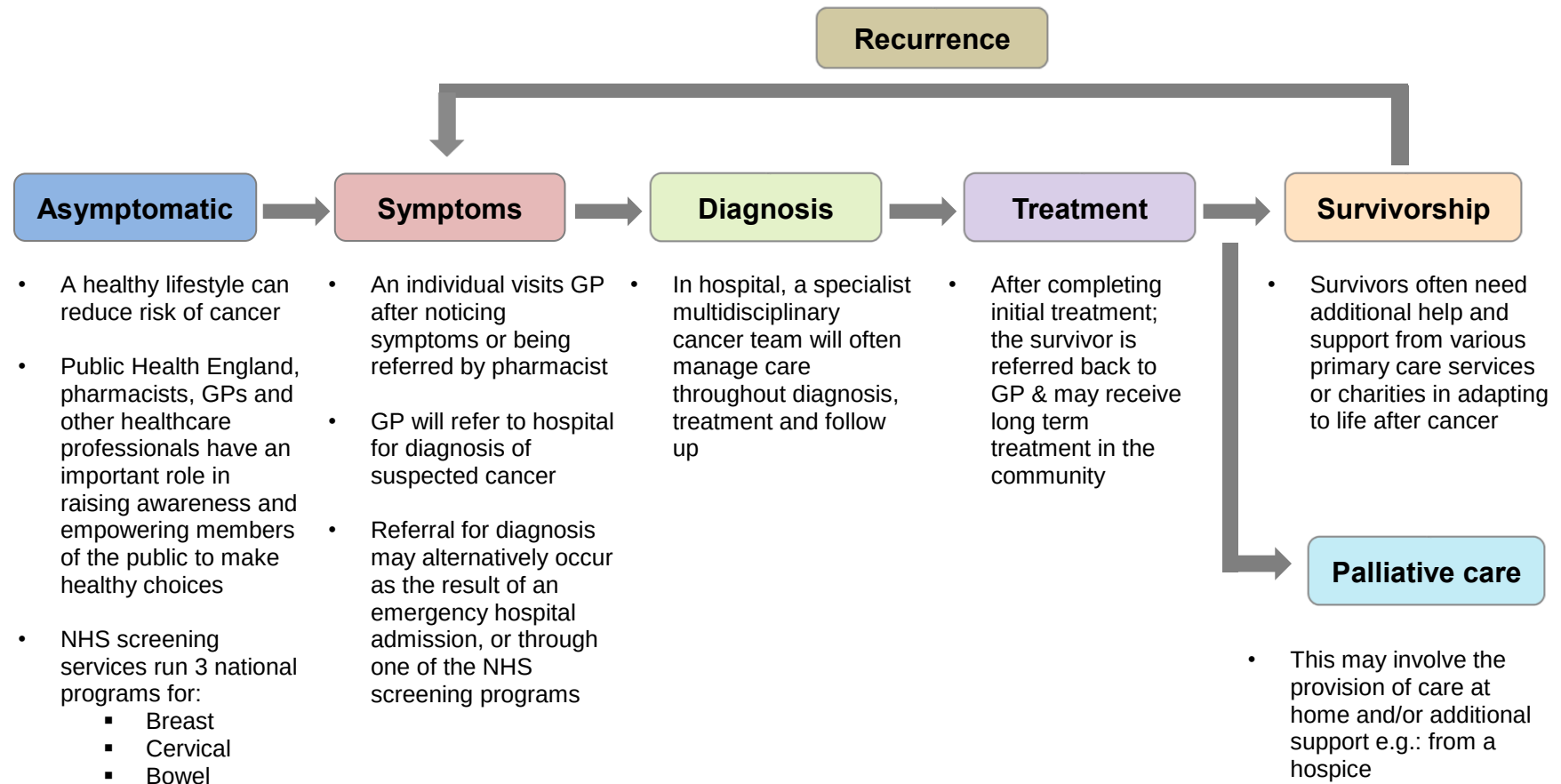
3.1 The cancer journey

The cancer journey, sometimes referred to as the *patient journey* or *cancer pathway*, refers to the various stages a person might go through as part of living with cancer (Figure 1).^{31, 32} The journey not only includes the stages of diagnosis, treatment and recovery, but also includes the stages prior to this, such as before the individual experiences any signs or symptoms of cancer. At this stage, preventing cancer may be possible.³³ Once a person experiences signs or symptoms of cancer, they would usually visit their general practitioner (GP). Depending on the severity of the experienced sign or symptom, an individual may instead seek emergency care.³⁴

Alternatively, signs and symptoms of cancer may become apparent when being treated for another condition or when taking part in one of the NHS screening services. In any of these scenarios, the individual is usually then referred to secondary care for confirmation of diagnosis and initiation of treatment from the appropriate specialist multidisciplinary cancer team.³⁴ The treatment received will depend upon factors such as the site and severity of the cancer, but may involve surgery, radiotherapy, chemotherapy, or any combination of treatments.³⁵ After the initial treatment is complete, the patient is monitored with follow-up hospital appointments.³⁶ For some cancers, adjuvant treatments may be prescribed; these aim to reduce the risk of cancer recurrence and can often be managed by the GP.³⁷ Any

necessary palliative care or survivorship services usually occur in primary care.³⁷

Figure 1: The cancer journey



3.1.1 Prevention of cancer

At the start of the cancer journey, before an individual gets diagnosed, there is opportunity to reduce their risk of developing cancer.³⁸ On an international level, the World Health Organisation promotes the importance of prioritising cancer prevention in national healthcare policies; reporting that preventable cancer cases account for as much as 30% to 50% of the worldwide total.²⁷ Addressing lifestyle factors within a given population such as diet, physical activity, alcohol intake and tobacco use can reduce the risk of many cancers. Exposure to some infections, such as human papilloma virus (HPV), hepatitis B and helicobacter pylori, are likewise risk factors for certain cancers; vaccinating against these where possible is vital. Finally, environmental factors such as air pollution, exposure to radiation, asbestos and other chemical carcinogens should be minimised.^{27, 38}

In accordance with these recommendations,²⁷ the importance of working to prevent cancer has been recognised as a priority in several of the national policy publications discussed within the previous section (2.2 Cancer healthcare policies in the UK).³ On a broader scale as well, the importance of preventing ill-health in general has been recognised as key to achieving longer, healthier lives amongst the national population and safeguarding the long-term stability of health and social care services in this country.²⁵ Whilst people are now living for longer, recent years have seen an increase in long-term conditions, and health inequalities remain an issue. Given the impact of promoting good health

and wellbeing on the country as a whole, the Department of Health and Social Care have recently released a policy to prioritise this agenda; *Prevention is better than cure: Our vision to help you live well for longer*. Whilst the report considers all aspects of health and wellbeing, its relevance to national cancer strategy is notable.³⁹

This report asserted the Government's responsibility to make it easier for people to lead healthier lives. This included initiatives to reduce air pollution, for example. For the healthcare service, empowering individuals to make positive changes towards leading a healthier lifestyle was a priority for preventing ill-health. Allowing local authorities to manage service provision according to the health needs of local communities was recommended to aid prevention and improve the integration of health and social care. Prioritising funding investments in the primary care setting was seen as an important strategy, since a great deal of prevention can be tackled through developing healthcare and support services within the community setting.³⁹

One of the biggest advocates of healthy living in the primary care setting is Healthy Living Pharmacies (HLPs). Accredited for their focus on public health, HLPs aim to improve the health and wellbeing of the local community and reduce health inequalities. As well as taking an active role in opportunistic health promotion, HLPs collaborate locally with other healthcare providers and commissioners to provide various public health services that conform to local requirements. These include

smoking cessation, weight management, NHS health checks and alcohol consumption, for example. HLPs are a valuable resource in cancer prevention as their work focuses on reducing many of the risk factors linked with cancer. Another aspect of their role is to support and promote local, national and international campaigns; these address a range of issues, with many opportunities to play a role in preventing cancer, promoting early diagnosis, or supporting survivors, such as during Cervical Cancer Prevention Week, World Cancer Day or Breast Cancer Awareness Month, for example.^{40, 41}

3.1.2 Diagnosing cancer earlier

The importance of early diagnosis of cancer has been continually addressed throughout national healthcare policies. New models of care introduced at The Cancer Vanguard aim to address the whole cancer journey, however their work is particularly focused on early diagnosis. Additionally, their Cancer Champion scheme in Greater Manchester, for example, has recruited over 2000 people (members of public, patients and healthcare professionals) to raise public awareness of early diagnosis, as well as prevention.^{42, 43}

Despite the progress made in diagnosing cancer earlier, the national survival rates of common cancers are still not as good as in comparable countries. *Prevention is Better Than Cure* once again highlights this agenda, pledging that by 2028, 75% of cancers will be diagnosed in the

early stages (stages one and two) when chances of long-term survival are optimised.

A barrier to this is when patients present to their GPs, symptoms of cancer are often vague and therefore difficult to diagnose or refer appropriately.³⁹ One example of how this issue is being addressed in practice is through a daily clinic established at Guys and St Thomas' Hospital Trust, which assesses these patients and ensures quick access to the required treatments. Although this is just one example of supporting community healthcare providers in securing quick and efficient diagnoses, the service has already helped hundreds of people get diagnosed.³⁹

In accordance with the recommendations of *Achieving outcomes: A strategy for cancer*,² several resources have been developed to support GPs to make earlier diagnoses through becoming more proficient in recognising and referring possible cases of cancer. Many organisations have released summaries of the related NICE guidance, while the Royal College of General Practitioners (RCGP) developed an e-learning module to support GPs in this role.⁴⁴ Simultaneously, Macmillan Cancer Support developed a *Top Tips for GPs* pack, along with a Cancer Decision Support Tool; an electronic tool that can be used alongside the existing practice software to support GPs in recognising possible cases of cancer by considering the medical history of the patient and their associated risk of cancer.⁴⁵⁻⁴⁷ The annual

National Cancer Patient Experience Survey reported that improvements are being made in this area, with an increase in the number of people who felt they were referred to the hospital as soon as they thought was necessary. In 2017, 77% of patients only saw their GP once or twice before being referred.⁴⁸

Whilst the role of the GP is vital, diagnosing cancer earlier also requires individuals to seek prompt care. *Be Clear on Cancer* is an initiative run by Public Health England in collaboration with Cancer Research UK, NHS England, and the Department of Health. It aims to assist in diagnosing cancer earlier through raising public awareness of the signs and symptoms of cancer and the importance of visiting their GP as soon as any concerns arise. Since 2011, campaigns have targeted various cancer types, including breast, lung, bowel, ovarian, kidney and bladder, skin and gastro-oesophageal. Campaigns are often piloted at local level before being rolled out nationally, and are promoted in public areas through internet and radio advertising, as well as in community healthcare settings such as GP practices and community pharmacies. As part of these campaigns, resources are also produced to support GPs, nurses, community pharmacists and pharmacy teams in responding to related symptoms.^{47, 49}

Screening individuals for cancer is another effective way of achieving earlier diagnoses, since these tests may identify cancerous cells before any signs or symptoms develop. The NHS currently runs three national

screening programmes: breast, bowel and cervical. Breast screening is routinely offered every three years to women aged 50-71, but current trials are looking at extending this age range. There are two types of bowel screening: a home testing kit, posted to men and women aged 60-74; and a bowel scope screen, which is a newer test currently offered in some areas to those aged 55. Cervical screening is routinely offered to women aged 25-64 every 3 to 5 years.⁵⁰⁻⁵²

Whilst automatic invites are sent to all those eligible for any of the national screening programmes (provided they are registered with a GP), uptake currently stands at 71.7% for breast and cervical, and 57.7% for bowel screening, showing some room for improvement.⁵³ Increasing screening uptake for bowel cancer, in particular, is a priority for the NHS, so there could be a role for healthcare providers in primary care to support with this. Several interventions have been trialled to improve uptake. Whilst the success of interventions to increase awareness, such as advertising and distributing relevant information in the local community can be hard to measure, advice from healthcare professionals (such as over the telephone or as part of an education event), primary care endorsement letters and the distribution of an enhancement pack piloted by Cancer Research UK have all proved effective interventions.⁵⁴

Community pharmacists, in particular, have been identified as having opportunity to improve the uptake of screening services. This role could

support pharmacies in achieving Healthy Living Pharmacy accreditation, for example through collaborating with local screening centres, promoting the national screening programmes, and educating patients on how to use the bowel screening kits and the importance of testing.^{47, 55} It has also been suggested that in the future there may be scope to expand this role by providing access to screening services through community pharmacy.⁴⁷

3.1.3 Treating cancer in the community setting

Since cancer has traditionally been managed in the hospital setting, the delivery of treatment in primary care is still in its infancy.³⁷ In most cases, cancer management is complex; involving a combination of treatments that often requires specialist supervision - such as surgery, radiotherapy or chemotherapy.¹⁴ Some treatments however, such as oral chemotherapy and adjuvant treatments are suitable to be managed by primary care healthcare professionals.^{3, 56}

Until recently, cancer treatments provided in the community mainly consisted of hormone and endocrine therapies for breast and prostate cancers, as well as medication to manage any side effects of cancer or its treatments. *The Five Year Forward View* and subsequently, *Achieving World-class Outcomes: A Strategy for Cancer* have supported the delivery of chemotherapy in the community through bringing about new models of care, integrated care pathways,

dissemination of successful cases and guidance on which chemotherapies are considered safe for community administration.^{16, 39}

Chemotherapy in the community has been shown to improve patient experience as it provides convenient access to treatment. It also provides a potentially safer setting for treating immunocompromised patients.⁵⁶ Whilst there are several examples of effective chemotherapy services in the primary care setting, widespread availability of this service is limited by the complex nature of many treatments, as well as cost-related factors. Chemotherapy services vary greatly, ranging from the medication being self-administered in the patients' home to specialised clinics in GP practices, in which treatment is given by a specialist nurse.^{2, 56} The chemotherapies developed by Amgen (a biotechnology company) for example, are suitable for use in GP practices and homes. Denosumab, used to prevent bone damage in those with breast cancer, is another example of a medication that is being made increasingly available in the community setting. An NHS toolkit has been developed to support the implementation of local denosumab services.³

Community pharmacy-based support services for those taking oral anti-cancer medicines also exist. A recent review of literature on such services revealed a variety of interventions and pilots. Examples included a text message-based intervention to remind patients to take their medication and keep a diary of any symptoms; a specialised

Medicines Use Review (MUR) (described below) for those receiving oral chemotherapy to support in counselling and medicines optimisation;⁵⁷ and several interventions involving information sharing. The transfer of patient data between care settings was cited as a key issue across the literature. Successful initiatives to address this included faxed and electronic referrals from hospital and use of Summary Care Records. However, the report raised information governance concerns that could exist with the use of fax or email. Several patient-held information documents were also trialled but were seen as less effective due to the need for the patient to be proactive in sharing the information. The key recommendations to come out of the review included a referral system in which patients can be referred both ways between the hospital and community pharmacy, ensuring community pharmacists have access to chemotherapy treatment protocols and finally the need for training on cancer and medications for pharmacists and pharmacy teams.⁵⁶

Medicines Use Reviews are one of the advanced services provided under the Community Pharmacy Contractual Framework. The service provides individuals with the opportunity to have a structured one-to-one discussion with an MUR-accredited pharmacist about how they use their medicines. The pharmacist will provide information on medicines and advise on adherence, as well as using the opportunity to promote healthy living. The service is offered annually to those on multiple medications. MURs also target those on long-term medications, of

which 70% are required to focus on specific target groups: respiratory disease, cardiovascular disease, high risk medicines (including non-steroidal anti-inflammatory drugs (NSAIDs), anticoagulants, antiplatelets and diuretics) and those recently discharged from hospital with changes to their medicines.⁵⁸

Whilst those receiving treatment for cancer would not usually fall into the target groups (except in cases of certain comorbidities, for example) the service may still be offered to this group. As mentioned above, MURs have previously been used to support those receiving chemotherapy.⁵⁶ The pharmacist who offered the trial service reported on her experiences; explaining that patients were initially unsure how useful the intervention would be, but it proved popular. To prepare for the intervention, the pharmacist gathered some signposting resources from cancer charities locally, and also used the Macmillan website. Following the MUR, she retained periodic telephone contact with the service users and made herself available to answer any questions they had. Whilst the trial outcomes were not formally analysed or published, the pharmacist reports improved patient understanding of their condition and the side effects of chemotherapy, along with improved professional relationships with other healthcare providers and local charities.⁵⁷

3.1.4 Survivorship support

Cancer survivorship can be defined in different ways; in some cases it relates to a specific stage of the cancer journey after all cancer treatment has been completed. One possible definition is “*the health and life of a person with cancer post treatment until the end of life. It covers the physical, psychosocial, and economic issues of cancer, beyond the diagnosis and treatment phases*”.⁵⁹ Meanwhile, in other cases, survivors can also include anyone who has received a cancer diagnosis, regardless of what their cancer journey looks like. In terms of the services discussed in this section, their scope encompasses supporting individuals living *with and recovering from* cancer and therefore potentially at other stages of the cancer journey.

The Recovery Package outlined in the NCSI’s 2013 report *Living with and Beyond Cancer* consists of four interventions: Treatment summaries; the HNA, and care planning; the Cancer Care Review (CCR); and health and wellbeing events. The Recovery Package set out to help individuals prepare for the future after receiving a cancer diagnosis - providing holistic and individualised support to help them get back to everyday life, such as enabling them to return to work.^{16, 60}

Treatment summaries (paper or electronic) are completed in the hospital setting following a phase of treatment, usually by the multidisciplinary cancer team. The purpose of this record is primarily to provide the GP with detailed information on the treatments

administered, along and any recommendations in terms of continued care. The GP can then use this information when carrying out a CCR, for example. A copy of the treatment summary is retained in the hospital records and a second copy is provided to the patient for their own information, this can be shown to other healthcare providers as required.⁶⁰

The HNA is a questionnaire to be completed by an individual at various stages of their cancer journey. Available on paper or online – electronic Health Needs Assessment (e-HNA), the questionnaire is used to establish any practical, physical, emotional, social and spiritual needs experienced by the individual at any one time. From the findings of the questionnaire, a personalised care and support plan is developed. This process is usually undertaken in the hospital setting by the assigned cancer nurse specialist or key worker. The resulting care plan can be shared electronically with the multidisciplinary team and the GP and data collated from e-HNAs can be useful in the development of local cancer services.⁶⁰

The CCR aims to assess an individual's holistic care needs and help them understand what information and support is available to them in the community setting; empowering them to take responsibility for their own care. The intervention forms the element of the Recovery Package designed to be conducted in primary care, undertaken by a GP or other primary care healthcare professional and where possible, informed by

the outcomes of the other Recovery Package interventions. As part of their contract, general practices are incentivised to meet certain Quality and Outcomes Framework (QOF) requirements to ensure they are providing high quality care. One such requirement is that a CCR is undertaken with an individual within six months of receiving a cancer diagnosis. As with the HNAs, CCRs are designed to be carried out at various intervals over the course of the cancer journey; the frequency of which can be agreed to meet the care needs of the individual. Whilst there are no official requirements for what should be discussed during a CCR, Macmillan Cancer Support have put together several resources. Initial CCRs were found to be largely opportunistic and not inclusive of both clinical and non-clinical care needs. High numbers of survivors were unaware of the intervention or whether they had received it. In response to this, Macmillan devised some guidance and a CCR template to support in conducting the intervention. This highlighted the importance of a holistic and planned approach, ensuring that survivors are fully informed and have the opportunity to involve a carer if required.^{60, 61}

The Macmillan Integrated Cancer (MiCa) programme is a collaboration between Macmillan Cancer Support and UCLH Cancer Collaborative; aiming to improve patient experience, quality of life and outcomes for those living with and recovering from cancer.⁶² They are currently working on a range of projects, one of which is the CCR quality improvement pilot. This service involves providing CCR training to

healthcare providers in GP practices along with CCR template software that can be integrated into existing practice software. Evaluation data is being collected from both clinicians and patients with the aim of optimising the CCR service.⁶³

Another important source of support for those living with and after cancer is Boots Macmillan Information Pharmacists (BMIPs). The role involves supporting survivors and those close to them by providing advice on treatments, side effects, emotional and practical issues, as well as signposting to various sources of information and support. The idea behind the role is to facilitate quick and easy access to advice and support in a convenient and familiar setting. The Boots-Macmillan partnership has been in existence since 2009 and uptake has been successful, with over 2,200 trained BMIPs nationwide. The collaboration also led to the development of the Boots Macmillan Beauty Advisor role: Through completing specially-developed Macmillan training, these beauty advisors are equipped to advise on skin, hair and nail care for those living with and recovering from cancer.⁶⁴⁻⁶⁶

3.1.5 Palliative care

The aim of palliative and end of life care is to help you live as well as possible and die with dignity.⁶⁷ The transition from treatment to palliative care is usually gradual, as hope of being cured starts to fade, and preparations for worse-case-scenarios set in.³⁷ Depending on the

needs of the individual, a range of healthcare professionals may be involved in care; from community nurses and GPs to palliative care specialists in the hospital setting. A personalised care plan is normally devised by a multidisciplinary palliative care team in collaboration with the individual and/or their representatives.⁶⁸ Similarly to primary care, the focus of palliative care is a holistic approach; incorporating physical, emotional, social, practical and spiritual care needs, as well as supporting family members. Evidence shows that individuals normally prefer to die in their homes and in the majority of cases, specialist supervision is not required, creating opportunity for primary care involvement.³⁷ Palliative care provision in this setting has also proven to be highly cost effective. Currently, due to inadequate service provision, particularly out-of-hours, many people are unable to die in the way that they choose.² Part of the role of the GP is to advise individuals and their family members on the palliative care services available, however evidence shows that sometimes contact with the GP is not maintained after cancer diagnosis, meaning the GP may not be fully aware and able to support with palliative care requirements.^{37, 67} To combat these issues and support primary care, integrated care pathways, advance care planning and improved interdisciplinary collaboration are required.^{2, 37}

Macmillan Cancer Support have spearheaded multiple programmes providing palliative care in the community setting. *Macmillan Specialist Care at Home* was launched in 2014 following the success of *Midhurst*

Macmillan Specialist Palliative Care Service in 2006. Based on the latter, the model involved a multidisciplinary palliative care team led by a consultant and based at a central co-ordination hub. The team would ensure that, where possible, they made early contact with service users to develop relationships and were also equipped to respond to emergency situations, reducing hospital admissions. The programme was successfully implemented in six areas across England with the composition of each team varying to meet local needs - usually including a mixture of specialist and non-specialist healthcare providers as well as volunteers.⁶⁹

In 2009, Macmillan launched a pilot for a Macmillan Pharmacist Facilitator role, of which there were four posts across Greater Glasgow and Clyde. The 4-year pilot aimed, through the new role, to increase the availability and standard of palliative care services in the primary care setting. The project initially identified the need for improved communication within and between healthcare settings, information resources to support healthcare professionals and patients, training for pharmacists and pharmacy teams. Based on this, a selection of tools and resources, including care planning templates, prescribing prompt cards, pharmacist facilitator activity logs, and information resources folders were developed to address these issues and a new service model was designed around the new role.⁷⁰

Following the success of this pilot, additional funding was secured in 2013 to roll out the service nationally under the Macmillan Pharmacy Service project. The role has proven useful in establishing new care pathways, developing training to support integrated care and improved communication, introducing new tools to promote the safe use of medicines and providing up to date clinical information to health and social care teams. Whilst the project took place in Scotland, the benefits were seen throughout the UK since the tools and resources developed as part of the project have been widely disseminated, adapted and implemented at local level to improve palliative care services in primary care settings. The resource pack in particular, has been endorsed by the Royal Pharmaceutical Society.⁷¹

3.2 Opportunities for future services

Several cancer-related healthcare and support services are now available in primary care. However, since the nature of cancer management is becoming increasingly long term, the need for healthcare providers in this setting to continue to develop their role is well established.³⁷ Other factors too, such as cost of healthcare services for the NHS and the convenience of the local setting for service users, make primary care an increasingly favourable setting for healthcare provision.^{37, 56} Recent years have seen several changes in national policy to facilitate this move and work is ongoing to trial new cancer interventions and models of care.^{3, 22}

3.2.1 Strategies to facilitate the development of future services

In the primary care setting, strategies and resources to support the development of future services are being introduced. One such example is the Primary Care Cancer Toolkit, developed by the Royal College of Physicians in collaboration with Cancer Research UK. This provides a collection of resources to support primary care healthcare professionals in the drive to expand their roles; helping them to realise the potential impact they could have on health outcomes and patient experience throughout the cancer journey. The information is categorised by journey stage and includes national guidance, resources and courses to support continuing professional development (CPD); information for patients; details of upcoming cancer events in primary care; and resources to support in developing cancer services in this setting through either designing and commissioning new services, or making improvements to existing ones.⁴⁴

To further support training needs for primary care healthcare providers, the Royal Marsden NHS Foundation Trust, in collaboration with Health Education England South London has produced a free e-learning programme that covers cancer prevention and screening, early diagnosis and cancer stages, cancer treatments, and support for those living with and beyond cancer.⁷²

National healthcare priorities promote patient choice and an approach to healthcare that focuses on the health and wellbeing of an individual

as a whole person, rather than on any condition they may have. Similarly, current cancer policies seek to improve the care provided throughout the cancer journey.^{2, 22} The annually-commissioned National Cancer Patient Experience Survey supports this agenda through monitoring changes in experiences and providing important data to influence practice and contribute to service improvement.⁴⁸

The 2017 findings of the survey show progress on previous years but there was a lot of variability in responses: Whilst overall experience was rated 8.8 out of 10 on average, when broken down, results showed that patients rated their hospital care more positively than the care provided in the community setting. Likewise, feelings about the level of information provision varied depending on the subject matter in question and the stage of the cancer journey. Just 41% of patients reported that they felt the GPs and nurses at their practice did everything they could to support them during their cancer treatment.⁴⁸ Responses such as these further highlight the need for improved care in the community setting.

3.2.2 Where can primary care make a difference?

There is clear scope for primary care to be involved in cancer management at all stages of the cancer journey. However, given the current roles of the healthcare providers in this setting and the national priorities in terms of cancer policy, some stages of the cancer journey provide more opportunity for involvement and impact than others.

Cancer prevention and early diagnosis are, of course, vital in improving outcomes and most effectively addressed in the community setting. Since this setting offers the easiest access to members of the public, particularly through community pharmacies, there is considerable opportunity here to participate in health promotion and address health inequalities. Many of the healthcare providers in primary care are highly experienced in promoting healthy lifestyles and responding to symptoms. Whilst cancer prevention and early diagnosis are undoubtedly important, they are the points in the cancer journey where primary care already has a well-established role. Over the years there has been an abundance of local and national campaigns to support this agenda and healthcare providers in this setting continue to work towards improving outcomes here.^{37, 47}

A key role for primary care that has emerged in recent years is survivorship support. Many factors contribute to the increasing need for improvements in care here; the increase in prevalence and survival rates of cancer, the advances in cancer treatments, the drive to bring the UK's cancer outcomes in line with the best in the world, the focus on patient experience in national healthcare and cancer policies, and the feedback from survivors themselves that they need more care.^{37, 73}

22, 48

Internationally as well, the number of survivors is increasing and the need for survivorship care is becoming greater. With this, the scope for

healthcare providers in primary care to develop their roles is being explored. Primary care has been commended for its holistic approach, access to medical records, and knowledge of managing long-term conditions and comorbidities; all of which make it well-equipped to deliver survivorship services. Evidence suggests that such services would need to tackle issues such as the late effects of treatment (side effects that develop or continue after the treatment has been completed) and the psychological effects of cancer on which the healthcare professionals concerned may need training to ensure they have the knowledge and skills to assess survivors, provide advice and support or signpost as required. Further research is needed to more clearly define the roles of healthcare providers in primary care and optimise models of care for survivors, including gaining a better understanding of late effects and other survivor care needs.³⁷

Specialised survivorship care is a relatively underdeveloped field. As survivor populations grow, treatments advance and healthcare models change, the care needs of survivors will likewise evolve.³⁷ The evidence presented here highlights the necessity for improved cancer services in primary care. Within this, there is particular scope to develop services and interventions that provide long-term care and support to survivors after they have received initial treatment. This important research area will provide the focus for this thesis, further exploring opportunities to support survivors in the primary care setting.

3.2.3 The role of community pharmacists

As an integral part of the primary care workforce, community pharmacy has potential scope to take on a larger role in cancer services.

Community pharmacy is widely regarded as one of the most accessible sources of healthcare. The Pharmaceutical Services Negotiating Committee describes it as *“a socially inclusive healthcare service providing a convenient and less formal environment for those who cannot easily access or do not choose to access other kinds of health service”*.⁷⁴ The accessibility of the setting coupled with the wide-ranging skillset of community pharmacists could make them particularly well-placed to be involved in cancer services. Various reports have acknowledged the potential for community pharmacists to support survivors throughout the cancer journey, particularly with prevention, early diagnosis and survivorship care.^{2, 22, 47}

Community pharmacists - through programmes such as HLP and Be Clear on Cancer campaigns, as well as in their day-to-day practice involving responding to symptoms, signposting to other healthcare services and promoting healthy lifestyles - are already carving out their role in terms of cancer prevention and promoting early diagnosis. In terms of survivorship, however, there is limited service provision. The BMIP role provides an example of how community pharmacists can support survivors. Meanwhile, various pilot interventions to support chemotherapy users in the community have revealed scope for community pharmacists to expand their roles and anecdotal evidence

also shows chemotherapy MURs to be potentially effective.^{56, 57} Further research has been called for to support the development of new survivorship services in community pharmacy; national policies have identified a need for interventions to be piloted that tackle adherence and manage the consequences of treatment.^{2, 22} The importance of researching patient and community pharmacist perspectives has also been identified, establishing the support needed by patients and the training requirements of community pharmacists to deliver such services.⁵⁶

4 Breast cancer

This research explores the role of the community pharmacist in breast cancer services. Until now, this chapter has covered cancer in general terms, exploring the extent of cancer; how the problem is being tackled on a national level through healthcare policy; what the cancer journey currently looks like from a primary care perspective in terms of healthcare service provision; and what we know, or can deduce about the opportunities for future services in primary care, particularly community pharmacy. This overview has illustrated the magnitude of the problems faced by cancer survivors and the importance of developing new services and interventions to provide care and support in the community setting for individuals on their cancer journey.

Given the vast range of cancer types, the many potential opportunities for primary care involvement and the size of the task at hand, narrowing

the focus is a sensible approach. This section deals with breast cancer as a condition of its own. In addition to discussing the rationale for making breast cancer the focus of this research, it provides an overview of the condition and how it is currently managed, as well as detailing the known pharmaceutical care issues that individuals with breast cancer often live with. Based on this evidence, the section then begins to piece together a picture of the potential scope for community pharmacists to support breast cancer survivors; forming the basis of the overall research question.

4.1 The relevance of breast cancer

Globally, female breast cancer is the most common cancer and the leading cause of cancer-related death.⁷⁵ In the UK, breast cancer is the most prevalent cancer (based on 5-year prevalence figures from 2018). In terms of incidence, breast cancer is the most commonly diagnosed cancer affecting women and, until recently, was the most common cancer overall in the country. Latest figures - from 2018 - show breast cancer is now the second most common cancer overall, accounting for 14.5% of all new cancer cases, whilst prostate cancer was responsible for 14.7%.^{73, 76}

Despite the prevalence of breast cancer, UK survival rates are increasing and have doubled over the last 40 years.⁷⁶ This can mainly be attributed to advances in cancer treatments and the prioritisation of earlier diagnosis in healthcare policy. Figures show that 87% of women

in England and Wales survive five years or more, whilst 78% survive for ten years or more and 65% survive for at least 20 years.⁷⁷ The increasing incidence of breast cancer along with continuing improvements survival rates has led to increasing numbers of breast cancer survivors who require treatment and support throughout their cancer journey.

The management of breast cancer, unlike some other cancers, usually requires long-term oral treatment to prevent recurrence; such treatment is often managed in primary care. A detailed overview of treatment guidance is provided in the following section (see section 4.2 Current management). The need for ongoing treatment coupled with the trends in survival has resulted in breast cancer being increasingly considered as a long-term condition. Breast cancer survivors have been recognised as a unique but substantial group that must be educated in the long-term effects of their treatment and the importance of a proactive approach to their general health.⁷⁸

Since the management of long-term conditions forms a key role of primary care services, community pharmacists are experienced in supporting those living with a variety of long-term conditions - through the MUR service or the New Medicines Service (NMS), for example. The latter promotes medication adherence through an intervention supporting those initiated on a new medicine prescribed to treat a specific list of long-term conditions including asthma, chronic

obstructive pulmonary disease (COPD), hypertension, type 2 diabetes, and conditions requiring antiplatelets or anticoagulants.⁷⁹ The Royal Pharmaceutical Society (RPS) have additionally noted that pharmacists have the expertise and clinical skills required to monitor those with long-term conditions, optimise treatment, manage side effects, promote adherence, manage multimorbidity and polypharmacy issues, and provide holistic support as part of their routine practice. To further develop this role, their 2016 report called for more multidisciplinary collaborations that routinely involve pharmacists, and for prescriber training to be made more accessible to members of the profession.⁸⁰ The emphasis on pharmacist roles in the management of long-term conditions, particularly over recent years, has further created scope for community pharmacists to utilise their skills and expertise to support breast cancer survivors in a similar way.⁵⁶

The need for breast cancer survivorship services is at an all-time high, and community pharmacy has been identified as having scope to provide a variety of support to survivors.⁸¹ Whilst there is still relatively little research exploring the potential role of the community pharmacist in breast cancer survivorship, new studies are increasingly emerging worldwide. The need for survivorship care in breast cancer is proving to be an international issue and the need for primary care practitioners, including community pharmacists, to step up is widespread. In the United States of America (US) for example, an increasing shortage of oncologists has further added to this problem.⁷⁸ National guidelines

from the American Society of Clinical Oncology and the American Cancer Society endorse a shared care approach between oncologists and primary care physicians for breast cancer survivors. In terms of the roles for primary care practitioners, the guideline highlighted the importance of promoting adherence to long-term endocrine therapy (ET), managing the physical and psychological effects of treatment, working to improve quality of life through health promotion and survivorship care plans.⁸¹

One US study exploring the views of healthcare providers in primary care towards supporting breast cancer survivors found that, whilst the majority of practitioners felt breast cancer survivorship support was a role for primary care, most reported lacking the confidence in their own abilities to deliver such services. These included managing consequences of breast cancer treatment and monitoring for signs of recurrence. The findings of the study highlighted the importance of evidence-based training to be provided to current primary care professionals. Interestingly, the study, despite including a range of primary care professionals, did not consider the views of local community pharmacists, focusing only on clinic staff in two areas within the same US state. The authors recognised the limitations of including such a small area in their study.⁸²

Another study, conducted in Jordan, explored the views of 1000 community pharmacists on their knowledge and attitudes towards

breast cancer. Whilst the study's main focus was the promotion of screening practices, it also reported more generally on breast cancer knowledge and training. Only 55% of respondents felt they had received adequate oncology education during their pharmacy degree, yet 62% had not completed any CPD on breast cancer or oncology. When assessed on their individual knowledge of breast cancer (risk factors, signs and symptoms, screening), half of respondents were described as having poor knowledge. Overall attitudes were positive, with over 80% agreeing that it is the community pharmacists' responsibility to provide breast cancer counselling to patients. However, several barriers were identified; the biggest being lack of time, lack of privacy and lack of skills. Pharmacists were encouraged to undertake CPD and collaborate with other healthcare professionals.⁸³

A study recently conducted in Singapore used focus groups to explore the views of GPs and community pharmacists about community-based services for breast cancer survivors. The study investigated implementing shared care plans, as in the US. Previous research had highlighted concern amongst survivors about whether GPs have the expertise to take over some of the management of their care. Findings from this study showed that although GPs had little contact with survivors, community pharmacists reported frequent encounters, with survivors themselves and their families. Queries included information about over the counter (OTC) traditional Chinese medicines that are safe given their condition and treatments. Perceived barriers to shared

care included concerns about survivor perceptions of primary care practitioner expertise, lack of healthcare provider time, the culture of visiting multiple GPs, and the cost to the survivor of the follow-up appointments – which may affect attendance. Despite these barriers, the participants responded positively to taking on a larger role in supporting breast cancer survivors.⁸⁴

These studies provide some useful insight into how survivors are supported in other countries and highlight some potential barriers that may apply when considering how we can support breast cancer survivors in the UK. However, it is important to note the differences in healthcare systems from country to country. The roles of the community pharmacist – current and potential – will likewise exhibit differences across countries. Some of the issues raised in these studies are not applicable to the UK setting. For instance, financial costs to patients or the issue in Singapore that survivors are not registered with a single GP or practice. Meanwhile, there may be opportunities and barriers here in the UK that do not exist elsewhere. In order to develop new interventions to support breast cancer survivors in community pharmacy, it is important to understand what the cancer journey looks like for breast cancer survivors in the UK and conduct research into the types of services required and whether these can be feasibly provided within this setting. The remainder of this chapter summarises how breast cancer in the UK is currently managed and presents what is already known about the types of care issues experienced by breast

cancer survivors. Finally, it will establish the most appropriate focus for this research.

4.2 Current management

In order to understand what services are needed to support breast cancer survivors, it is important to establish how the condition is currently managed in this country. The role of NICE is to produce national guidance and advice to improve health and social care in England. The organisation has produced several guidance documents on breast cancer that have been implemented nationally; this section provides an overview of the most current management guidance.

NICE has divided its breast cancer guidance into two main documents: *Early and locally advanced breast cancer* and *Advanced breast cancer*.^{32, 85} As we have seen, NICE has previously produced guidelines to promote the timely diagnosis of cancer.²⁰ Once an individual receives a diagnosis of early or locally advanced breast cancer, NICE recommends providing information advice and support on various topics. Initially, each survivor should be allocated a CNS or keyworker to act as their main point of contact and oversee their treatment journey. Everyone should be offered psychological support at early stages, along with advice on lymphoedema, clinical trials, healthy living, fertility and menopause.⁸⁵

In terms of treatment, it is initially necessary to determine the type of breast cancer present. Certain types of tumour cells have receptors that respond to different hormones or proteins, causing the cancer to spread. These include oestrogen receptors (ER), progesterone receptors (PR), or human epidermal growth factor (HER) 2. The status of the tumour will dictate the most suitable treatment option in terms of neoadjuvant therapy. Neoadjuvant therapy describes the treatment given prior to the main treatment; aiming to reduce tumour size. This may involve a type of chemotherapy; for example, HER 2 positive breast cancer is usually treated with pertuzumab. Alternatively, for those women who are post menopause and have ER positive breast cancer, endocrine therapy is the neoadjuvant therapy of choice. For premenopausal women, chemotherapy is more likely to be successful for most tumour types.^{85, 86}

The main treatment for breast cancer is surgery. NICE recommends that it should be the first choice for all invasive breast cancers, regardless of the age of the patient. However, where the patient has other comorbidities that would make surgery unsafe, endocrine therapy alone is recommended. For those with locally advanced breast cancer who have already had neoadjuvant therapy, a mastectomy is recommended, followed by radiotherapy. Immediate breast reconstruction should be offered, and the patient should be advised the advantages and disadvantages of having reconstruction immediately or delaying it. Where axilla (armpit) surgery is required, NICE

recommends leaving unaffected lymph nodes alone. Following surgery, the guidance states that patients should immediately be given daily exercises to support rehabilitation.⁸⁵

Following the main treatment, adjuvant therapy is usually recommended to prevent recurrence. This can include chemotherapy, radiotherapy, endocrine therapy, bisphosphonate therapy or biological therapy. The latter involves the use of trastuzumab, a monoclonal antibody used to treat HER 2 positive breast cancer. The type and severity of breast cancer will inform the treatment plan for adjuvant therapy. Chemotherapy is only required in severe cases, for example. Where the risk is considerable, a combination treatment involving a taxane (such as paclitaxel or docetaxel) and an anthracycline (e.g. doxorubicin, daunorubicin, or epirubicin) is suggested. Radiotherapy is recommended in some cases and can be given to the whole, or part of the breast, depending on the type of surgery, the cancer stage and whether micro metastases were present in the lymph nodes. Meanwhile, NICE recommends bisphosphonate therapy (sodium clodronate or zoledronic acid) for postmenopausal women who have breast cancer present in the lymph nodes. It is also sometimes given to other postmenopausal women, if they are assessed to be at high risk of recurrence.⁸⁵

Endocrine therapy is a common type of adjuvant therapy, and effective against recurrence of ER positive breast cancers. The current

guidelines recommend that endocrine therapy be continued for at least five years. Endocrine therapy is therefore usually prescribed in the community setting after being initiated in hospital. Aromatase inhibitors (AIs) have, over recent years, become the most common choice of endocrine therapy due to the vast evidence base attesting to their efficacy. There are three AIs: anastrozole, letrozole and exemestane. Aromatase inhibitors, despite their effectiveness, are only suitable for postmenopausal women. Meanwhile, an alternative endocrine therapy, Tamoxifen is recommended for premenopausal women and also for men with breast cancer. It is additionally recommended for postmenopausal women who are assessed as being at low risk of breast cancer recurrence, or in cases where AIs are not suitable.⁸⁵

Whilst the recommended duration of endocrine therapy treatment is currently five years, there is mounting evidence that a 10-year treatment course would be more effective. There are therefore some situations in which NICE has recommended extending treatment.

Postmenopausal women with a high or medium risk of recurrence who have taken tamoxifen for two to five years should be recommended an AI. Extended AI treatment should also be considered for those that fall into the low risk category. For those who have taken tamoxifen for more than five years, continuing on the same therapy could be considered.⁸⁵

In terms of follow-up care, NICE recommends a written care plan be put together for each patient, a copy of which should be sent to the GP.

The care plan should include contact details for relevant healthcare professionals, dates of planned mammographies (which are recommended on an annual basis), dates for review of adjuvant therapies, any signs or symptoms to look out for that require immediate medical attention and details of any relevant support services.

Guidance has also been produced to support healthcare professionals in dealing with some of the complications of breast cancer treatment. Arm mobility can be an issue post-surgery; NICE advises that local guidelines be developed in collaboration with physiotherapists to support those who need it. Lymphoedema is another common complication, often caused or worsened by a post-surgery infection. Guidance outlines the importance of educating survivors on lymphoedema and how to reduce the risk of infection. It also makes some recommendations surrounding exercises to help with the condition and the implementation of procedures for immediate referral.

In order to treat the menopausal symptoms that patients may experience, the guidance advises against the use of hormone replacement therapy (HRT) as well as a list of herbal remedies that are commonly used (e.g. vitamin E, soy, red clover, black cohosh).

Selective Serotonin Reuptake Inhibitors (SSRIs) are recommended for treating hot flushes and other menopausal symptoms but are not advised for those taking tamoxifen. Finally a link to guidance on neutropenic sepsis (an inflammatory response to an infection, usually presenting as fever and affecting those receiving chemotherapy) is also included.⁸⁵

In terms of advanced breast cancer (stage 4), NICE have produced a separate guideline. In terms of the information and support recommended, the guidance calls for an individualised approach that considers the needs of the patient. A variety of diagnosis techniques are recommended to fully assess the extent of any metastases in the bones and organs. The ER and HER status of the tumours should also be assessed for changes following recurrence. The guidance in advanced breast cancer is more complicated since combination treatments are often recommended and the choice of these depends not only on the receptor status of the cancer, but also on what combination of treatments were previously given and what was being taken when the cancer recurred. Treatment options usually involve a combination of chemotherapies, sometimes in conjunction with a biological therapy or an endocrine therapy.³²

The guidance also provides some brief recommendations for managing some of the complications of advanced breast cancer, mainly through helping to improve quality of life. Although these will not be discussed in this section, it is worth noting the issues that survivors with advanced breast cancer might face: bone or brain metastases, pain relief in palliative care, lymphoedema, and cancer-related fatigue.³²

4.3 Pharmaceutical care needs

The need for support services for survivors in the community setting is well-evidenced.^{37, 81, 87} In order to provide these services, we must first

establish what support is needed. This is a big question, and the need for research in this area has been established throughout this literature review. The national guidelines on the management of cancer provide some insight into some of the problems that survivors may encounter: menopausal symptoms, lymphoedema, reduced arm mobility, pain and cancer-related fatigue.⁸⁵ Further to this, there is a wealth of research exploring the issues related to long-term treatment for breast cancer (predominantly endocrine therapy-related). These studies, which will be reviewed in this section, provide some additional insight into the care needs of breast cancer survivors. These can be used to support the development of the objectives for this research study.

The evidence supporting 5-year adjuvant endocrine therapy use, as recommended by NICE⁸⁵ for the prevention of breast cancer recurrence is unsurprisingly sound. A worldwide review of tamoxifen trials, for example, demonstrated that clinical outcomes improved with treatment duration. Recurrence and mortality rates decreased by 42% and 22% respectively after five years on tamoxifen, compared with only 25% and 15% reduction at two years.⁸⁸ More recently, cohort studies conducted in Scotland,⁸⁹ the United States⁹⁰ and Asia^{91, 92} also demonstrated that early discontinuation, interruption and poor adherence to endocrine therapy are associated with an increased risk of poor breast cancer treatment outcomes, including mortality.

Meanwhile, a recent Australian study on postmenopausal women with breast cancer reported that those who switched between endocrine therapies less than two years after ET initiation were at “*substantially higher risk of early discontinuation of all endocrine therapy*.”^{93(p.e167)} Pro-active monitoring was therefore recommended to promote persistence.⁹³

The above studies demonstrate the importance of adherence and persistence in adjuvant endocrine therapy regimes. However, problems with poor adherence and interruption are well documented, highlighting the need for the development of survivorship services that address this care need. One review of long-term medical issues for breast cancer survivors reported that persistence to a 5-year adjuvant endocrine therapy regime ranges from 30% to 70%. It additionally acknowledged that reasons for non-persistence and non-adherence are often complex and interlinked, but cited side effects and lack of patient understanding on the importance of continued therapy as the most notable contributors.⁷⁸

In addition to the abundance of literature supporting the need to continue ET treatment for five years, several clinical trials have recognised the benefits of extending the treatment to 10 years, hence the NICE recommendations for considering extended adjuvant endocrine therapy in certain cases.⁸⁵ The Adjuvant Tamoxifen: Longer Against Shorter (ATLAS) study for example, reported that continuing

tamoxifen treatment to 10 years could reduce mortality rates in years 10-14 by 50%. This did however come with the caveat that adverse effects would also increase in line with more long-term use. This large international study, which originally ran from 1996 to 2005, was continued for a further 5 years (until 2010) to provide this data. The extended proportion of the study involved over 6800 participants, randomly recruited from 36 countries/regions.⁹⁴ Following the proven success of extended therapy with tamoxifen, another landmark trial – the MA.17R trial – was conducted to assess the benefits of extended therapy with letrozole. This trial proved that extended adjuvant treatment with letrozole (regardless of duration of initial treatment with tamoxifen or AIs) significantly improved disease-free survival, which subsequently led to extended letrozole therapy being implemented internationally.^{95 96}

Given this evidence, it is possible that in the future we might see a move towards implementing a 10-year adjuvant endocrine therapy regime as standard. However, taking into consideration the adherence-related care needs that already exist with 5-year regimes, a 10-year alternative would likely present an even greater challenge. It is therefore vital to establish the common reasons for interruption and non-adherence and implement strategies to address promote adherence and address any relevant care needs.

As with any pharmacological treatment, endocrine therapies can cause adverse effects. Whilst the adverse effects of other breast cancer treatments, such as chemotherapy, can be more severe, clinical trials have established endocrine therapies to be generally well-tolerated.⁹⁷ Despite this, the long-term treatment requirements of adjuvant endocrine therapy regimes mean the associated adverse effects often negatively impact on quality of life. This in turn, can exacerbate poor adherence.⁹⁸⁻¹⁰⁰

Aromatase inhibitors are generally associated with fewer adverse effects than tamoxifen, but various studies have reported high numbers of adverse effects for both. One US study involving 538 women receiving endocrine therapy for early stage breast cancer found that 94% experienced adverse effects. Meanwhile 18% of these women self-reported discontinuing their endocrine therapy early (22% took AIs, 44% took tamoxifen and 34% took both). Over one quarter of those who discontinued early reported doing so without consulting a healthcare professional. The two most common reasons for early discontinuation were adverse effects and reduced quality of life.¹⁰¹

Aromatase inhibitors are associated with a decrease in bone mineral density, arthralgia, bone pain and fractures. Other adverse effects include nausea, diarrhoea, hot flushes, fatigue, weight gain, vaginal dryness, depression, increased cholesterol levels, cardiovascular events and thrombotic events.^{97, 98}

Meanwhile, tamoxifen is most commonly associated with menopausal symptoms, such as hot flushes, cold sweats, night sweats, headaches and reduced libido.^{97, 100} Menopausal symptoms can, of course, affect women who are not receiving endocrine therapy – one UK study, conducted surveys with 108 patients and found that 69% of tamoxifen users experienced menopausal symptoms compared to 20% of breast cancer patients who did not receive endocrine therapy or other adjuvant treatment.¹⁰⁰ Other common side effects of tamoxifen include light-headedness, nausea, thromboembolism, endometrial thickening, vaginal bleeding, vaginal discharge, rash and fatigue.^{97, 98}

Many women diagnosed with breast cancer suffer from psychological problems, both as a result of treatment and the cancer diagnosis itself. These are often long-term issues; one year after completing breast cancer treatment, approximately 30% of women are affected by depression and 25% by anxiety.¹⁰⁰ As part of the prospective cohort study Breast Cancer Quality of Care (BQUAL), which followed women on endocrine therapy over a two year period, explored some psychosocial indicators of non-persistence. They found women who reported intrusive or avoidant thoughts about breast cancer were less likely to be persistent with their endocrine therapy. This was concerning considering 25% of women suffered from emotional distress levels equivalent to post traumatic stress disorder. The study therefore recommended early interventions to detect emotional distress and improve psychological well-being.¹⁰²

Further to this, a review of long-term medical issues for breast cancer survivors highlights the effectiveness of lifestyle changes in improving survival. Various studies within this review demonstrated the importance of maintaining a healthy weight, leading an active lifestyle, eating a healthy diet and promoting emotional resilience for survivors. The study therefore recommended that healthcare providers step up to ensure these priorities encompass a larger proportion of their routine practice.⁷⁸

Several potential care needs for breast cancer survivors have been identified here, including the need to effectively manage adverse effects, promote adherence and tackle quality of life concerns associated with adjuvant endocrine therapy treatment. Research therefore advocates developing improved support strategies for survivors, including interventions to manage adverse effects; manage treatment expectations; educate patients on the importance of adherence and empower them to make informed decisions on treatment and lifestyle.^{78, 98, 101, 103}

4.4 Rationale for this research

As demonstrated throughout this literature review, there is a strong and growing demand for breast cancer survivorship services in primary care. Due to large numbers of people living with and after breast cancer, developing specialised services for this population will likely have widespread impact. Furthermore, as the future of community

pharmacy practice tends towards the provision of services and opportunities for more clinical roles, it is important to recognise the scope of the community pharmacist's role in providing long-term support for those affected by conditions such as cancer. Managing cancer as a long-term condition is increasingly necessary due to early diagnosis, advances in treatment options and improved survival rates. This project, whilst focusing on breast cancer specifically, will demonstrate how community pharmacy can embrace these new opportunities and reach out to a wider population of customers through the introduction of specialised cancer services.

In order to design an intervention or service, underpinning research is initially required. As part of its guidance on *Developing and Evaluating Complex Interventions*, the Medical Research Council (MRC) recommends that when developing a new intervention, a systematic approach should be applied using a three step process; 1) Identify evidence base; 2) Identify/develop theory; 3) Model process and outcomes.¹⁰⁴ This guidance can be utilised to inform the design of this research and ensure good practice. Firstly, to identify the evidence base; this literature review was conducted, informing the research objectives.

Step 2 of the MRC guidance states that an effective intervention requires the developers to understand the rationale for the intervention and how change will be achieved; rather than taking an empirical

approach. This includes applying any pre-existing theories and, where necessary, conducting new research to develop theories.¹⁰⁴ It is therefore recommended to conduct initial studies (for example, epidemiological, qualitative or descriptive) as necessary to provide deeper understanding of the current situation and generate theories on how to influence it.¹⁰⁵ To facilitate the development of new breast cancer survivorship services in primary care, a deeper understanding of the current UK treatment pathways for breast cancer survivors is initially required. Findings generated will then inform the subsequent phases of the research, exploring the needs of breast cancer survivors and how community pharmacists could provide support. This will provide the required data to enable the development of an intervention - Step 3; modelling the process and outcomes.⁷⁸ Whilst the latter step will not be addressed as part of this research, it should be considered when designing or conducting any future work that further builds on its findings.

5 Aim and objectives

5.1 Aim

To identify the opportunities for community pharmacists to develop their role in providing support and improving health outcomes for people living with and after breast cancer.

5.2 Objectives

- To understand the patient characteristics, treatment pathways and healthcare needs of service users
- To identify points in the breast cancer journey where community pharmacists could support patients in their use of medicines and patient goals, to help improve outcomes and quality of life
- To explore the requirements, attitudes and opinions of breast cancer survivors towards new community pharmacy-based cancer services
- To investigate community pharmacist views of introducing a service or intervention to meet these care needs; exploring potential opportunities and barriers surrounding implementation within a community pharmacy setting
- To establish the views of relevant stakeholders, such as commissioners, other healthcare providers and cancer charities towards the introduction of a new community pharmacy-based service for breast cancer survivors, including next steps and future work

Chapter 2: Methodology and methods

1 Introduction

This chapter will provide an initial overview of the methods and methodological approach to identifying opportunities for community pharmacists to develop their role in breast cancer survivorship services. It will go on to discuss the quantitative and qualitative phases of the research in detail, outlining and justifying the methods of data sampling, collection and analysis. Finally, it will consider the scientific rigour, strengths and limitations of the chosen approaches.

2 Overview of methodological approach

This research adopted a mixed methods approach to address its aims and objectives. An overview of the research process is provided in Figure 2.

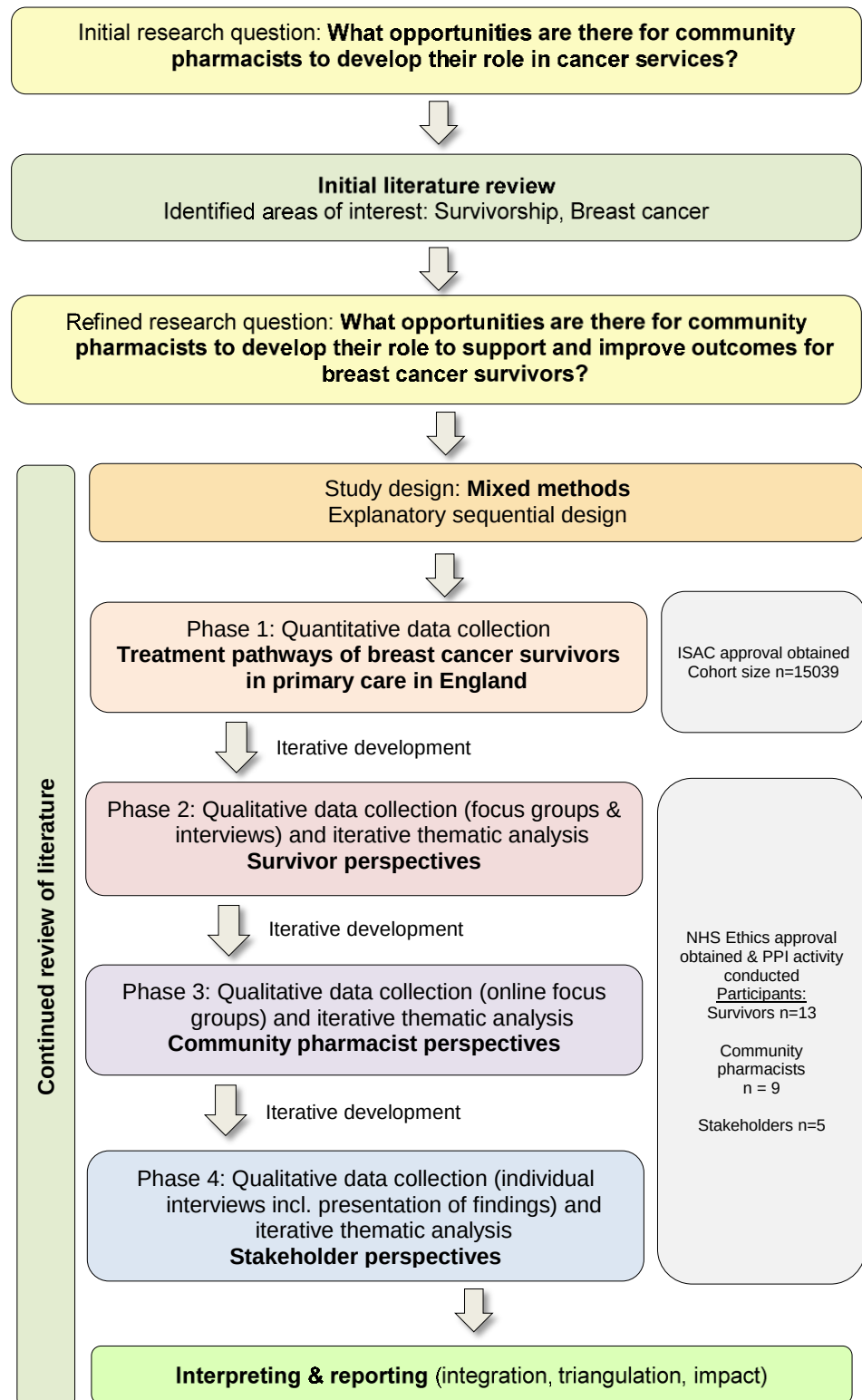
In accordance with the MRC guidance, a literature review was initially conducted to establish the existing evidence and refine the research question. Staying up to date with the literature was also an ongoing process that was carried out throughout the course of the research.

Once the research question was refined and the methods required to address each of the objectives was selected, the required approvals were obtained to undertake the research. Data collection and analyses were conducted in four sequential phases using a process of iterative

development to integrate the findings from each phase into the refined design of the subsequent phase. The initial phase, which quantitatively addressed the objective '*to understand the patient characteristics, treatment pathways and healthcare needs of service users*'; analysed national primary care prescribing data from the Clinical Practice Research Datalink using descriptive statistics.

The subsequent three phases were qualitative in nature and used a combination of focus groups and individual interviews to collect data, which was then analysed using a process of iterative thematic analysis. Phase 2 addressed the objectives '*to identify points in the breast cancer journey where community pharmacists could support patients in their use of medicines and patient goals, to help improve outcomes and quality of life*' and '*to explore the requirements, attitudes and opinions of breast cancer survivors towards new community pharmacy-based cancer services*' through utilising focus groups and interviews to explore the experiences and views of breast cancer survivors on the cancer care they received in primary care. The participants also explored how community pharmacists might potentially address any unmet care needs and better support breast cancer survivors.

Figure 2: Overview of research process



Findings were then followed up in phase 3; which set out *'of introducing a service or intervention to meet these care needs; exploring potential opportunities and barriers'*. This was likewise conducted as a focus group.

The final phase of data collection and analysis involved a variety of stakeholders. It consisted of a summary presentation of findings followed by an individual interview *'to explore the views of any relevant stakeholders, such as local and national commissioners, towards the introduction of a new community pharmacy-based service for breast cancer patients; including next steps and future work.'*

3 Methodology

3.1 Choice of methodology

There are a variety of available quantitative, qualitative, or mixed methodologies that could have been employed to explore the objectives of this research. Each of these comes with its own strengths and weaknesses. Quantitative research is grounded in post positivist assumptions; the philosophy of cause and effect.¹⁰⁶ Here, the researcher traditionally employs a deductive approach, drawing on existing knowledge and theory to generate a hypothesis, test it, and eventually revise existing theory as required based on the findings.¹⁰⁷ Quantitative work often uses numbers and statistics to explore the breadth of the issue at hand; large amounts of data are usually required

to ensure the study has the required power and that the findings are generalisable. Examples of quantitative strategies include experimental or observational studies; collecting data using structured questionnaires or through measuring specific variables; or carrying out statistical analyses.

Qualitative research has traditionally been utilised in social sciences and is generally concerned with how people and things interact in the environment. This interpretivist philosophy is based on developing an understanding of the world through exploring how people interpret it. In contrast to quantitative research, this approach is largely inductive in nature; exploring experiences to generate data, from which new theories and ideas can be developed. In contrast to quantitative analysis, qualitative approaches usually use smaller sample sizes as the emphasis is on the unpicking the detail within the data and exploring an issue in-depth. Qualitative research examples include interviews, focus groups and ethnographies.^{106, 107} Where quantitative and qualitative approaches meet, the 'mixed methods' methodology has developed and is becoming increasingly prevalent.¹⁰⁶ Generally speaking, the advantage of mixed methods is that it "*combines the power of stories and the power of numbers*" to ensure that a particular type of evidence is not overlooked.^{108(p.30)} Although mixed methods can be complex in that it combines the opposing philosophies of quantitative and qualitative approaches, there are many advantages to this type of research, particularly when the research question calls for

the breadth and depth of a topic to be explored. Pluye and Hong identify three possible reasons for electing to conduct mixed methods research: 1) Combining both methods to understand a qualitatively identified phenomenon whilst quantitatively measuring the associated magnitude causes, effects, and trends; 2) Using qualitative and quantitative methods sequentially to generalise qualitative findings; and 3) Utilising qualitative methods to add depth and context to quantitative results.¹⁰⁸ The design of this research project adopts the latter of the three strategies.

When designing this research, several methodological options were considered before the mixed methods approach eventually evolved out of the design process. In order to develop a community pharmacist-led intervention to provide support and improve health outcomes for people with breast cancer, a qualitative methodology was initially selected. This would facilitate the collection of highly detailed information from breast cancer survivors as potential service users, community pharmacists as service providers, and various relevant stakeholders; providing the means to fully explore and understand the subject from the perspectives of all parties concerned and ensure any recommendations of the research would be worthwhile, feasible, and acceptable to all. Applying qualitative methods in this way would produce a level of detail and depth of understanding that could not be achieved with quantitative approaches, making it the obvious choice.¹⁰⁸

The initial literature review revealed a lack of current information on breast cancer treatment pathways in primary care within the UK or England, or any feasible model for incorporating survivorship support into current practice in this setting. In order to inform the in-depth qualitative approaches, a broader picture of the breast cancer journey in current practice was required to establish treatment patterns and where unmet care needs may exist. Due to the need to look at larger data sets, quantitative methods producing descriptive statistics were incorporated into the study design.

The need to explore both the breadth and depth of the potential role of community pharmacists in breast cancer services clarified the importance of employing a mixed methods approach.¹⁰⁶ As discussed in chapter one, the MRC guidance on *Developing and Evaluating Complex Interventions* promotes a 3-step process; this research encompasses steps 1 (identifying the evidence base through a comprehensive and regularly updated literature review) and 2 (conducting new research). Step 2, in this case, initially used quantitative approaches as a useful tool to provide insight into current primary care treatment pathways and potential care needs. This then informed the subsequent qualitative stages involving, as recommended by the MRC, “those targeted by the intervention, or involved in its development or delivery”.^{104(p.9)} This was achieved through an in-depth exploration of the issues raised and the potential roles of community pharmacists in addressing these.

3.2 Philosophical underpinnings of this research

Epistemology can be defined as “*the branch of philosophy concerned with the study of knowledge*”.^{109(p.37)} When designing a research project, the applied epistemological stance dictates the philosophical assumptions that underpin the chosen methodology, and frame the way in which the knowledge is obtained and interpreted.¹⁰⁹

Mixed methods unites the differing epistemological viewpoints of qualitative and quantitative approaches, and in doing so, utilises the benefits of both. Since the approach relies on a complex mixture of philosophical underpinnings with groundings in both quantitative and qualitative research, the epistemological stance underpinning the methodology has been the subject of much discussion. Several possibilities have been put forward, describing varying levels of compatibility between philosophies. Examples range from the *incommensurable stance*, which suggests that quantitative and qualitative research stem from very different epistemologies and should not be compared or combined at all; the *complementary strengths stance*, *dialectic stance*, *aparadigmatic stance*, and *design stance*, which all propose varying levels of compatibility; and finally, the *alternative paradigm stance*. The latter describes the theory that a single paradigm founded in pragmatism provides the underpinning for the mixed methods methodology.^{110, 111}

Pragmatism can be interpreted into many different forms, but essentially it is a stance that is not grounded in any one philosophy. Instead, truth is considered to be fluid and changeable depending on the context and time point; sometimes described as an anti-philosophy.^{106, 112} In a research context, it endorses a theory that informs effective practice.¹⁰⁶ The focus of pragmatism is on the research question itself, requiring the consideration of all available approaches to better understand and explore it. This freedom to choose the most appropriate methods for a specific study rather than be constrained by steadfast rules associated with a specific philosophy, allows researchers to employ a combination of qualitative and quantitative methods as required.^{106, 112} Researchers must, however, have a clear rationale for adopting a mixed methods approach; ensuring that they have selected the most appropriate methods of data collection and analysis to achieve the intended outcomes of the study.¹⁰⁶

Whilst problem solving is an important element of pragmatism, the paradigm also places great importance on human experience, making it valuable in modern social research.¹¹³

“Research never occurs in a vacuum, so how it is influenced by the historical, cultural, and political contexts in which it is done...We need to pay more attention to how these factors influence both

the choices we make and the ways that we interpret the outcomes of those choices."^{113(p.1051)}

Founding pragmatists such as John Dewey argued that traditional philosophical arguments placing importance on specific epistemologies were out-dated and neglected to consider the importance of human experience on research. As Dewey posited, human experience is based on two cyclical concepts; an individual's actions are informed by their beliefs; and in turn, the actions they take and the outcomes of these inform their beliefs.¹¹³

Being a community pharmacist by background, my previous role involved spending a lot of time having conversations with patients; hearing about their experiences and supporting them to get the most out of their treatment and lifestyles. Human experience is therefore naturally of great importance to me, and this translates to my research. The role also involved a lot of thinking on my feet; employing practical and effective methods to solve problems with prescriptions, medicines or pharmacy processes. This fits in well with pragmatic values, as does my belief that truths can change over time.

4 Methods

4.1 Overall study design

This research, whilst adopting a mixed methods approach founded in pragmatism, employed an explanatory sequential design.¹⁰⁶

In mixed methods research, qualitative and quantitative approaches can either be carried out concurrently or sequentially, as dictated by the objectives of the study. In this case, a sequential design was implemented; initially using quantitative approaches to build a picture of the current treatment pathways of breast cancer survivors within primary care. From these findings, potential unmet healthcare needs and other relevant topics for discussion were established, and these informed the subsequent qualitative approaches. A design in which qualitative methods are utilised to add depth and meaning to, or *explain* initial quantitative findings, is commonly referred to as an *explanatory sequential design*.¹⁰⁶

As outlined in the beginning of this chapter (section 2 Overview of methodological approach), the overall study design consisted of four phases of data collection and analysis. The sequential design of the research allowed the findings from each phase of the study to inform the final design of the subsequent phases. This process of iterative development is a key strength of the research; ensuring the study design is rigorous.

A detailed description of the individual methods used in each of phases is provided below: 1) treatment pathways of breast cancer survivors in primary care; 2) survivor focus groups and interviews; 3) community pharmacist focus groups; 4) stakeholder interviews.

4.2 Quantitative phase: Treatment pathways of breast cancer survivors within the primary care setting

4.2.1 Choice of quantitative data source

In order to provide insight into the treatment pathways and potential care needs of breast cancer survivors in England, any selected source would need to include data from across the country (or otherwise be representative of the national population). There were two key sources of quantitative primary care data available within England that could have been utilised; GP prescribing data or community pharmacy dispensing data; this research uses prescribing data.

The process of medication utilisation in primary care involves several steps between the decision to prescribe a medication and the patient taking it (the prescription has to be collected from the prescriber, taken to the pharmacy, dispensed, collected by or delivered to the patient, then the patient must finally make the decision to take the medication). The main advantage of exploring dispensing data is that, being further along in the process, it provides a more accurate proxy for the treatment actually received. However, since patients have the choice to visit multiple community pharmacies and there are no centralised pharmacy records, incomplete data is an issue; this could affect the validity of the research. Additionally, pharmacy records are often restricted to medication details; and rarely provide data on patient demographics, underlying conditions, or other clinical information.¹¹⁴

Due to the nature of this research, the capability to identify individuals with a breast cancer diagnosis was essential, along with any data that could provide insight into characteristics. This made prescribing data the more appropriate source of data to address this particular research question.

The Clinical Practice Research Datalink (CPRD) is a public health research service funded jointly by the Medicines and Healthcare products Regulatory Agency (MHRA) and the National Institute for Health Research (NIHR).¹¹⁵ CPRD contains fully anonymised primary care data from GP practice records for a representative 6.9% of the UK population.¹¹⁶ Longitudinal data, including patient demographics, diagnoses, consultations, prescriptions, tests and referrals are included.

In addition to being one of the largest primary care databases in the world and representative of the national population, there are a number of benefits to utilising CPRD as a data source. Being designed for research purposes, all data is quality checked and pre-coded before being uploaded; and the database is updated monthly with records going back as far as 1987.^{115, 116}

In order to maximise its research potential, CPRD data can be linked to various other data sources providing access to hospital data, disease registries, demographics, national audit data, or deprivation data.¹¹⁶ For the purposes of this research project, access to linked Hospital Episode

Statistics (HES) data was required. HES is a claim-based database containing details of inpatient attendances in NHS hospitals and treatment centres across England (not the UK as a whole). Linked data from consenting GP practices is available for 75% of England's practices.¹¹⁶ Utilising HES data is necessary to enable the index date (the date of discharge from hospital following initial treatment for breast cancer) for each patient to be accurately identified.

4.2.2 Study design

This retrospective cohort study used data from CPRD and HES between 1st November 2005 and 31st October 2015.

Since the extraction of the data for this study from CPRD was carried out in late 2015, the latest available data at the time was from the November 2015 release. The open cohort was therefore able to be followed up until the 31st October 2015; providing the study end date. When considering how far back to go in the data, ten years was selected as an appropriate inclusion period; making the study start date 1st November 2005. Whilst both CPRD and HES contain data going back further, there have been various advances in treatment and updates in guidance over the years and since the objective of this study was to build a picture of *current* treatment pathways it was concluded that a longer study period would not provide relevant data or further enhance the study findings.

This protocol has been reviewed and approved by the Independent Scientific Advisory Committee (ISAC) (protocol number: 16_202R; Appendix 1, page 389).

4.2.3 CPRD data

CPRD data is organised into ten files in total. Of these, there are main files (*Patient*, *Practice* and *Consultation*); and a further seven event files (*Clinical*, *Additional*, *Therapy*, *Referral*, *Test*, *Immunisation* and *Staff*). For the purposes of this study, the majority of the data was obtained from the *Patient*, *Clinical* and *Therapy* files. *Patient* included personal data about each individual (gender, year and month of birth, practice registration data and death date) listed under a unique identifier (*PatID*) to ensure anonymity. The *Clinical* file contained data on all clinical events such as diagnoses or symptoms, as well as dates, the patient involved and the staff member involved. Clinical events are coded in the database using *Medcodes*; which is a coding system specific to CPRD and based on Read codes (described further in section 4.3 Cohort selection). The *Therapy* file provided prescription data; including date, drug, strength, form, quantity, and dose prescribed. Medication was coded using *Prodcodes*; a CPRD-specific system similar to *Medcodes*, but for medicinal products. A *Bnfcode* field also enabled each drug to be categorised according to the chapter of the British National Formulary under which it was listed.

CPRD data was accessed using a CPRD GOLD licence. This provided online access to the data, along with several tools to facilitate data extraction. Since the data is pre-coded, one of the initial stages of study design involves identifying the relevant codes needed to identify the cohort. The code browser tool facilitates this; allowing users to explore and identify any *Medcodes* and *Prodcodes* relevant to their study. The *Define* tool then allows the user to identify their cohort; applying desired inclusion and exclusion criteria. Once a cohort list has been established, the *Extract* tool allows the user to download the required data for that cohort. Finally, the *Refine* tool provides the ability to filter the data as needed.¹¹⁷

4.2.4 HES data

HES contains data on all admissions, outpatient appointments, and Accident and Emergency (A&E) attendances at NHS hospitals across England. Each time a patient receives NHS treatment in hospital, various data on their stay and treatment is collected as part of the Commissioning Data Set. This is submitted to NHS Digital for processing, enabling healthcare providers to be reimbursed for care delivered. This data is then entered into the Secondary Uses Service (SUS); a data warehouse managed by NHS Digital. *Secondary uses* refers to all non-clinical applications of the dataset, such as its use in research. At monthly intervals, data is extracted from SUS. This is then quality checked and validated to form the HES dataset. In addition to its uses in academic research, HES data is also utilised by the government

and various NHS bodies; for example, to analyse service use, inform policy making, or monitor performance.¹¹⁸⁻¹²⁰

For the purposes of this study, the most recent HES available at the time was used; set 10. The HES dataset included data from April 1997 through until March 2015. Similar to CPRD itself, the linked HES data is organised into various files; of which there are eleven in total. Along with the data, CPRD provides a data dictionary; a document detailing the structure and content each HES file. The three files required for this study were: *Patient*, containing the unique identifier numbers for the patient and practice as used in CPRD. This file also contains ethnicity data for the patient, as recorded in HES. The *Diagnosis Episodes* file was key in identifying the index date for each individual. Contained within this file was information on each event at which care was provided; including the patient involved, the diagnosis code they received and the dates on which the episode started and concluded. Finally, the *Procedure* file contained data on the medical procedures linked to each patient and episode, and the relevant dates. In this case, the procedures of interest related to breast surgery. Information on how the study cohort was identified using the information in these files is discussed in the next section.

4.3 Cohort selection

The study population consisted of women in England who were newly diagnosed with breast cancer, discharged from hospital following initial

treatment and followed up for two to ten years. HES-linked female patients, over 18 years of age at index date (the date at which they entered the study), who were discharged from hospital within the study period (1st November 2005 -31st October 2015) following their first confirmed breast cancer diagnosis, and whose data was classified as 'up to standard' (i.e.: recorded whilst a practice is meeting specified minimum quality criteria)¹¹⁶ were included in the study (Figure 3). The study end date, 31st October 2015 was selected as it included the most recently available data at the time.

Individuals with a breast cancer diagnosis were initially identified either in CPRD using Read codes (Appendix 2, page 392), or in HES using International Classification of Diseases (ICD) 10 breast cancer codes (Appendix 3, page 394). The Read clinical classification system is widely used across the NHS, particularly in GP practices. It uses alphanumeric codes to facilitate the electronic recording of clinical data such as conditions, signs and symptoms, clinical procedures, and social/occupational information.¹²¹ For the purposes of this study, a list of relevant Read codes was compiled using the CPRD data dictionary, which was cross-referenced with codes used in existing literature,¹²² together with any relevant QOF codes. Using the *Define* tool in CPRD, a search based on the resulting list was then conducted within the *Clinical*, *Referral*, *Consultation* and *Test* files (Figure 3).

Meanwhile data is recorded in HES using ICD 10 codes, which is the tenth revision of the standardised hierarchical classification system adopted by WHO.¹²³ It is used to define all diseases, disorders, or related health conditions. In addition to being adopted in HES, it is used worldwide for clinical and research purposes.¹²⁴ For individuals identified in HES, as well as for those identified in CPRD, data records from CPRD files *Patient, Practice, Therapy, Clinical, Observation*, and *Other* were extracted (Figure 3). The two resulting datasets were then compared and merged to enable the cohort to be further refined.

4.3.1 Exclusion criteria

In order to confirm breast cancer diagnosis (and rule out any possibility of incorrect code entry), the patient lists identified from CPRD and HES were compared. Individuals were excluded from the study if they did not have a breast cancer diagnosis code in both databases and diagnosis could not be confirmed using HES breast surgery procedure codes (Appendix 4, page 395) and CPRD codes for endocrine therapy prescriptions (Appendix 5, page 397). This ensured that all individuals in the cohort had a breast cancer diagnosis that had been correctly recorded.

The decision to exclude males from the study was based on several factors. The rationale for conducting this research is linked to the high prevalence of breast cancer and the associated need for additional primary care services. However, whilst breast cancer is the most

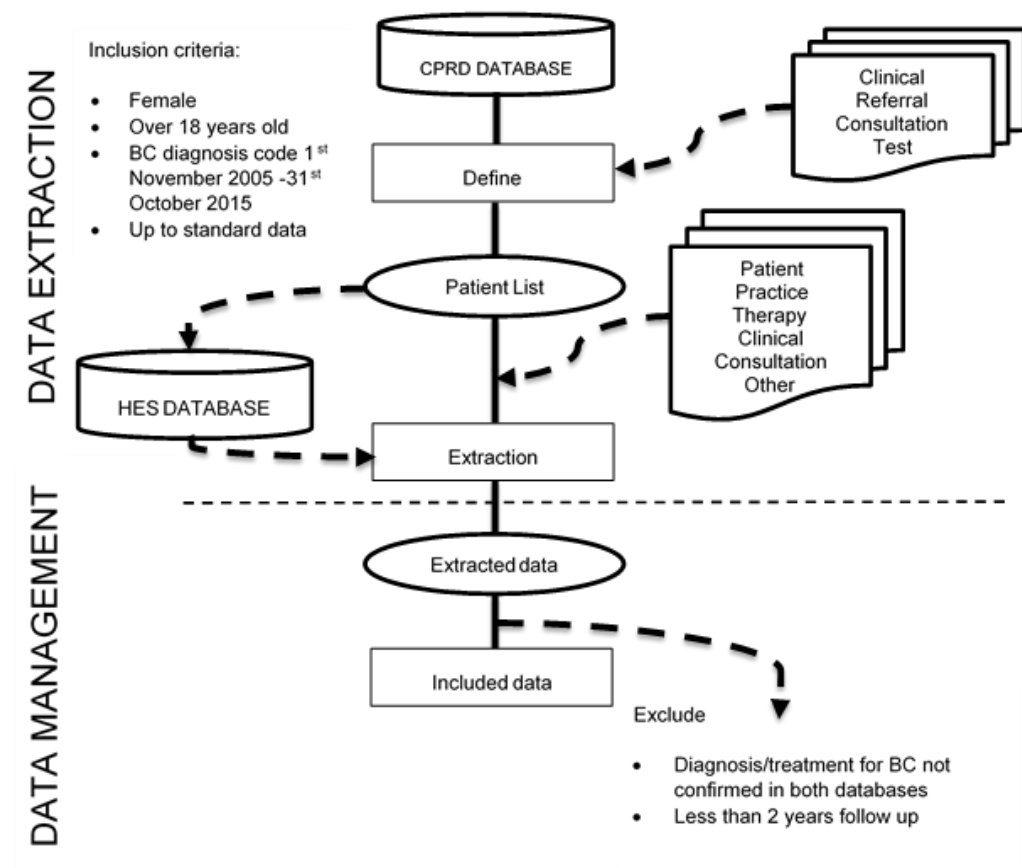
common cancer in the UK, it mainly affects women and male breast cancer is rare. Over the course of a year, there are only around 370 new cases of male breast cancer in the UK, compared to 54,800 new cases in women.⁷⁶ Although supporting men throughout their breast cancer journeys is equally important, any future community pharmacy-based service or intervention that is developed from the findings of this research is less likely to be accessed by men; due not only to the rarity of breast cancer in this group, but also the lack of men known to access pharmacy services compared to women.¹²⁵ Therefore, for the findings of this study to have maximum impact, it was important for the research to focus on exploring the trends in treatment pathways and healthcare needs of women with breast cancer. Similarly, breast cancer in under 18s is extremely rare so this group was likewise omitted from the study.⁷⁶

4.3.2 Follow up periods

Eligible patients were followed in CPRD from the index date until the end point. The index date, obtained from HES records, was defined as the date of discharge from secondary care following initial treatment for breast cancer. The end point, meanwhile, was the earliest of three dates; the study end date (31st October 2015); date of death (as recorded in CPRD); or the date of being *transferred out* (i.e.: leaving their GP practice and therefore CPRD). Follow-up duration was defined as the period between their index date and end point.

The study of treatment pathways requires the use of longitudinal data. Additionally, since breast cancer treatment often requires long-term management with ET (recommended to be continued for 5 years) it was necessary to limit the cohort to those individuals with sufficient follow up data to provide some insight into their journey. Two years was considered the minimum follow up duration to enable an individual's treatment journey to be mapped out, or to indicate any potential healthcare needs for the cohort. Therefore, individuals who had a follow up duration of less than two years were further excluded from the study (Figure 3).

Figure 3: Data extraction and management process



4.4 Outcome measures

4.4.1 Patient characteristics

For each individual, the age at index date was calculated based on the year of birth recorded in CPRD. Ethnicities of the cohort were measured using HES data (from the *Patient* file). Although CPRD does contain some ethnicity data, HES provides a more complete record; with 79.4% of individuals in HES having a recorded ethnicity in 2012, compared to just 27.1% of individuals in CPRD in the same year.¹²⁶ The duration of available follow-up for each individual and time to mortality (or study exit) were also measured from the extracted data.

4.4.2 ET treatment pathway

ET treatment pathway was mapped out by measuring whether ET was prescribed, type of ET prescribed, occurrence of switching ET and ET initiation lag time. The latter was defined as the duration from index date to the first date of the first ET prescription record in CPRD. ET exposure time was also measured. This was defined as the duration from the date of the first ET prescription to the ET discontinuation date. Discontinuation was defined as the date at which the cover for the last ET prescription issued within the study period ended. Switching was defined as the discontinuation of the current therapy followed by the initiation of an alternative ET during study period.

4.4.3 Commonly prescribed medications

Commonly prescribed medication was measured using all prescriptions issued to the cohort during the study period. Each medication was categorised by drug class according to British National Formulary chapter. The categories were then ranked by the total number of prescriptions issued to the study cohort. Categories were defined as commonly prescribed if more than 10,000 prescriptions were issued over the study period. For this subgroup, the frequency of individuals prescribed each class of drug was calculated.

4.4.4 Cancer care review records

Any records of CCRs were identified from CPRD's *Medical* file. The number of CCRs recorded and the initiation lag time were measured. Initiation lag time of CCRs was defined as the duration between the index date and the date of the first recorded CCR.

Recording of CCRs in CPRD dates back to 2005. However, it may not be routinely recorded since QOF incentivisation only requires CCRs to be conducted within six months of cancer diagnosis, therefore provision after this time could be under-recorded.¹²⁷ Regardless, the data may still be useful in providing insight into treatment review practices and care received in the community setting.

4.5 Data management

Following data extraction and cohort refinement, there were several data management issues to take into consideration before proceeding with the analyses. When conducting research using big datasets, it is good practice for researchers to clean and check the data first.¹²⁸ Whilst the quality of the data provided had already been checked by CPRD, a plan for dealing with imperfections in the data also needed to be established, which would normally involve imputing data, where possible, or omitting observations. Before beginning each analysis, the relevant files were examined for missing data.

The only relevant missing data from the dataset related to the prescriptions in the *Therapy* file. In total 1934 prescriptions (0.04%) were missing details on the name of the medicine and the corresponding BNF information. However all entries had specified a *Prodcod*, from which the name of the medicine was able to be imputed.

In addition to dealing with missing data, there was also the possibility of errors or duplicated records in the data. Any implausible values were imputed where possible, or otherwise omitted. Where an entry was duplicated, such as instances where two prescriptions for the same quantity of the same medication were printed on the same day, the duplicated record was removed from the analysis.

4.6 Data analysis

The data, which included both categorical and continuous variables, were primarily analysed using descriptive statistics. Since the aim of this study was to build a picture of treatment pathways of the cohort, descriptive statistics were sufficient for this purpose. All data was managed and analysed in STATA SE 14,¹²⁹ Microsoft Excel was used to present data in various graph formats.

4.6.1 Patient characteristics

Age at baseline was analysed using mean and standard deviation, since the data was normally distributed. Ethnicity was reported by proportion. Follow-up duration was reported using two measures; the proportion of individuals alive and registered within each patient-year of follow-up, and the frequency of individuals in patient-year stratified according to age at baseline (under 55, 55-59 and 70+ years). Mortality data (time to death or study exit) was presented using a Kaplan-Meier curve, which was stratified by age groups (18-52, 53-62, 63-71, 72+ years).

4.6.2 ET treatment pathway

Descriptive statistics were used to report the proportion of individuals that were prescribed ET, including proportion of individuals initiated on each individual drug and the ET exposure time for each individual. The ET initiation lag time was categorised into pre-and post- six months of

index date. The proportion of individuals who switched ET was also reported. Individuals were then categorised according to the number of switches they experienced; reported as a proportion of the ET-receiving cohort. A decision tree was used to demonstrate the order in which each individual was initiated onto (or switched between) each ET. The proportion of individuals at each branch of the treatment pathway was also provided.

4.6.3 Commonly prescribed medications

The most commonly prescribed medications were categorised as described in section 4.4 Outcome measures. Frequencies and proportions of individuals prescribed each medication were reported.

4.6.4 Cancer care review records

The proportion of the cohort with one or more CCR records was reported. Further analysis then categorised individuals as having one record, two records, three records, or four and above records, presenting frequencies and proportions. Of those with 4 or more CCR records, range of records per patient was also reported. Timing of the first CCR (within or outside of six months of index date) or was also reported by proportion.

5 Qualitative approaches

This section discusses the methods adopted during the three phases of qualitative research – 1) survivor perspectives, 2) community pharmacist perspectives and, 3) stakeholder perspectives.

5.1 Choice of qualitative data source

For the purposes of collecting data from breast cancer survivors and community pharmacists; focus groups were selected as the most appropriate method over individual interviews. The natural conversational context and informal atmosphere is conducive to exploring participants' experiences and perspectives; enabling individuals to raise or clarify concerns that are significant to them.^{107, 130,}

¹³¹ This was particularly advantageous for the survivors, since discussing their experiences of cancer is a potentially sensitive topic. Being around others who have been through a similar journey could help put them at ease though creating a comfortable environment.

Additionally, the data produced by focus groups is often richer than individual interviews and they are a particularly beneficial technique for supporting the generation of ideas; making focus groups a commonly adopted method within health services and pharmacy research.^{130, 131}

This was certainly seen in this research; since some of the survivors were unable to attend the focus groups - due either to timing issues or being unable to travel - these participants were interviewed individually

so that their perspectives could still be included. Generally, focus groups produced more data per participant, since responses from one participant would often trigger ideas or additional perspectives from others.

Due to the wide variety of roles held by the stakeholders, the use of focus groups was not so beneficial. Although a focus group is more convenient for data collection, it is unlikely to have produced the same depth to the data as with the other participants. Additionally, stakeholders from across England were involved, so as a result of potentially long travelling distances coupled with the likelihood of busy working schedules, it was decided that individual interviews would be an appropriate alternative to a focus group where this was not practical.

5.2 Design of qualitative phases

Semi-structured focus groups were used to investigate the experiences and perspectives of breast cancer survivors. Due to the potentially sensitive nature of the discussions and the possibility that participants may not be in full health, some flexibility in the data collection approach was afforded. Therefore, where participants were unable to attend a focus group, individual interviews were held as an alternative.

Semi-structured online focus groups were carried out with community pharmacists to explore pharmacist views of introducing a service or intervention to meet survivor care needs; exploring potential

opportunities and barriers surrounding implementation within a community pharmacy setting.

Finally, individual semi-structured interviews were conducted with relevant stakeholders to explore their views towards the introduction of a new community pharmacy-based service for breast cancer patients; including what data would need to be captured in order to commission the proposed service. As part of the interview, stakeholders would be presented with a summary of the combined findings from the previous phases of the research project, on which they would be asked to comment.

5.2.1 Development of interview guides

To facilitate the collection of the data, a semi-structured interview guide (Appendix 6, page 400) was developed prior to each phase of data collection. A semi-structured approach was employed to allow freedom within the discussion to explore any relevant emerging topics, whilst also ensuring that the findings from the previous study phases were incorporated. The interview guides, which were submitted as part of the ethical approval process prior to study commencement, were kept deliberately brief since many of the topics to be discussed would be dependent on the findings from each preceding study phase. The iterative nature of data collection allowed for supplementary topic guides to be created prior to each data collection activity.

5.2.2 Patient and public involvement activity

Involving members of the public, such as patients or potential service users in the design of research project can be highly beneficial in ensuring its quality and relevance.¹³² Separate to participating in research or engaging with the dissemination of findings, considering patient and public perspectives during the design phases, such as to identify research priorities, take part in a steering group, develop user-friendly data collection tools or information or enhance recruitment strategies, can provide important insights that might have otherwise been overlooked.^{132, 133}

Whilst the first qualitative phase of the research centred on exploring the perspectives of breast cancer survivors through their participation in interviews and focus groups, patient involvement in the design of the study was also considered to be important. A patient and public involvement (PPI) activity was therefore undertaken in the form of a preliminary interview with a breast cancer survivor.

The participant was purposively selected to act as an 'expert patient' based on their survivor status and background in pharmacy practice research; enabling them to provide unique and valuable insights into the issues faced by breast cancer survivors whilst helping inform the development of the data collection tools from a research perspective. During the interview, the research questions and study design were shared with the participant, and their experiences and views were used

to develop a list of key themes for discussion (Appendix 7, page 403); these were then used by the facilitator during the focus groups and interviews to supplement the interview schedule.

5.3 Qualitative sampling and recruitment

Due to the nature of qualitative research, the exact number of participants required can be difficult to calculate in advance. However, the sample sizes needed are often smaller than those required for quantitative approaches. Whilst some researchers make arguments against wasting resources in collecting data from too large a sample,¹⁰⁷ ensuring sufficient amounts of data can be subjective and is not necessarily dictated by the number of participants involved. One suggestion is that data collection should be concluded when the researcher feels that they can largely predict the data that is likely to emerge.¹³⁴

This research used opportunity (or convenience) sampling and purposive sampling. Opportunity sampling occurs when a researcher uses their knowledge or experience and considers the practicalities when selecting a sample. For example, this could include utilising a previous knowledge of an area, using professional connections to contact participants or recruiters, or using participants who are accessible and available within the given time constraints.¹¹⁸ This technique was used when recruiting survivor and community pharmacist participants. Here, sample size is largely dictated by the

potential representativeness of the data; for example, whether participants were heterogeneous enough.^{135, 136}

Purposive sampling, meanwhile, occurs when participants are selected based on a desired characteristic. In this research, stakeholder participants were purposively sampled for their expert knowledge on breast cancer services or community pharmacy services. The sample size in purposive sampling is dictated by the point at which the data is inclusive.¹³⁶

These are both types of non-probability sampling and are conducted when random sampling is not possible or necessary. There are advantages and disadvantages to these techniques. Firstly, they allow the study to be conducted within the limitations of the available resources and, in the case of purposive sampling, are useful for ensuring rich data is collected. They can also be useful when the population size is too large, vulnerable, not easily identifiable or not equally accessible – this was the case when recruiting breast cancer survivors, in particular. The limitations of these approaches include their subjective nature, which introduces biases. This could include researcher bias, self-selection bias from participants, and hidden biases caused by outliers. This results in reduced generalisability on the data, and therefore reduced external validity (see also section 7 Methodological considerations).^{135, 136}

5.3.1 Survivor recruitment

When recruiting survivors, I decided that three focus groups would be arranged initially, and if required, further data collection would subsequently be undertaken. The number of participants within each focus group can influence the quality of data collected. Current literature considers a maximum of 6-8 participants per focus group optimum within pharmacy practice research; allowing in-depth discussion whilst ensuring even inclusion of members.¹³⁷ Meanwhile three participants were considered an acceptable minimum for a focus group (although in practice this did not happen, as explained later in this section).

Three geographical regions were selected within which to conduct the survivor focus groups. Including survivors from more than one location aimed to account for possible differences in the care provided across different areas and increase the overall representativeness of the findings. South Warwickshire, Lincolnshire and Nottinghamshire were selected due to both their adjacency and their high numbers of pharmacists with an active interest in improving cancer services; this was expected to maximise recruitment opportunities.

Within these regions, survivors were recruited through community pharmacies, which were approached to display recruitment posters and flyers (Appendix 8, page 407). Pharmacies supporting with recruitment were initially identified through existing professional contacts with

pharmacists and snowball sampling, i.e. the recruited pharmacists used their own professional contacts to identify and invite other pharmacy teams to support with recruitment. This method has practical advantages, making it easy to reach out to potential participants. However selection and gatekeeper biases may affect the study.¹³⁸

Survivor participants either volunteered after seeing recruitment literature or, in cases where recruiting pharmacists were BMIP-trained, eligible survivors already accessing the BMIP service were opportunistically invited to participate. Potential participants could either contact myself (the researcher) directly, or inform a member of the pharmacy team who would provide an information sheet and pass their details to the researcher.

The survivor participant information sheet (Appendix 9, page 408) was provided to all participants at point of recruitment. Where participants contacted me directly to volunteer, the information sheet was emailed out to them. Additional copies were also taken to each focus group and were supplied on request.

To assist with the recruitment, participating pharmacies were provided with a recruitment pack which included a letter explaining the recruitment process (Appendix 10, page 411), the recruitment posters and flyers, the participant information sheets, and a sheet to record the contact details of participants (Appendix 11, page 413).

Insufficient recruitment was minimised by monitoring recruitment figures on a weekly basis. As the study progressed, recruitment numbers were lower than initially anticipated. To address this issue, more pharmacies were needed to support with recruitment. A letter requesting support with this (Appendix 12, page 414) was sent to twelve pharmacies within each area. The included pharmacies were selected based on their proximity to the pharmacies already involved.

To ensure each focus group contained enough participants, efforts were made to reschedule focus groups in cases where fewer than three participants were able to confirm attendance. However, during one focus group, one of the three scheduled participants did not attend so for pragmatic reasons, the focus group was conducted with just two participants. Although not an ideal situation, the two participants had a very successful discussion; collaborating well as well as challenging each other when ideas or experiences were different. The data produced was likely far richer than if they had been interviewed separately. The third participant made contact at a later date and an individual interview was scheduled to gather her perspectives. The other focus groups ran smoothly; in some cases, data collection was delayed until enough participants were recruited within a particular location, or where acceptable to participants, they were asked to travel to attend the nearest convenient focus group.

Before taking part in a focus group, prospective participants had to undergo an eligibility check to confirm their suitability for the study. This was carried out at the point of recruitment; either in the pharmacy, or directly with the researcher. The applied selection criteria are described below (Table 1). Exclusion criteria have been kept to a minimum; allowing participant diversity and improving transferability of study findings.

5.3.2 Community pharmacist recruitment

The community pharmacist participants were selected through convenience sampling. Existing professional contacts were utilised to facilitate this, along with snowball sampling. Efforts were made to include pharmacists from across England, as well as a variety of community pharmacy experience – large multiples and independents, permanent staff and locums, and Boots Macmillan Information Pharmacists were included. Taking into account expected uptake and the time limitations, one focus group of 6-10 participants was initially considered appropriate to gather the required data. However, in practice the initial focus group involved only four participants, so recruitment was extended to enable a second focus group to be conducted. Increasing the sample size also ensured a more heterogeneous sample of community pharmacists were recruited, therefore increasing the potential transferability of study findings to the national population of community pharmacists.

Table 1: Outline and justification of inclusion criteria for survivor participants

Inclusion criteria	Justification
Able to give informed consent	Required for ethical reasons
Able to understand or communicate in English	Survivors needed to be able to communicate in English in order to participate in a group discussion. However, plans were made accommodate any minor communication issues (hearing or visual impairments, minor language difficulties) as far as possible
Females over 18 years of age	This reflects the inclusion criteria applied in phase 1; important since this phase builds on those findings. See also Treatment pathways chapter, section 4.3.1 Due to the extremely low prevalence of breast cancer in males and under 18s, these populations would be less likely to access any service that results from this research. Additionally, their very small numbers make them highly difficult to study due to the lack of potential participants
Treated for breast cancer within primary care in England	Participants to have experienced treatment for breast cancer within England's primary care setting to be able to contribute to the discussion
Minimum of two years since the first diagnosis of breast cancer was confirmed	As in phase 1. Additionally, including only those with a reasonable amount of time since diagnosis ensured survivors would have enough experience to reflect upon how their needs changed as they progressed through their cancer journey, and how care might be improved at the various stages.
Living within (or able to easily travel to) the selected geographical areas of recruitment	This was necessary for practical reasons

To ensure that any prospective participants would be suitable to take part in the study, they were required to be currently practising as a community pharmacist in England (Table 2). Eligibility was confirmed by the researcher at point of recruitment.

Table 2: Outline and justification of inclusion criterion for community pharmacist participants

Inclusion criteria	Justification
Currently practising community pharmacy in England	Kept brief to enable any practising community pharmacist from anywhere in England to take part. This aimed to maximise recruitment potential, support the recruitment of a heterogeneous sample and enhance the representativeness of the findings to national level.

Contact with participants was made via email, to invite, confirm eligibility, schedule the focus groups and share relevant paperwork including the participant information sheet (Appendix 13, page 416) and the consent form (Appendix 14, page 419). Since the community pharmacist focus groups relied upon co-ordinating the schedules of several participants, a Doodle poll (an online scheduling tool where participants can confirm their availability against a range of possible dates) was set up to collate the most appropriate options for these events.

5.3.3 Stakeholder recruitment

Stakeholder participants were sampled using expert sampling; a type of purposive sampling in which participants are selected for their expertise.¹³⁶ They were contacted through existing professional contacts. All communication, including the initial invitation, scheduling and subsequent paperwork was conducted using emails.

In total, five stakeholders were interviewed: A commissioner, a local pharmaceutical committee (LPC) chair, a Macmillan GP, a hospital oncology pharmacist and a representative from Macmillan Cancer Support. Whilst it was important to establish the views and opinions of stakeholders, the main purpose of this final research phase was to help contextualise the findings of the preceding phases; highlighting important considerations and 'next steps' for continuing this research and eventually implementing changes to practice. In order to best achieve this, the selected stakeholders were from a range of fields, bringing expertise in pharmacy, primary care service development and cancer care, rather than including multiple participants with similar backgrounds or expertise. Due to the required variation within the sample, the transferability of the findings for this particular phase was less important (since it would be unreasonable to conclude that the views expressed by each individual would represent those held within their respective field as a whole). Similarly, sample size was less of a concern as the sample needed only to be large enough to include a

variety of participants. Accordingly, the inclusion criteria for this phase were kept broad to reflect this required variety (Table 3).

Table 3: Outline and justification of inclusion criteria for stakeholder participants

Inclusion criteria	Justification
Job or voluntary role relevant to the development of breast cancer services in community pharmacy in England	Designed to enable any relevant stakeholders from anywhere in England to be included, therefore maximising recruitment opportunity and facilitating the consideration of views across a variety of fields and geographical locations
(Self-defined) Knowledge of current practice regarding cancer services in primary care, specifically community pharmacy	To ensure the participants have the necessary knowledge and expertise to make a worthwhile contribution to the study

5.4 Survivor data collection

5.4.1 Survivor surveys

Along with the required consent form (Appendix 15, page 420), a short survey (Appendix 16, page 421) was distributed to participants upon arrival at the focus group (or interview). The purpose of this was to gather potentially private information that the participant may not have wanted to disclose to the group, as well as to establish background information from the participants on demographics and treatments received. Answers were reviewed immediately before commencing

qualitative data collection and served the purpose of providing context for myself as the facilitator; ensuring the relevance of ET use-related questions and themes. Building on the findings of phase one, survey answer facilitated investigation into survivor experiences of ET-associated medicines-related problems.

Data was collected on age, area of residence, current ET prescription, previously prescribed ETs, duration of ET use and reasons for ET switch.

5.4.2 Scheduling the focus groups and interviews

To maximise focus group attendance, every effort was made to accommodate each participant's schedule. Selected venues were required to be within convenient travelling distance from participants; quiet enough to allow a group conversation to be held and audio-recorded with minimal background noise; and appropriately private ensure the focus group could not be overheard and confidentiality was maintained throughout. The chosen venues included a seminar room at the University, a village hall, and a meeting room at a business centre. Additionally, two individual interviews were conducted over the telephone to accommodate survivors who could not travel.

5.4.3 Facilitating the focus groups

As the main researcher, I acted as the facilitator for the focus groups. Given my experience of community pharmacy, this may have introduced some researcher bias to the study (discussed further in section 7: Methodological considerations). I initially welcomed the participants, provided refreshments and ensured the necessary paperwork was complete. Following this my role involved opening the discussion and encouraging participation by asking questions, introducing topics and prompting responses as required. I also endeavoured to keep the conversations on topic and ensuring every participant contributed to the conversation and had a chance to share their views.

The two larger focus groups were also attended by a second researcher, who adopted the role of observing and taking field notes to support the transcribing process. These notes primarily included an outline of the order in which the participants spoke and a brief summary of what was said. After each of the sessions, we would reflect on the experience together and discuss any additional topics to explore further when planning for the subsequent focus groups. As well as ensuring the safety of myself as the researcher, the second opinion also helped strengthen the credibility and confirmability of the study (see also section 7 Methodological considerations).

5.5 Survivor data analysis

5.5.1 Survey data

Due to the small number of participants, it was not appropriate to present survey data using descriptive statistics. Age group, area of residence and current ET drug were reported by frequencies. Previous ET use was categorised according to the number of previous ETs prescribed and the choice of drug; frequencies were once again reported for these. Duration of ET use data was categorised into yearly intervals then presented by frequency. Finally, reason for switch; an open question, was presented as a list since the sample size was small and no reasons were repeated, categorisation could not occur.

5.5.2 Focus group and interview data

To facilitate data analysis, all focus group and interview data was initially transcribed verbatim from the audio-recordings. Once the transcripts were prepared, data analysis was conducted as part of an iterative 4-step process. In order to adopt a clear and high-quality approach, the Green *et al.* framework was employed.¹³⁹ This recommends that data analysis should consist of 4 steps: 1) Immersion in data – this is also referred to by some researchers as *familiarisation*,¹⁴⁰ in which the researcher attempts to absorb the data by reviewing any field notes then printing, reading and annotating transcripts with any initial ideas; 2) Coding – this involves assigning labels to relevant ideas within the data, whilst taking into consideration

the context surrounding the excerpt; 3) Creating categories – this involves grouping codes by the factors that link them, forming a complete and explainable concept to describe that group of individual codes; and finally, 4) Identifying themes – this is emphasised as the most important step since it involves a more interpretive approach.

Whilst categorising codes provides a *descriptive* account of experiences, themes provide an *explanation* of findings within the wider context of the situation and taking any relevant theory into account. By comparing findings to what is known about other settings, the transferability of the results can be determined.¹³⁹

It is important to note that thematic analysis should be an iterative process and therefore the researcher will often need to move back and forth between each of the four stages in a cyclical process of reviewing and recoding data as required with each emergent category or theme.^{139, 141}

The process of coding, creating categories and identifying themes was conducted using NVivo 11 software to facilitate data management. The resulting codebook (a list of codes, categories and themes along with their descriptions) was reviewed by a second researcher who independently coded a third of the data (one interview and one focus group transcript) to confirm agreement with initial analyses. An example of the data and how it was coded can be seen in Appendix 17 (page 422).

5.6 Community pharmacist data collection

5.6.1 Using online focus groups

Focus groups were selected over individual interviews to promote discussion and the generation of ideas. The variety of experiences and perspectives from each participant enabled ideas to be confirmed or challenged, increasing the potential feasibility of agreed suggestions. Since the community pharmacists were recruited nationally, a face-to-face approach was not possible. However, the internet can be a useful research tool to support qualitative studies. Whilst traditional focus groups employ a face-to-face approach, online focus groups are becoming increasingly popular in health and social sciences research since they provide a practical solution to issues such as the geographical separation of participants, poor recruitment rates (for example due to busy schedules), and time constraints of the research, as well as facilitating anonymous discussion of potentially sensitive topics .^{142, 143}

The main advantages, however, are related to the data collected: When directly comparing online and face-to-face focus groups, previous studies have shown online methods to be similar, or even superior, particularly for generating ideas.^{142, 144, 145} They have also been found to produce more high-quality and objective data since participants tend to answer more honestly and thoughtfully during online discussions; removing risk of social desirability bias.¹⁴² Furthermore, written

responses afford every participant the opportunity to share their perspectives, eliminating any issues relating to dominating the conversation or lack of participation.^{142, 144} Online participants are also less likely to talk about irrelevant or 'off-topic' subjects.¹⁴⁵ Although the use of video chat is an option, the majority of online focus groups rely on typed messages. This carries a number of data analysis benefits for the researcher since it removes the need to transcribe the data; saving time and resources and improving the accuracy of data analysis through the lack of transcription errors or transcriber bias.^{142, 145}

Meanwhile, disadvantages to using online focus groups as an alternative to face-to-face focus groups include the need for all participants to have access to a computer and the internet and be comfortable with using the software involved. If the focus group involves the use of typed messages, difficulties in reading, typing or writing may also be problematic.¹⁴³ Additionally, the need to respond in writing has also been reported to slow down the focus groups, causing them to take longer or have less interaction.¹⁴³ Interestingly however, studies have shown that despite reduced communication with online focus groups compared to face-to-face methods, the number of ideas generated or answers provided are similar, suggesting that responses are more relevant.¹⁴⁴ Online focus groups can therefore be advantageous in providing participants with more time to reflect and provide more considered responses.

Another potential issue associated with online focus groups is that without non-verbal or visual cues, communication can sometimes lose some meaning; increasing the risk of misinterpretation of messages. Arguably however, a lack of these cues can also be advantageous since participants will be less aware of interpersonal differences and therefore more comfortable expressing their opinions; this allows for the inclusion of a more diverse group of participants, which has been shown to be more conducive to generating ideas.¹⁴⁶ It is also worth considering that some responses may not be sent; for example, if the topic moves on or is covered by other participants during the time taken to type up the response. In this scenario, the participants may choose instead to delete the message rather than send it.¹⁴⁴

Online focus groups can be either synchronous; i.e. conducted in real time, or asynchronous; i.e. participants can log on at a time that suits them and contribute to an ongoing discussion.^{142, 147} For the purposes of this study, the focus groups were conducted synchronously.

Asynchronous focus groups are further removed from the traditional face-to-face approach, often taking place over several weeks and therefore lacking the more natural conversational element that encourages the generation of ideas; one of the reasons focus groups were favoured for this research. The potential lack of interaction and loss of momentum within the discussion together with the additional data collection time made this option less suitable for this study.

Additionally, the advantages of asynchronous methods, including

circumnavigating scheduling conflicts, providing more time to digest information and supporting those with less computer literacy¹⁴⁷, were less relevant for this study given that the participants were practicing community pharmacists. As such, they were used to utilising computers and the internet in their day-to-day job roles and need to be skilled in processing information quickly and making evidence-based decisions. Additionally, all participants were aware of the subject matter before taking part in the focus groups and, since much of the conversation related to their expertise and job role, additional time to respond was unnecessary. More valued, was the more conversational ideas-generating discussion that a synchronous approach would provide.

5.6.2 Facilitating the focus groups

As with the survivor focus groups, I acted as the facilitator. This role was slightly different in the virtual environment since different skills are required. Whilst facilitator roles may be reduced in an online setting due to anonymity supporting a more inclusive and honest conversation, it is more likely that conversations may occur in parallel as participants respond to different ideas simultaneously. Facilitators must therefore be able to terminate or encourage these streams of conversation as required. Additionally, facilitators must be familiar with possible alternatives to non-verbal cues employed in an online setting such as the use of phonetic spelling, colloquialisms, acronyms or emoticons.^{146,}

¹⁴⁷

Prior to the focus group I communicated with all the participants by email to make sure they understood how to log on. I also shared my telephone number with them so that they would be able to get in touch if they were having problems with their internet connection. Initially, my role involved ensuring everyone had logged on and could fully participate in the conversation. To further support participants in logging on and using the software, I put together a brief guide to the software, detailing the login process and the features we would be using (Appendix 18, page 423).

The focus groups were conducted using Skype for Business. This software was chosen since it could easily be accessed online by those who do not have the software installed on their computer. It can be used on both PCs and Macs and was considered to be fairly intuitive to use. Additionally, it has the capability to share documents or present PowerPoint slides.

As the facilitator, I had originally intended to share the findings from the survivor focus groups over a PowerPoint presentation, which I would talk through over audio. Following this, we would then carry out the discussion itself using the instant message facility to type our questions, views and responses. However, during testing, almost all the participants experienced technical difficulties; either with the audio or accessing the presentation slides. To avoid wasting valuable data collection time attempting to troubleshoot technical problems, I made

the decision to conduct the focus groups using instant messaging only. This approach, although slightly more time consuming, proved effective.

After welcoming everyone and allowing them to introduce themselves, I started by outlining the findings from the survivor focus groups and interviews, in terms of the concerns and barriers to care identified by survivors. I then facilitated a discussion about potential solutions. Within this, I also shared the survivors' suggestions for improving care and encouraged discussion on the feasibility of ideas suggested.

5.6.3 Recording the data

Since the focus groups were carried out using instant messaging, a written record of the discussion was automatically produced. Following the conclusion of each focus group, a complete copy of the discussion transcript was created; this would later be used as part of the data analysis process.

5.7 Community pharmacist data analysis

Data analysis of the community pharmacist focus groups was conducted using iterative thematic analysis. The web chat transcripts were uploaded to NVivo 11 and the data was analysed using the same process used for the survivor data analysis (see section 5.5.2 Focus group and interview data)

5.8 Stakeholder data collection

Focus groups are a popular data collection method within health services research, due partially to their ability to support cooperation and the generation of ideas (see also Chapter 2, section 5.1 Choice of qualitative data source). For the final phase of this research project, a focus group was originally envisaged; providing an opportunity for stakeholders from different fields to collaborate and share views.

However due to scheduling conflicts together with the wide geographical distribution of participants, this was approach proved impractical. After some consideration, individual stakeholder interviews were selected as an appropriate alternative. These were conducted on a face-to-face basis where possible, since this approach was better suited to including the planned presentation of findings; where this was not possible, the presentation slides were emailed in advance and the interview then took place via the telephone.

5.8.1 Conducting the interview

As outlined in the interview guide (Appendix 6, page 400) each interview began with a presentation summarising the findings of each of the previous study phases (Appendix 19, page 427). The presentation was informal, and participants were encouraged to comment throughout, drawing on their knowledge and experience. Following the presentation, the participant was encouraged to offer their opinions of any aspects of the findings. Follow-up questions were then asked, in

order to explore the raised issues in depth, including anything the participant found to be particularly interesting, feasible or problematic; and considering possible future work in terms of research or implementing changes in practice. All interviews were digitally audio-recorded.

5.9 Stakeholder data analysis

A process of iterative thematic analysis was similarly conducted to analyse data from the stakeholder interviews. In this case, however, the audio files were uploaded directly to NVivo and rather than fully transcribing the data, the coding process was carried out on the audio file itself.

The stakeholder interviews took the form of an informal discussion. Since the objective was to gather stakeholder views on findings, much of the interview time was taken up with the presentation; during which participants would often interject to put forward their views. Whilst this approach produced a vast amount of interesting data, fully transcribing the combined presentation and interview data seemed unnecessary. Having fully transcribed the survivor focus groups and interviews, I was aware of the skill involved, as well as some of the advantages and disadvantages of the approach. I felt that within this context, it would be a waste of resources. I was aware of the concept of audio-coding so decided to research further and eventually concluded that it might

provide a more appropriate method of data analysis for this study phase.

5.9.1 The audio-coding approach

Computer Assisted Qualitative Data Analysis Software (CAQDAS) is a collective term for all the programs designed to support the management and coding of qualitative data;¹⁴⁸ this includes programs such as NVivo, ATLAS.ti, and MAXQDA. This type of software has been routinely used in qualitative research since the eighties, but newer releases of the software over the last decade have enabled the coding of sources other than text.^{149, 150} NVivo and ATLAS.ti, for example, now support coding of audio files, video files and images. These improvements in technology have provided new ways to analyse qualitative data and have led some researchers to question the value of traditional transcribing practices.¹⁵¹

The process of transcribing data provides an opportunity for researchers to become immersed in the data; however, it is a highly time-consuming task so many researchers outsource this activity to those outside of the research team. This therefore negates the data immersion benefits as well as incurring additional costs.^{149, 151}

Transcribing errors (due to misheard words or typographical errors) are also a concern; often requiring further resources to check transcripts against the original audio.¹⁵²

Aside from the obvious benefits of saving time and money by not transcribing the data,¹⁴⁹ it can be argued that in coding directly from audio files, the researcher can become more immersed in the original data as it was captured.¹⁵³ Transcriptions carry a risk of misinterpretation since the context in which the original statement was made is lost.¹⁵² Audio-coding, on the other hand, enables the researcher to consider tone, emotions, the flow of conversation, silences, intonations, and participant-researcher interactions when analysing and interpreting data; all of which could be vital in qualitative research, given that it is concerned with gathering naturalistic data that aims to represent the social world in its natural state.^{150, 151}

Thematic analysis traditionally uses a quote from the dataset to illustrate a theme. When audio-coding, selective transcribing of relevant quotes for such purposes is normally carried out. Although it can be argued that selective transcribing is preferable to fully transcribing an interview or focus group, (due to optimising resources, reducing the risk of transcribing errors, and minimising the removal of data from its natural context) it still oversimplifies and transforms the data. It has been suggested that ideally, a truly transparent and replicable study would report findings and include links to a place on the original audio file; therefore, allowing peers to hear the raw data and interpret it for themselves.¹⁵⁰ However, alongside the technological implications of reporting all qualitative studies in this way, there would also be ethical

considerations to providing access to audio-recordings, and steps would need to be taken to preserve participant anonymity.¹⁵³

Despite the many advantages of audio-coding, it is not routinely adopted by many researchers. A systematic review by Wood *et al.*¹⁵⁴ in 2016 showed that whilst many papers had not directly reported on how researchers had coded their data, audio-coding was seen to be more commonly used in conjunction with other techniques to triangulate data or to ensure the accuracy of coded transcripts.¹⁵⁴ Potential reasons for this apparent lack of uptake could be due to the challenges discussed above, or simply a slow pace of change to current practice. The authors also acknowledge that their study did not include methodological journals; a potentially preferred medium for reporting new techniques. They also suggest that small word count allowances in journal papers together with the lengthy process of getting a paper published could account for the lack of literature on the topic.¹⁵⁴

Whilst audio-coding can be useful when applied correctly, it does have some disadvantages. Importantly, it should not be seen as a 'shortcut'.¹⁵⁵ Audio-coding needs to be subject to the same systematic approaches as traditional transcript coding. Any qualitative analysis needs to be scientifically rigorous as well as being a creative and highly iterative process.¹⁴⁹ In 2010, Wainwright and Russell explored the concept of audio-coding and applied it to their own study; they reported on their experiences and offered advice on employing this method in

future studies; their advised approaches have since been applied in several other studies.^{149, 151, 156-158}

As with other qualitative analysis techniques, audio-coding requires skill and experience. Audio data can seem less tangible than written text and it can be more challenging to decide where an excerpt should begin and end, or see overlaps between codes.^{150, 151} Audio-coding can, in some cases, be more work than coding a transcript since the process requires the researcher to frequently stop and replay sections of audio, rather than simply reading back a few lines.¹⁵⁵ It has been suggested that the use of concise annotations can ease this issue; Wainwright and Russell recommend writing down just the subject or point of the excerpt so as to avoid transcribing the quote.¹⁵¹ This will promote a more analytical process since the researcher would need to replay the audio clip rather than just relying on the written text and therefore losing the non-verbal elements of communication.¹⁵¹ For the purposes of reporting data, a written publication is the usual approach.

On balance, audio-coding can potentially be a highly useful method when correctly applied. For the purposes of analysing the stakeholder data in this study it has a lot of potential to produce a rich analysis; uninhibited by transcription errors, misinterpretation of emotions, or loss of context. The potential disadvantages here, such as the potential to be time-consuming or difficult, can be considered to be worth the risk for a method that otherwise seems robust and reliable. Additionally, it is

important for researchers to explore newer approaches, so this will also be useful in terms of developing new skills.

6 Research ethics

6.1 Gaining the required ethical approvals

When considering the ethical implications of conducting this research, there was no need to seek approval for the quantitative phase. CPRD as a database already has ethical approval from the National Research Ethics Service Committee (NRES) for any purely observational research that utilises data from both the database itself and any of the linked databases.¹¹⁶ This approval therefore covered the planned analyses. However, the use of CPRD did require the study protocol to be reviewed and approved by the MHRA's ISAC.¹¹⁶ (Appendix 1, page 389)

In terms of the qualitative phases of this research project, establishing which ethical approvals were required was not as straightforward. Since the project involved collecting data on current service provision from patients and service providers, and discussing improvements and new services; there was initially some discussion over whether this project might come under 'service evaluation'. If this were deemed to be the case, ethical approval would not be necessary. After looking into service evaluation in more detail and seeking advice from the NHS Health Research Authority (HRA) and the University's Research

Governance department; a consensus was reached that ethical approvals would be required, since exploring the potential to develop a new service and was considered research.

Another consideration was whether ethical approval would be required from the NHS; the alternative being to seek approval from the relevant Research Ethics Committee (REC) within the University. Since survivor recruitment involved displaying posters and leaflets in community pharmacies and relied upon self-selection rather than recruitment through NHS services, there was not necessarily a need to obtain ethical approval through NHS channels for the survivor focus groups.

However, in terms of interviewing pharmacists, the initial advice from Research Governance stated that NHS REC approval would be required for this phase. The reason for this advice was based on a lack of clarity surrounding whether community pharmacists are subject to the same requirements as NHS employees in terms of whether NHS REC approval would be needed to interview them.

Although not employed by the NHS, community pharmacists deliver NHS services and therefore it could be argued that discussing the future role of their profession in breast cancer services could impact upon the services they carry out on behalf of the NHS. In line with this advice, the process of seeking REC approval through the NHS HRA was then initiated.

During the approval process, further advice on this issue was sought from several CCGs in the chosen data collection locations and from the HRA themselves. The responses from the CCGs largely suggested that their involvement, and in turn HRA approval would not be necessary, but where there was uncertainty, it was recommended that contact should be made with the HRA directly to confirm.

Although the protocol was submitted to the NHS for REC and HRA approval, further discussions led to the eventual agreement that NHS approval had not been necessary for this study. Correspondence from the HRA further confirmed that there was no need for them to review the study. However, since the protocol had already been reviewed and approved (subject to some minor amendments to the consent form) by an NHS REC, it was agreed that the best course of action was to proceed with the amendment and subsequent NHS REC approval, which was awarded in March 2017 (Appendix 20, page 434).

Further to this, (and although not an ethical issue) a minor amendment was submitted in July 2017 to allow the inclusion of a PPI activity, and to include that where focus groups were not possible, participants would be interviewed individually as an alternative.

6.2 Ethical considerations

Before carrying out the data collection, it was vital to ensure all potential risks to the participants or researchers involved would be minimised.

Breast cancer may have been a sensitive topic for survivors and there could have been an associated risk of distress. To combat this, survivors were encouraged to discuss only those experiences they felt comfortable sharing; promoting a friendly and 'safe' atmosphere. The participant information sheet (provided also to community pharmacist and stakeholder participants) contained written information about the study to ensure realistic expectations. This covered issues such as confidentiality, withdrawing from the study, complaints procedures and researcher contact details for any queries. Opportunities were provided at several stages during recruitment, scheduling and at the beginning of the focus group (or interview) to confirm understanding and discuss any questions or concerns.

Both myself, as the interviewer/facilitator and the second researcher who attended the survivor focus groups, are registered pharmacists with experience in recognising signs of emotional distress and supporting people with health conditions such as cancer. We were both aware of this possible risk and aimed to be responsive. We have also completed training in safeguarding, which may have been required if a relevant safeguarding issue had been disclosed during data collection. For the survivor participants, the requirement for a minimum of two years since diagnosis was expected to reduce the amount of emotional distress caused since there would have been time to come to terms with the diagnosis. Additionally, to promote an informal and relaxed atmosphere, light refreshments were available to survivors throughout

each session and time was set aside before each focus group or face to face interview for serving tea and coffee, introductions and chatting whilst the paperwork was completed. This appeared to work well as the participants chatted and seemed very comfortable around each other.

Personal information collected during recruitment was kept to a minimum (name and telephone and/or email). Any information disclosed during the study was treated as anonymous and University procedures with regards to confidentiality and data protection were adhered to. Identifiable information was stored securely with any paper documents or recordings being locked away, and electronic files being password protected.

Survivor participants were advised that although it was unlikely that any issues would occur that would necessitate breaking confidentiality, if they shared something that indicated they were at risk of harm, they would have been advised on the appropriate course of action to take, such as contacting their GP or another healthcare provider. Fortunately, no such issues occurred and the data collection ran smoothly.

All participants were required to provide written consent to being involved in the study. The consent form, as well as the participant information sheet and other study paperwork, was reviewed as part of the ethical approval process and provided prior to data collection.

7 Training and Personal Development

In order to develop my research skills, I undertook a variety of training courses throughout my PhD. These equipped me with the skills and knowledge needed to undertake key research activities and understand the underpinning methodological considerations of the research methods.

The majority of the first year was dedicated to completing modules and short courses. Having previously undertaken a research project as part of my MPharm degree, I already had some basic knowledge of conducting research, however, this needed to be further developed and updated for the purposes of my PhD. I initially signed up to modules providing the fundamental skills and knowledge for PhD level such as Research Design, Practice and Ethics; which explored research traditions and their ethical implications, as well as delving into the concepts of validity and reliability in the context of social research. I also completed modules that provided the underpinning knowledge of both qualitative and quantitative methodologies. Since it was likely that my project would likely involve developing cancer interventions in the primary care setting, I additionally attended a module in evaluating interventions, services and policy in health research. Together, these core modules helped me understand the philosophical underpinnings and applications of different research methodologies.

As my own research design began to take shape, I started to attend some more specialised courses that provided me with a more in-depth understanding of the work I was undertaking. Consequently, I completed a two-day block course on mixed methods approaches, specialising in the approach within health research. This module developed my understanding of the benefits and challenges of mixed methods approaches and provided me with an appreciation of the wide variety of study designs within the methodology.

I also undertook modules on Epidemiology with Basic Statistics and Advanced Statistics. These helped me to develop my skills with managing big datasets and using data analysis software such as Stata.

In order to further develop my qualitative research skills, I signed up to courses in advanced qualitative methods, conducting individual interviews and focus groups, and using NVivo software to support data analysis. I also participated in several research activities with other researchers in my department, which provided further insight into qualitative methods and helped me hone my qualitative data collection and analysis techniques. This included observing a focus group led by an experienced academic, quality checking transcripts for a PhD colleague, and participating in a focus group with PhD and academic colleagues to review some thematic analysis conducted by one of the PhD students. As a group, we discussed the data coding and came to an agreement about the chosen themes.

To further support my personal development as a researcher and in preparation for writing my thesis and undertaking my viva, I attended various short courses, such as managing long documents in Microsoft Word, writing efficiently, enhancing motivation, improving presentation skills and preparing for the viva.

8 Methodological considerations

One of the most crucial considerations when designing research is to ensure that the chosen protocols will be sufficiently rigorous. There were several important factors to consider when measuring this, particularly given the combination of methodological approaches used and how they fit together.

In quantitative research, the rigour of a study can be determined by assessing its *validity* and *reliability*. In simple terms, the concept of validity deals with how far the study measures what it aims to measure.¹⁵⁹ Reliability meanwhile, is related to how consistent the findings would be if the study were to be repeated.¹⁰⁷ The validity of a study can be affected by internal factors that influence how well the study was conducted, or external factors that deal with the generalisability of the findings.

The use of CPRD introduced several advantages to enhance the rigour within the quantitative phase of this research project. Since the database is designed for research purposes, it contains vast amounts

of data that is designed to be representative of the whole UK. Although this study focused only on England, the external validity of this study is expected to be strong. The use of the HES linkage to confirm diagnosis contributes to the internal validity of the study, triangulating the data to eliminate the risk of coding errors. Meanwhile, the reliability of the quantitative findings is maximised through the use of pre-approved protocols and clearly defined code lists. (See also Chapter 6: Summary Discussion and Conclusions, section 3 Strengths and limitations for a further discussion of these issues).

When assessing the rigour of qualitative research, the measures employed are slightly different; validity and reliability are arguably less relevant in qualitative work due to the assumption that reality is constantly changing, the use of small sample sizes, and the roles and beliefs of the researcher can have some impact on the data collected. Opinion on the most appropriate means of assessing rigour in qualitative studies is slightly divided; some frameworks exist to support in producing high-quality studies, such as the COnsolidated criteria for REporting Qualitative research (COREQ) and Standards for Reporting Qualitative Research (SRQR) checklists.¹⁶⁰ However, some researchers argue that using predetermined measurements of rigour implies that truth is absolute and therefore contradict the ontological underpinnings of qualitative research.¹⁵⁹

Some have addressed the issue by developing alternative terms to validity and reliability that fit more with qualitative philosophies. One example is Lincoln and Guba's¹⁶¹ concept of *trustworthiness*, a term which encompasses *credibility*, *transferability*, *dependability* and *confirmability*. Credibility asserts that the findings determined by the researcher are acceptable to others; this can be confirmed by employing good practice and *triangulation* (using multiple methods or data sources).¹⁶¹ Triangulation is a major advantage of mixed methods research (discussed further below). Good practice was attempted through the involvement of additional researchers in the study (e.g. my supervisors) with whom I was able to discuss the selected methods and reach a consensus about the most appropriate choices. Another example of a way in which enhanced credibility could have been achieved was through *member validation* (where study participants review findings and confirm that they agree with the researchers' interpretations).¹⁰⁷

Transferability is similar to the quantitative concept of external validity and considers whether findings could be applicable to an alternative time period or setting. It has been acknowledged that the importance of this issue may vary between studies, so sufficient detail should be provided in reporting to allow audiences to make their own judgements on this.^{107, 161} Several measures were taken as part of this research to maximise transferability, including recruiting participants from across England (or where this was not possible, three different counties, as

was the case for the survivors) and ensuring that the selection of community pharmacists and stakeholders encompassed a variety of experiences and backgrounds.

Dependability mirrors the concepts of reliability, and measures the replicability of the research.¹⁰⁷ Further to this, the importance of theory in producing high-quality transparent research has been highlighted by Lau and Traulsen,¹⁴¹ who emphasise the need to consider how theories impact on the research process as a whole. This includes both theory informing methodology and theory related to the interpretation on findings. It is vital for example, to be explicit about the epistemological stance taken by the researchers since this will influence methodological choices. Transparency in terms of how the data analysis was carried out and the extent to which theory was employed is also required.¹⁴¹ In order to achieve dependability and transparency, this thesis has included detailed explanations and justifications of the methods employed to produce the data, as well as how the data was interpreted and the relevance of the findings in the real-world context.

Finally, confirmability involves ensuring that the researcher, as far as possible, takes an objective approach to the research to minimise the impact of their own values or theories; this can likewise be assessed by third parties.¹⁰⁷ As the researcher, my background in community pharmacy will have some influence on the way I conduct my research and interpret the results. Whilst this can be useful, it does affect the

confirmability of the research. Several steps were taken to ensure this effect was minimised. Firstly, my profession was not disclosed to the survivors for fear that it would affect their candour when discussing their opinions of community pharmacists in terms of their expertise, and the types of support they needed. During the first focus group, several medicines-related questions were posited. These were either addressed by the group or noted by participants as something they should discuss with their local community pharmacists.

The confirmability of the research was further enhanced by having a second researcher present at the focus groups to make observations. Likewise, the data analysis was also checked by a second researcher, who reviewed and confirmed the coding and themes.

A further concept to consider when designing a rigorous qualitative study is that of *reflexivity*. As a more involved and continuous activity than the process of reflection; reflexivity requires the researcher to employ an ongoing and in-depth examination of what impact they, within the context of their research, have on the world, and what impact the world has on them.^{107 162} Throughout the course of this research, I aimed to be mindful of how my beliefs, values and experiences might influence my research and affect how I interpret my findings.

This chapter has previously described how mixed methods research can be complex since it combines the opposing qualitative and

quantitative philosophies; in this case through adopting pragmatism as a philosophical stance. Despite this, there are many advantages to employing mixed methods and the popularity of this approach is increasing. The key advantage of mixed methods is, of course, the ability to explore the breadth and depth of an issue.¹⁰⁸ It also permits the triangulation of data; that is, comparing quantitative and qualitative findings as a means of validation. Depending on the complexity of the design, different degrees of triangulation can be conducted. Holistic description is a type of triangulation that provides additional context to the research, as is achieved in this study through the inclusion of the stakeholder perspectives. In contrast, simple triangulation can also be carried out using two qualitative or two quantitative methods, but this will simply test the reliability of the study, rather than the external validity.¹⁶³

In mixed methods research, the *integration* of findings occurs when the outcomes of the quantitative and qualitative approaches are brought together and combined, producing the overall findings of the study.¹⁰⁶

Since the process and extent of integration in mixed methods research can differ between studies, several interpretations and categorisations of the term have been suggested in mixed methods literature. Moran-Ellis *et al.*,¹⁶⁴ for example, argue that findings can sometimes be combined without being integrated, and define integration as:

“the generation of a tangible relationship among methods, data and/or perspectives, retaining the integrity of each, through a set of actions clearly specified by the research team, and that allows them to ‘know more’ about their research topic.” ¹⁶⁴(p.51)

They posit several different levels of integration; the highest of which being *integrated methods*. Here, integration occurs at every stage of the research process; beginning during conceptualization and continuing until the final report. Alternatively, integration can also be carried out during a later stage of the study, such as during data analysis (*analytic integration*); or interpretation (*interpretive integration*). The authors acknowledge that using integration at any one of these stages is valid providing the researcher understands how the process will occur and the impact it will have on the subsequent stages of the research process. ¹⁶⁴

Using the above definitions, this research project could be described as using *interpretive integration*, since its sequential design enables the findings of each phase to be interpreted in such a way that they will inform the data collection, analysis and interpretation of each subsequent phase. An alternative, and perhaps more fitting definition for this method of integration is provided by Creswell,¹⁰⁶ who describes this as *connected integration*, when one set of data builds on the findings of the other.

Regardless of the definitions used, the design of this research study and use of iterative development ensured that the integration of findings occurred systematically throughout the various phases of the research process rather than being conducted as a separate and final phase.

Upon taking many methodological factors into consideration, I feel that employing an explanatory sequential mixed methods design embedded in pragmatism and using the methods described in this chapter, was the best use of the time and resources I had to effectively identify the opportunities for community pharmacists to develop their role in supporting those living with and after breast cancer.

9 Summary and outline of subsequent chapters

This chapter provided an overview of the mixed methods approach utilised in this research project, discussed the methodology in terms of methodological choices and the underpinning philosophies; described the methods employed in each study phase; discussing various choices made in terms of the study design, data collection and data analysis; and reflecting any methodological considerations that arose.

The subsequent chapters report and discuss the findings of each phase of the research in the order that it was conducted. There are three results chapters in total; *Chapter 3: Treatment Pathways*, *Chapter 4: Patient Perspectives* and *Chapter 5: Pharmacist and Stakeholder Perspectives*.

Although the pharmacist focus group and the stakeholder interviews were conducted as two separate phases, I chose to combine the findings of both phases into one chapter. Since the purpose of both the pharmacist and stakeholder focus group/interviews was to explore their respective views and consider issues surrounding the feasibility and the commissionability of a prospective service, the similarities of these phases lent themselves well to being written up together. This enabled the findings to be presented and discussed in the most logical way, minimising repetition.

Finally, *Chapter 6: Summary Discussion and Conclusion* deals with interpreting the integrated findings from the quantitative and qualitative phases and provides an overall discussion considering the strengths and weaknesses of the research and making recommendations for future work. Finally, a conclusion is provided summarising the research, its impact and the implications for the future research and service provision.

Chapter 3: Treatment pathways of breast cancer survivors within primary care in England

1 Introduction

This phase of the research aimed to explore the treatment pathways and healthcare needs of female breast cancer survivors treated in England's primary care setting, on which there was little existing literature. For the purposes of this study, *treatment pathways* were defined as the medications prescribed to each individual throughout their inclusion in the study, either as part of, or in addition to their cancer treatment and the order in which they were prescribed. Through highlighting drug utilisation patterns in current practice, the potential care needs of breast cancer survivors were able to be identified. Findings were then used to inform the subsequent phases of this research. This included the development of a semi-structured interview guide containing key themes for discussion in the survivor focus groups.

Using descriptive statistics to analyse the data, this chapter begins by exploring the characteristics of the cohort, including age, ethnicity and time to death. The main focus of this chapter is to explore patterns in the use of endocrine therapy within the cohort; enabling treatment pathways to be mapped out and therefore any potential healthcare needs to be identified.

The ET-related outcomes investigated included:

- Whether each individual was prescribed ET
- When ET was initiated in primary care
- The duration of ET use
- Whether switching between endocrine therapies occurred
- How many times each individual switched
- The order in which the endocrine therapies were prescribed for each individual

As the ET treatment pathway for each individual emerged, a decision tree was created summarising the ET choices and switches for the entire cohort, along with the proportion of individuals involved in each branch.

In addition to the detailed exploration of endocrine therapy prescribing, this chapter also investigates other commonly prescribed medications within the cohort.

Finally, the records for CCRs are also discussed within this chapter.

Whilst the potential benefits of this intervention have been established,⁶⁰ inconsistencies in its delivery mean that survivors may not be fully benefitting from the service. Despite being a QOF requirement, many patients report being unaware of having received a CCR. Establishing the uptake of these could provide useful insight into

treatment review practices in primary care to supplement understanding of the treatment pathway for breast cancer survivors (see also Chapter 1, section 3.1.4 Survivorship support).

2 Findings

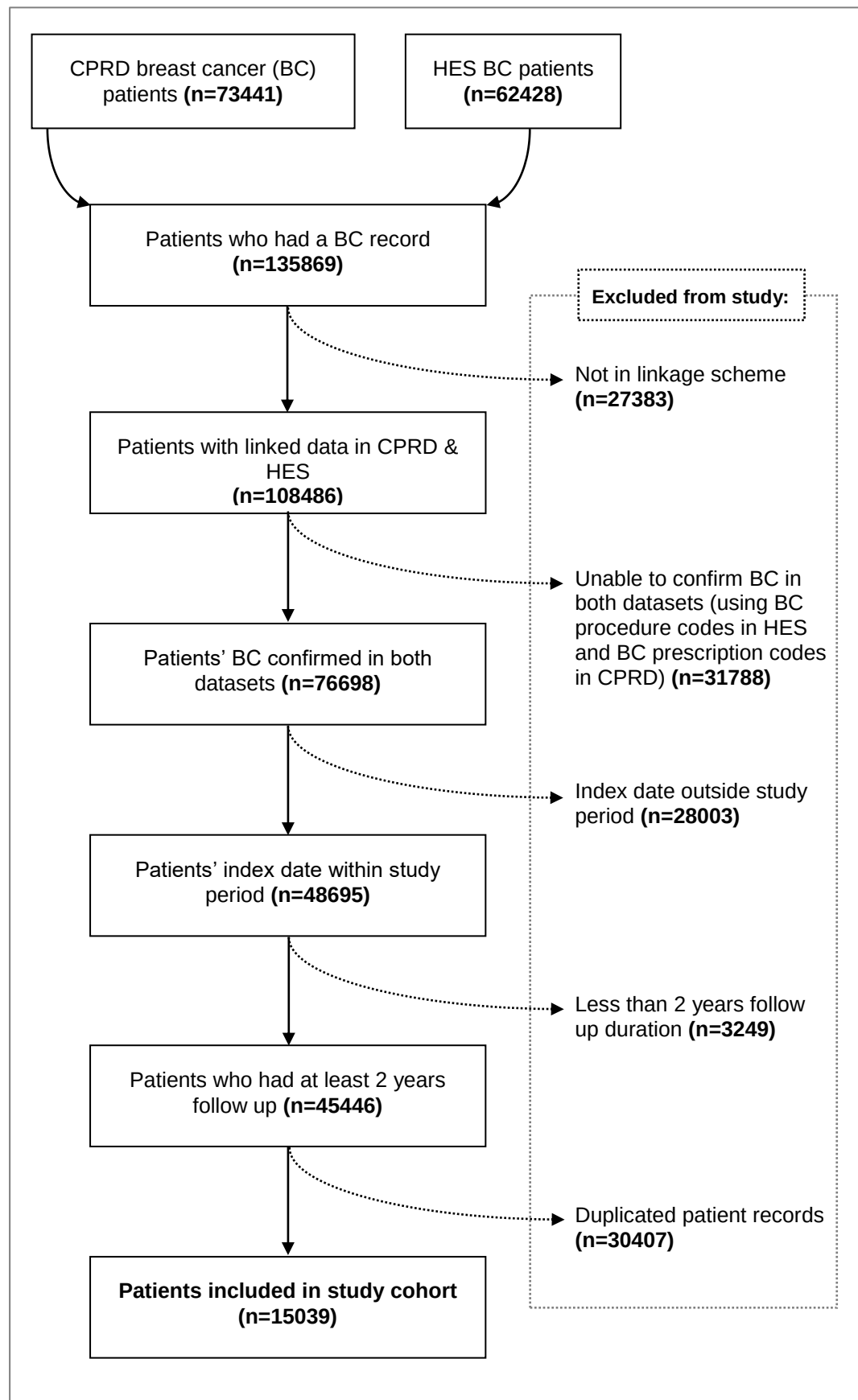
2.1 Cohort selection

Initially, 73,441 patients were identified as having breast cancer in CPRD and 62,428 in HES. Once patients were excluded due to (1) not being in the HES linkage scheme (n=2,383); (2) being unable to confirm breast cancer in both CPRD and HES using procedure codes indicating breast surgery in HES and prescriptions for a breast cancer medication in CPRD (n=76,698); (3) having an index date not within the study period (n=28,003); and (4) having less than 2 years follow up (n=3,249), this left 45,446 records in total. Of these, 30,407 were duplicates. This occurred due to initially combining records from two datasets (CPRD and HES). Finally, all duplicates were removed. (Figure 4).

2.2 Patient characteristics

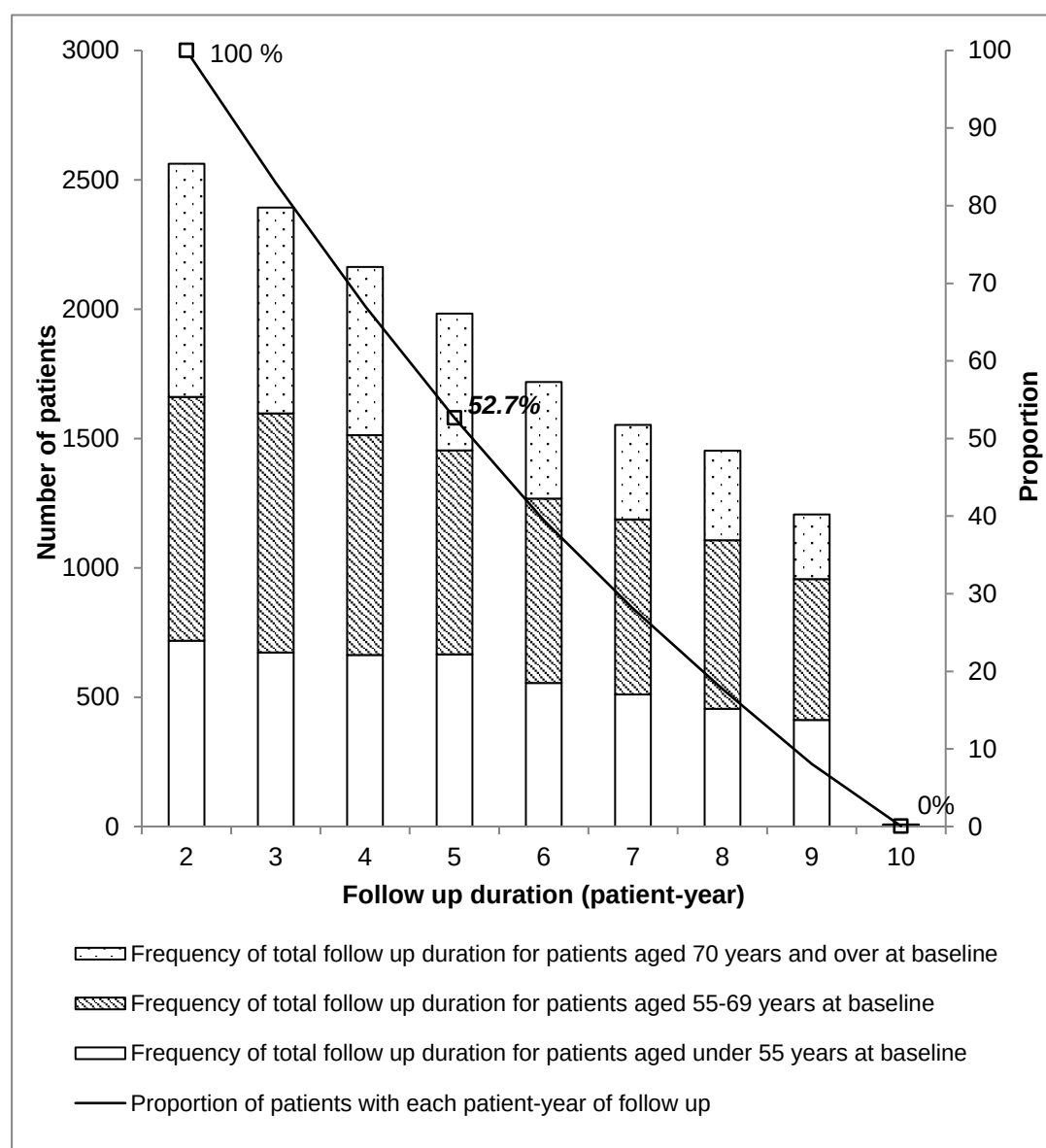
Overall, 15,039 breast cancer survivors with a minimum follow up period of two years were included in this study. The ages of the patients at index date were normally distributed, with a mean baseline age of 62.0 ± 13.3 years. Although ethnicity was unknown for 10% (n=1,515) of individuals, the majority were of white ethnicity (85.8%; n=12,898).

Figure 4: Cohort selection procedure



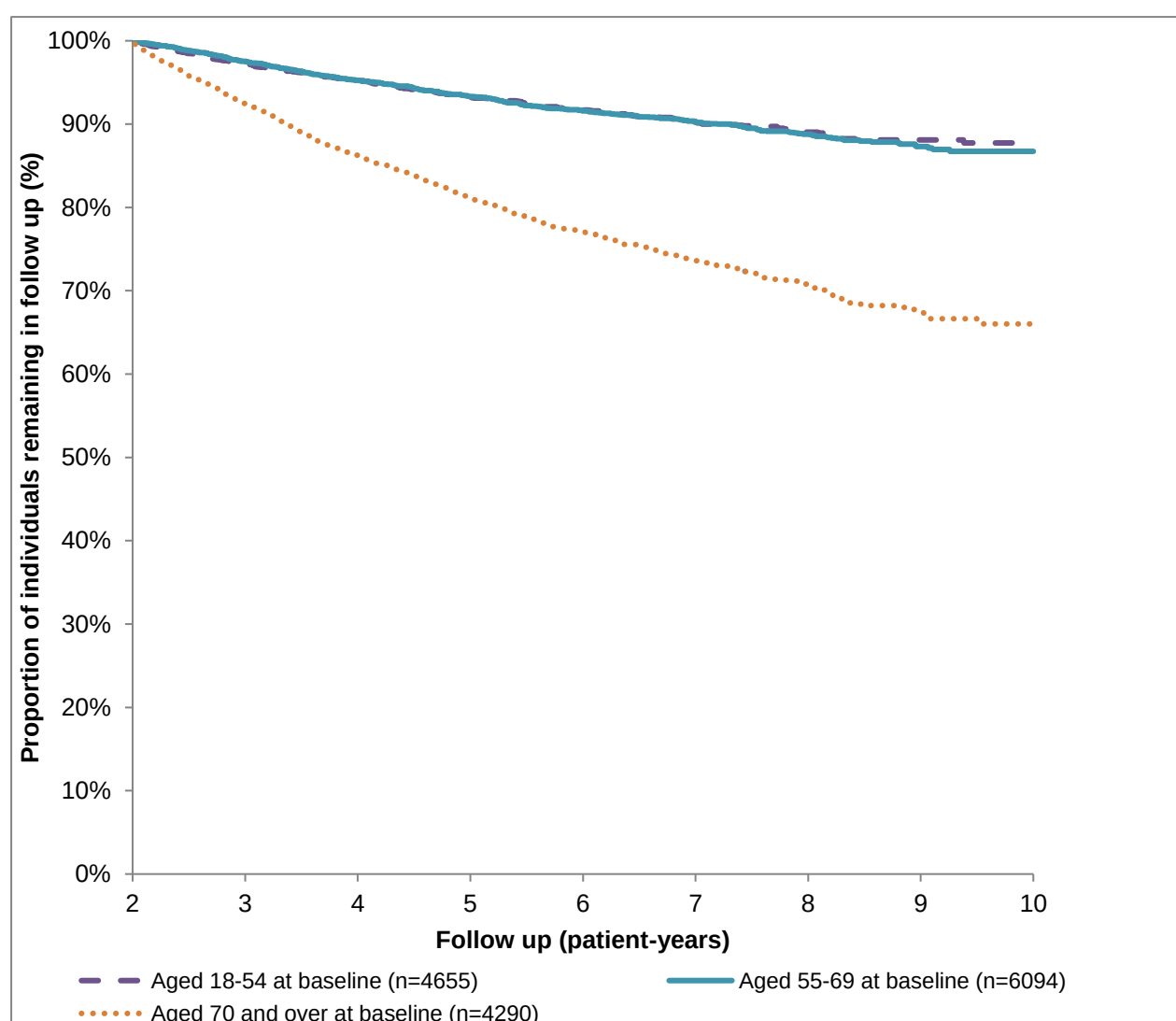
Follow up duration within the cohort ranged from two to ten years; with a median of 5.2 years and an interquartile range of 3.8 years. Just over half of the individuals (52.7%) were followed up for 5 years or longer (Figure 5).

Figure 5: Follow-up distribution of cohort



In total, 1,650 all-cause deaths (11.0%) occurred during the study period. The other reasons for exiting the study were transferring out from the GP practice (89.0%, n=13,389) and study end (81.3%, n=12,227). The five-year survival rate was 93.3% for both the under 55 years and the 55-69 years' groups, compared to 81.0% for the over 70 years age group. Ten-year survival rates followed a similar trend; with 88.7% and 86.7% survival for under 55s and 55-69s respectively, whilst ten-year survival for over 70s was only 66.0% (Figure 6).

Figure 6: Time to mortality or study exit



2.3 Endocrine therapy treatment pathways

2.3.1 ET exposure time

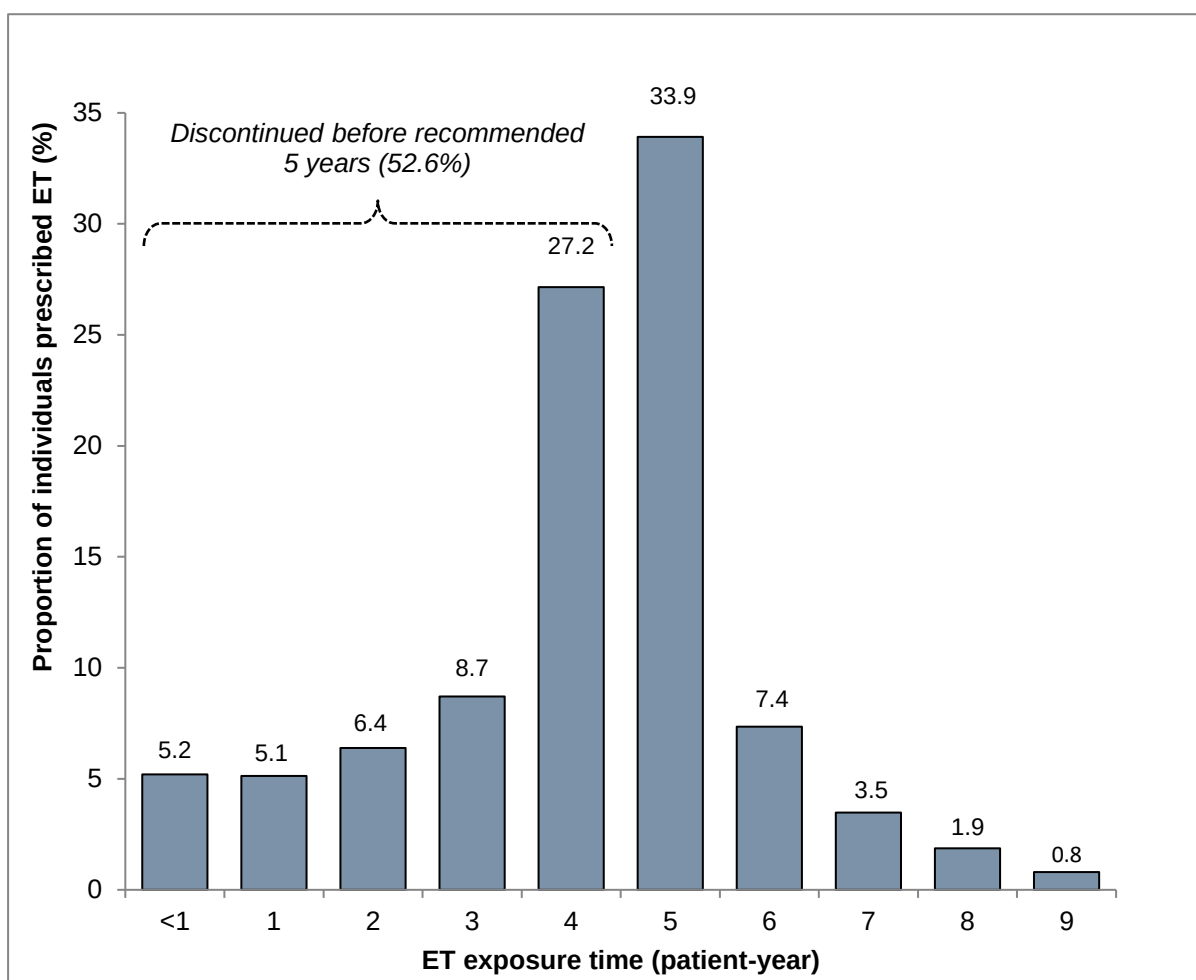
The majority of the cohort (81.8%; n=12,304) received ET treatment. Most individuals (70.6%; n=8691) were initiated on ET within 6 months of being discharged from hospital following their initial treatment. Comparatively, 23.9% (n=2939) received their first ET prescription six months to a year after the index date and 5.5% (n=674) were prescribed ET more than a year after index date. Of the 5867 (47.7%) individuals that were able to be followed up for a minimum of five years from their first ET prescription date, 52.6% (n=3085) did not continue their ET treatment for the full 5-year period recommended in national guidelines (Figure 7).

2.3.2 ET choice and switching patterns

2.3.2.1 Overview

The treatment pathways for those prescribed ET are complex. In total, 68.1% (n=8374) of the 12,304 ET cohort received a single therapy. However, 31.9% of patients switched ET at least once over the course of their treatment; 25.5% (n=3,134) switched once (receiving two ETs in total over the course of their treatment); 5.5%, (n=682) switched twice, 0.9% (n=111) switched three times, and 0.02% (n=3) switched four times, receiving a total of five ETs. Figure 8 provides a diagrammatic overview of the ET treatment pathways for the cohort.

Figure 7: Distribution of ET exposure time for individuals with a minimum of 5 years follow up from first ET prescription



2.3.2.2 Tamoxifen as first choice

When initiating ET, tamoxifen was the most common choice; prescribed to 47.3% (n=5824) of the patients. Of these, 60.9% (n=3548) remained on tamoxifen throughout their ET treatment. Anastrozole was the most common second choice for those patients who switched (22.4%; n=1306); followed by letrozole (9.1%; n=532) then exemestane (7.5%, n=437). One individual switched onto toremifene (Figure 8).

2.3.2.3 Aromatase inhibitor as first choice

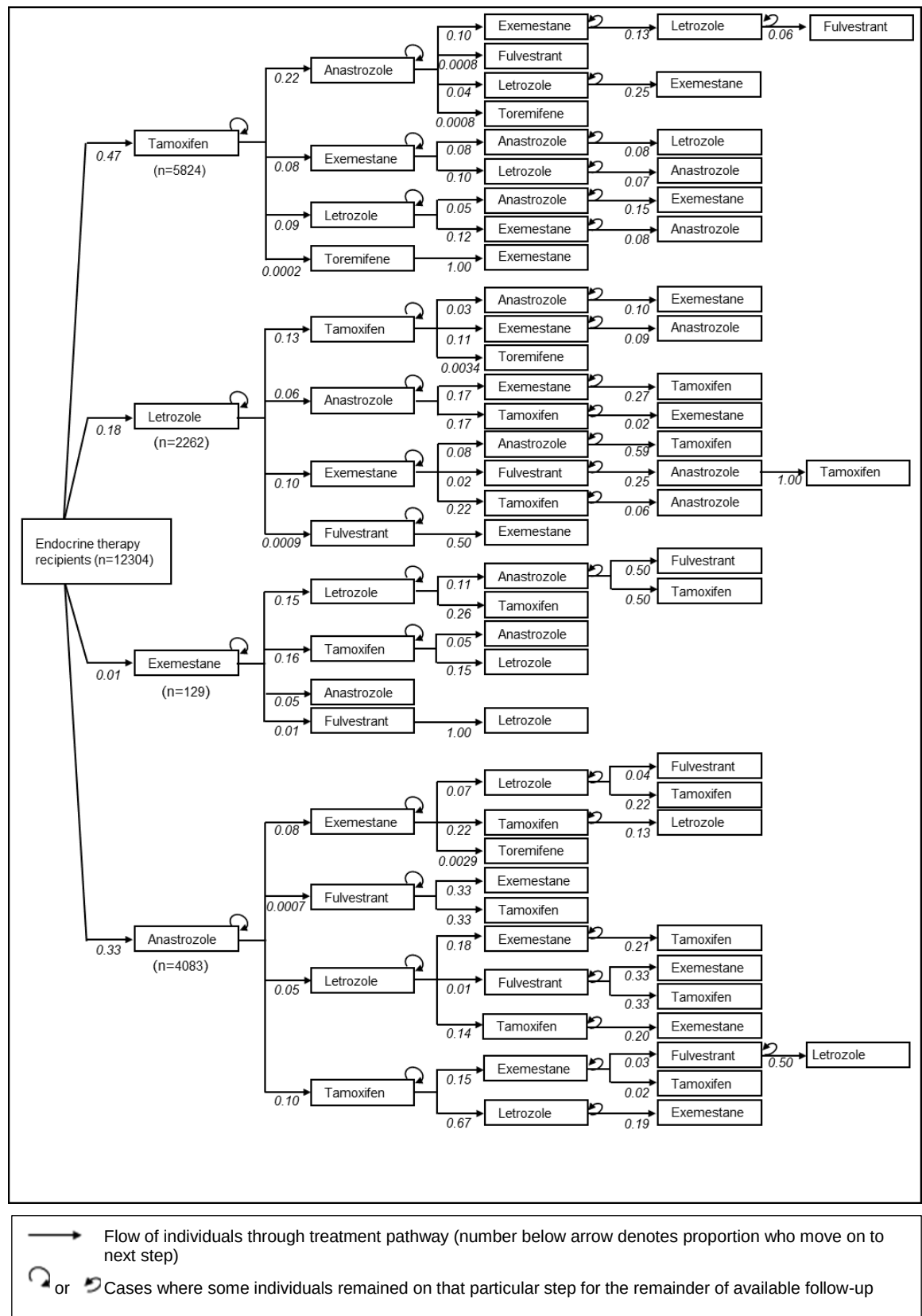
Of the individuals originally prescribed an AI (anastrozole/ letrozole/ exemestane) (52.6%; n=6474), tamoxifen was the most popular second choice (11.1%; n=716). Following this, 81.8% continued on tamoxifen. Meanwhile, the second choice for 14.3% (n=929) was an alternative AI. The majority of these individuals (75.5%; n=701) then continued on that second AI for the duration of the study (Figure 8).

Of the ET-receiving cohort, anastrozole was the first ET prescribed for 33.2% (n=4083) patients. Of these, 76.6% (n=3129) remained on anastrozole throughout. Tamoxifen was marginally more popular than the alternative aromatase inhibitors as a second choice of ET (9.7%, n=398), compared with 8.4% (n=345) who switched to exemestane and 5.1% (n=208) who switched to letrozole. Meanwhile, a very small percentage switched onto fulvestrant (0.07%, n=3).

Letrozole was the initial ET for 18.4% (n=2262) of the ET-receiving cohort. The majority of these individuals (71.3%; n=1612) remained on this therapy throughout the study. However, 13.2% (n=298) went on to be prescribed tamoxifen; 9.6% (n=218) exemestane, 5.8% (n=132) anastrozole and 0.09% (n=2) fulvestrant.

Exemestane was the first choice of ET for 1.0% (n=129) of the ET-cohort. Of these, 63.6% (n=82) remained on this therapy throughout. The most common switches were to tamoxifen (15.5%, n=20) and

Figure 8: Endocrine therapy prescription switching patterns



letrozole (14.7% (n=19). Anastrozole was a second choice for 5.4% (n=7) whilst fulvestrant was second choice for one individual.

2.3.2.4 Fulvestrant as first choice

The remainder of the ET-cohort were initially prescribed fulvestrant (0.05%; n=6) as a first ET, of which 3 individuals switched; one to exemestane, one to letrozole and one to tamoxifen (Figure 8).

2.4 Commonly prescribed medications

In addition to ET, the most commonly prescribed medications within the cohort during the study period were antibiotics, which were prescribed to 74.7% (n=11,235) of the cohort. This was followed by analgesics (70.3%, n=10,571), anti-secretory gastrointestinal drugs, (i.e. proton pump inhibitors and Histamine receptor 2 antagonists; 50.4%, n=7591), vitamin D compounds (40.4%, n=6078) and laxatives (33.3%; n=5000) (Table 4).

2.5 Cancer care review records

Over the course of the study period, 69.9% (n=10,517) of the cohort had any record of receiving a CCR. The majority (60.7%, n=6,388) of these individuals had only one recorded CCR, whilst 19.1% (n=2009) had two records and 7.6% (n=804) had three. Meanwhile 12.5% (n=1316) of patients had four or more records of CCRs. Of these, 63 individuals had between 20 and 89 CCR records.

Table 4: Top 20 commonly prescribed medications by number of patients prescribed each one

Category	Number of patients	Proportion of patients (%)
Antibiotics	11235	74.71
Analgesics	10571	70.29
Anti-secretory gastrointestinal drugs	7591	50.48
Vitamin D and compound preparations	6078	40.41
Laxatives	5000	33.25
Emollients	4544	30.21
Lipid regulators	4150	27.59
Hypnotics	3876	25.77
Selective serotonin re-uptake inhibitors	3354	22.30
Topical corticosteroids with antimicrobials	3328	22.13
Angiotensin-converting enzyme inhibitors	3327	22.12
Bisphosphonates and other drugs affecting bone metabolism	3293	21.90
Calcium-channel blockers	3269	21.74
Tricyclic and related antidepressants	3241	21.55
Respiratory medication	3211	21.35
Non-sedating antihistamines	2900	19.28
Topical nonsteroidal anti-inflammatory drugs & counter irritants	2866	19.06
Antiplatelet drugs	2829	18.81
Beta blockers	2757	18.33
Thiazide and related diuretics	2561	17.03

The initiation lag time of CCR (i.e. the time when patient discharged from hospital to the first CCR recorded in primary care) varied greatly amongst the cohort, from the same day as discharge to 9.5 years later. Of those with CCR records, the majority (90%, n=9415) had their first within six months after discharge.

3 Chapter Summary

This section provides a summary of the key findings reported in this chapter and discusses how these findings will be utilised to inform the subsequent phases of data collection and analysis within this research. An in-depth discussion of findings is provided in Chapter 6, section 2 Key Findings.

3.1 Key findings

Breast cancer survivors in England's primary care system are often exposed to ET for long periods. However, switching between therapies is common and almost one third of the population has switched ET one to four times. Furthermore, over half of individuals fail to complete the recommended five-year treatment period, increasing their risk of breast cancer recurrence and mortality. These concerning findings highlight the need for better survivorship services in primary care; addressing patient outcomes and their causes, such as medicines-related problems. As experts in medicines, community pharmacists therefore have scope to take on a more significant role in supporting breast cancer survivors.

Meanwhile CCR data highlighted that over 30% of individuals had no record of receiving a CCR, something that should be provided to all individuals within 6 months of diagnosis. Conversely, over 12% of the individuals were recorded as having received more than 4 with the number of interventions records per individual ranging from 4 to 89. Whilst the CCR intervention is designed to be repeated as needed, some of these figures were unexpectedly high. This suggests that measures to improve the accuracy of CCR records are required. Additionally, there may be a requirement for a more standardised approach to delivering CCRs, but further research is required to confirm these hypotheses.

3.2 Informing the subsequent study phases

Armed with a clear picture of the treatment pathways of breast cancer survivors within primary care in England, the scope for community pharmacists to take on a more significant role in breast cancer survivorship services is evident. The subsequent stages of the study must further explore the potential opportunities here, establishing what that role could look like for community pharmacists. This will be addressed through collecting qualitative data on the experiences of breast cancer survivors whilst being treated in primary care, with particular focus on any unmet care needs or medicines-related problems.

Medicines-related problems are a likely a key issue for this population. It is therefore important to explore this hypothesis further in future work. Through a process of iterative development, the findings of this research phase will inform the topics discussed in the survivor focus groups and interviews, providing some *a priori* issues for the topic guide. Importantly, the focus groups will explore patient experiences of medicines-related problems during ET treatment and consider how primary care services, particularly those in community pharmacy, could be improved to better support survivors.

Other issues of interest are the circumstances surrounding switching or early discontinuation of ET. Although causal links can be established through further quantitative work, the focus groups will provide an

opportunity to gather some rich data surrounding these experiences and how they affected the lives of survivors. Additionally, the issue of CCRs is worth further exploration. Although there is no limit to the amount of CCRs an individual can have, the surprisingly high frequency of individuals who had reportedly received between 20 and 89 interventions suggests a lack of accuracy in recording practices. By means of triangulating the data, it would therefore be interesting to explore survivor awareness of CCRs, their experiences of the intervention and whether they recall having multiple CCRs.

In summary, the findings of this chapter have revealed following issues to be discussed as part of the survivor data collection:

- Survivor experiences of adverse effects of treatment (if any) and how these were managed
- Experiences and views of adherence and persistence, survivor understanding of their treatments and why they were needed
- Survivor experiences of ET switching and reasons for switching
- Experiences and views of CCRs
- What unmet care needs do survivors identify? (Particularly in relation to medicines optimisation and medicine-related problems)
- Survivor perspectives on how community pharmacists could better support them to get the most out of their medicines?

Chapter 4: Survivor Perspectives

1 Introduction

This chapter explores the findings of the first phase of qualitative research. The previous chapter revealed the extent of early discontinuation and frequent switching within the national population of breast cancer survivors. This identified potential scope for community pharmacists to support survivors in optimising their endocrine therapy. It also raised some key issues to be explored further, including survivor experiences of taking endocrine therapy, medicines-related problems, experiences of care in the community setting and any unmet care needs. In order to fully understand survivor experiences and perspectives on these issues, the use of qualitative approaches to conduct an in-depth exploration was essential.

Through the use of focus groups and individual interviews with breast cancer survivors, this phase of the research set out to identify further potential opportunities for community pharmacists to take on a larger role in breast cancer survivorship support. In order to ascertain the acceptability and feasibility of any identified opportunities, insight into the requirements, attitudes and opinions of breast cancer survivors towards new community pharmacy-based cancer services was initially required. This phase also aimed to identify any particular points in the breast cancer journey where survivors felt community pharmacists could offer support. Using the findings from phase one to inform the

topics of discussion, a semi-structured interview guide was developed to support data collection. A detailed description of the approaches used was provided in Chapter 2, section 5 Qualitative approaches.

The remainder of this chapter will be made up of two sections: Findings and Chapter Summary. The former will report on emergent themes from the data, in terms of barriers to care from the survivor perspective, and suggestions for improving survivor experience. Finally, the chapter summary reflects on key findings and outlines how these can be utilised to inform the subsequent research phases. The strengths and limitations of the research, along with the implications of the findings will be discussed in the final chapter of this thesis.

2 Findings

2.1 Participant characteristics and experiences of endocrine therapy treatment

In total, 13 survivors participated in the study. This took the format of three focus groups (one in each of the selected regions; involving five, three and two participants respectively) and three individual interviews for those who were unable to attend. The duration of data collection ranged from one hour and five minutes to two hours and two minutes.

Prior to each focus group or interview, each of the 13 participants completed a survey to provide a small amount of background information which then informed the direction of discussion. Of the 12

survivors who provided information on their age (one participant declined to answer), the majority were aged 56-70 (n=7). Meanwhile four participants were aged 41-55 and one individual was over 70 years of age.

In terms of geographical location, the survey gathered data on which of the three involved counties the participants were based. However, it is of note that due to scheduling conflicts, not all participants were able to attend the focus group held nearest to them and agreed to travel elsewhere. Similarly, whilst several of the survivors lived in Nottinghamshire, for some, their nearest hospital was in neighbouring Lincolnshire. The largest proportion of survivors were those residing in Nottinghamshire (n=7). Meanwhile, four participants lived in Warwickshire and two lived in Lincolnshire.

Most participants (n=8) were currently receiving ET at the time of attending the focus group or interview. One participant was taking Herceptin and Pertuzumab, whilst the remaining four participants reported receiving no current medication for their breast cancer.

All the participants had received medicine to manage their breast cancer; either currently or previously. Nine individuals reported previously receiving ET or another medication to manage their breast cancer.

Aromatase Inhibitors (anastrozole or letrozole) were the most common initial prescription for the majority of participants (n=7). Following this, four of these individuals switched to alternative therapies; tamoxifen was provided as an alternative for three participants, and the fourth individual initiated on an alternative AI.

Tamoxifen was reported to be the first prescribed medicine for five individuals, of whom two individuals were currently continuing to take it and one had switched to anastrozole.

ET treatment duration most commonly exceeded five years (n=10). Of the three individuals who had continued treatment for less than the recommended five years, two were currently being treated with ET (continued for up to one year and up to two years respectively) and the third individual was currently taking Herceptin and Pertuzumab and had done so for up to three years.

Switching between therapies was reported by almost half the participants (n=6), of whom, all but one individual provided a reason for the switch. Reported reasons included spread of cancer (n=2), side effects (n=1), 'did not suit' (n=1), and doctor-recommended switch following completion of five years on initial ET (n=1).

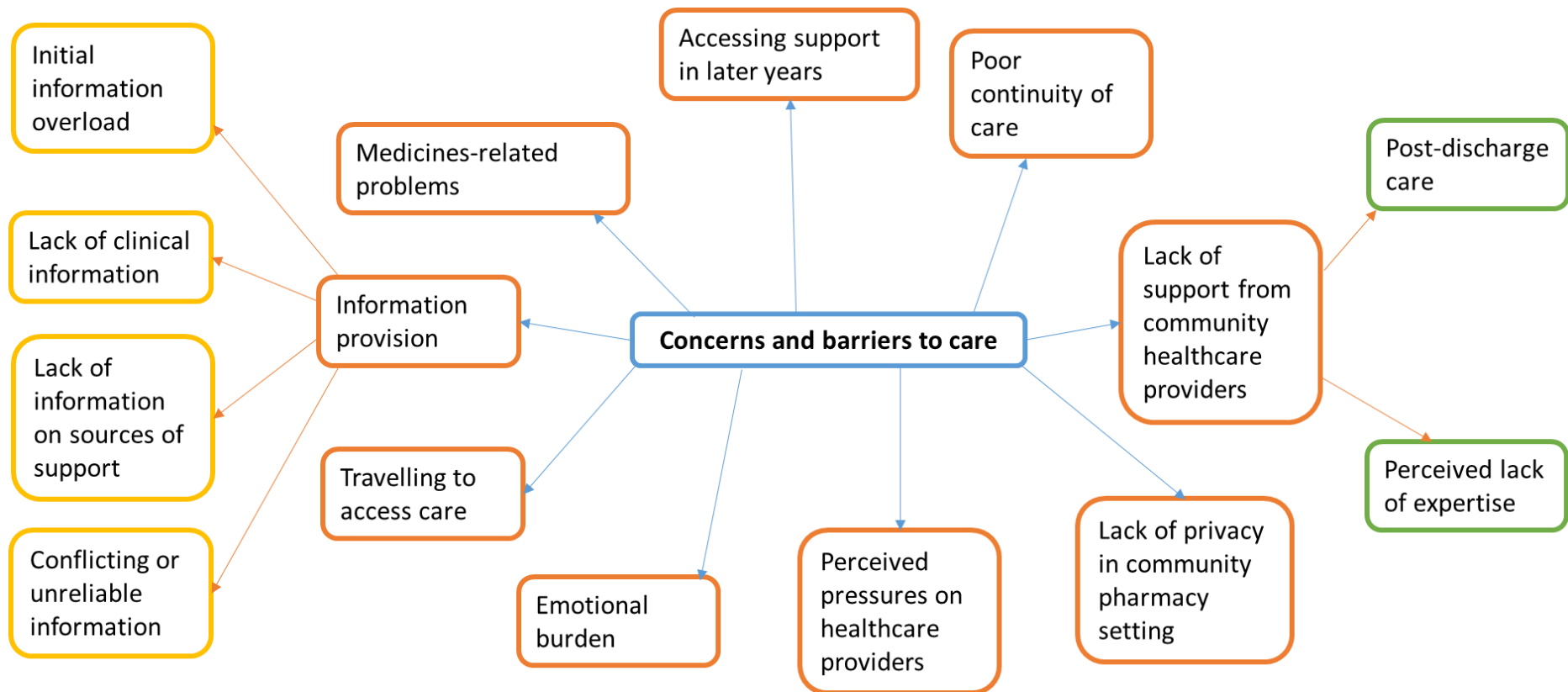
2.2 Qualitative themes

During the process of iterative thematic analysis, emerging codes largely fell into one of two overarching themes: *Concerns and barriers to care* and *Suggestions for improving care*; within these, there were several further themes and subthemes. The iterative nature of the analysis also facilitated a more in-depth exploration of underlying issues and highlighted linkages between existing themes. All emergent themes are reported and discussed below. Appendix 17 (page 422) provides an example of the coding process.

2.2.1 Concerns and barriers to care

The first of two overarching themes, *Concerns and Barriers to Care* describes the issues that survivors felt had negatively affected their cancer journey, or the care they received in the community setting (Figure 9). When considering this, survivors were asked to focus particularly on the care provided in the community setting following diagnosis and initial treatment, as well as the positive and negative aspects of their experiences in this setting. Where relevant, care provided whilst transitioning between settings or any simultaneous care provided in hospital setting was also discussed. Discussions also explored how survivors' needs and the care provided changed throughout various stages of the cancer journey.

Figure 9: Diagrammatic representation of the Concerns and Barriers to Care theme



2.2.1.1 Emotional burden

The most commonly occurring theme across the qualitative survivor data were the emotional aspects of their experiences. The breast cancer journey - from diagnosis, throughout treatment and recovery – can be very challenging and there are many potentially emotional issues. This section summarises the key concerns for the survivors and where they felt they were let down in terms of the care and support they received.

Many survivors reported a general lack of emotional support and often struggled to find the physical and emotional strength to actively seek it out.

“And you were saying about emotional support and I think that was the big thing that was... Even from the hospital actually. I wasn't offered any support at all...Only from my family and friends.”

- Survivor_08

Long waiting times and oversubscribed counselling services also compounded this issue (see also section 2.2.1.8 Perceived pressures on healthcare providers). However, emotional support was not only discussed in terms of formal counselling services; the level and type of emotional support needed varied greatly. For some, all that was missing was a friendly face to provide reassurance; for others their

concerns were more specific. The discussions highlighted a range of issues that caused considerable emotional distress, and many involved getting on with everyday life whilst living with breast cancer. Such issues included financial concerns, transportation issues, or anxiety about returning to work. Often all that was required to support with getting back to a normal life was simple practical advice or signposting to appropriate sources of help.

“It’s not just pills, potions that you need, its psychological help, you know. And to point you in directions of help so that you don’t...I mean you’re in this big hole and you’re trying to get yourself out and you can’t.”

- Survivor_11

Some survivors spoke about suffering from depression or anxiety and experiencing a lack of advice or non-pharmacological treatments.

“Talking to another GP it was all around ‘Well we can prescribe these antidepressants’ and I’m thinking ‘Oh my goodness! This is not a conversation that I want to be having. I’ll do something to pick myself back up but I shouldn’t have to just be told antidepressants are the only route; there must be other things that you can do other than take more drugs!’ And I think it’s quite sad that we get to that point.”

- Survivor_01

Many of the emotional burdens were linked to the treatment process itself; the shock of the diagnosis, fears around survival, not knowing what to expect in terms of treatment procedures, fears of potential side effects or how they will cope with life after treatment. Unfortunately, the majority of survivors felt that they were not supplied with adequate information to effectively cope with these concerns or to find the support they needed; these issues are explored in more depth later on in this chapter (see also sections 2.2.1.3 Information provision and section 2.2.1.4 Lack of support from community healthcare providers).

The recurrence of breast cancer was a fear that plagued many participants. Several noted struggling to cope with the worry and paranoia that still exists, even years later. This fear was magnified for those coming to the end of their 10-year courses of endocrine therapy.

“And then when you stop the tamoxifen, it’s actually been your crutch really. So if you get through 10 years cancer-free and then you stop taking the one thing that you’ve been given to stop you getting cancer; I think that’s when it’s going to be quite hard...mentally to kind of not take anything anymore. Because if you think taking a drug for 10 years; that’s a long...that’s a massive part of your life.”

- Survivor_12

In addition to fearing for themselves, survivors mentioned concerns over the potentially hereditary aspect of the disease. The question of

genetic testing came up a few times and one survivor was concerned about whether she should encourage her family members to seek care, but at the same time did not want to scare anyone unnecessarily.

“I’ve got two daughters and I got it in my 30s, so is there anything connecting up to see that they potentially get checked when they’re adults? I don’t know. So do we need to be proactive about that? I don’t know. Only I don’t think mine was hereditary, but is there any connected care because that was one of my first thoughts; my children and my sisters.”

- Survivor_07

The public perceptions of cancer survivors were a source of anger and frustration for some; examples were mentioned of using phrases that conjured images of battles, bravery, or fighting, which did not reflect how the survivors felt as they progressed through their cancer journey. One discussion noted that another popular reaction was to tell anecdotes about family members or friends who survived cancer, and whilst this was often meant to be a source of comfort, it could be very upsetting.

“It was somebody who was saying about his auntie, his granny, his sister, and Uncle Tom Cobley and all, ‘And they’re all still going today!’ And I actually wrote [in my journal] that I wanted to say ‘Oh that’s grand, but my sister died two years ago. How insensitive are you?!’ But I don’t think they are being insensitive; they’re trying to get you along aren’t they?”

Body image concerns were identified as not being talked about enough. Whilst some had encountered charities such as 'Look Good Feel Better', which were helpful, a need for more support with body image was identified. Reconstructive breast surgery for example, caused a great deal of nervousness since many of the survivors had heard horror stories about the surgeries not being successful, or were not offered the surgery of their choice. Survivors were also underprepared for the difficult recovery process or what the end result would be.

"One of the nurses told me that the surgeon had a website and you could actually click on it and see people that had had the reconstructive surgery. And that was really useful, because you think, well actually, no they don't look like freaks and, you know, if it's going to be that good, it really did put my mind at rest. It was very useful. But with the lymph nodes I didn't. And I didn't realise there was going to be. That upset me more than anything because there was sort of like a hole, you know, a real indent under my armpit that I wasn't expecting and nobody had prepared me for that. I suppose if you think about it there's got to be something; they've taken it away but that was really hard."

Other body image concerns included hair loss and unexpected changes during the regrowth, or coping with losing their nails. The issue of weight loss or weight gain was also a problem for some. A lot of the

concern was related to a lack of practical advice on how to deal with these issues to improve their quality of life. Several of the suggestions made for improving care were related to these (section 2.2.2.7.).

Survivors were also concerned about the emotional burdens their condition imposed upon friends, family and particularly young children. Participants felt there was no real support available for their loved ones, which left them feeling helpless. Several of them expressed a need for information sources designed specifically for supporting others. One survivor for example, described how her friends often looked things up on the internet, but getting her elderly mother up to speed was more of a challenge. Others mentioned similar challenges with reassuring their children.

Survivor_07: *"I felt sometimes my husband wanted to ask questions that I didn't want to know the answer to, so it might have been that that would have been a different conversation."*

Researcher: *"...So it would have been beneficial for him to see someone?"*

Survivor_07: *"Yeah; without me!" [Laughs]*

Survivor_06: *"The same for kids."*

Some survivors also admitted feelings of guilt from occasions when they gave their families a hard time because they were feeling scared or helpless.

"I did have a couple of sessions throughout my treatment when I was horrible to my husband at one stage; and then of course I started crying because I'd upset him. [Laughs] But I had two

sessions like that when I broke down and was in tears, one was...they all say you feel lonely and actually that's true. You're surrounded by people who care for you and love you but loneliness, or isolated loneliness I would suppose you call it... I can remember standing in the bedroom looking out the window and thinking 'God I'm all on my own!' I never used to think anything down. I was always up. Everybody always used to say to me "God, you're always laughing, you're always up" and all this that and the other. And I was thinking 'Oh God, I feel so empty inside! Oh dear, there's nobody here for me' and all this, that and the other. And I think my husband came upstairs to see where I was and I wouldn't look at him or anything because I thought 'You've let me down!'"

- Survivor_09

Findings demonstrate that the burden of providing emotional support initially falls to family and friends, who are often ill-equipped to provide the required support. This therefore suggests a potential role for healthcare providers in primary care to support with this burden.

2.2.1.2 Medicines-related problems

Medicines-related problems can be defined as “*an event or circumstance involving pharmacotherapy that actually or potentially interferes with a desired health outcome*”.^{165(p.535)} Such issues were commonly experienced by the survivors. Endocrine therapy side effects, in particular, were experienced by most and of these; menopausal side effects were especially common.

“I’ve been really struggling with the anastrozole side effects”

– Survivor_01

“I came off the tamoxifen and had the hysterectomy straight away because the tamoxifen had given me a large polyp in the top of the cervix which was causing haemorrhaging”

- Survivor_13

“I had an issue with my tamoxifen and I phoned my nurse and she said ‘Well come off it for three weeks’ I thought ‘Oh brilliant!’ because I had muscle pain and bone pain”

– Survivor_03

In addition to the endocrine therapy side effects that were experienced by the survivors, there was a lot of concern surrounding the risks of other potential side effects and discussion often turned to potential ways to minimise the risks of these.

“I don’t know if you’re aware, but when you take tamoxifen there’s different makes of tamoxifen. And I was told by the Macmillan nurse that if I had side effects with one, to switch the brand may help me. And I found that the tamoxifen by Wockhardt was the best in terms of least side effects...”

- Survivor_12

Before being initiated on endocrine therapy, the majority of survivors had received other treatments in the hospital setting; such as surgery, chemotherapy or radiotherapy. These too caused many adverse and late effects, which had both a physical and emotional impact on recovery for many survivors.

“I had radiotherapy and it was the worst experience for me because I really, really burned and the hospital didn’t want to give me any cream while I was having the radiotherapy because it may interfere with the treatment”

- Survivor_06

“I lost my taste buds...I couldn’t taste anything...But you get so fed up. And I still struggle with that today.”

- Survivor_10

The issue of adherence was also raised. Most of the survivors were prescribed a large number of medications and very cautious about making sure they took them. Several came up with their own strategies to remind themselves to do so; such as keeping a written record of what needed to be taken and when they had taken it, or requesting calendar packs from the pharmacy. Whilst most reported that their adherence was good, a few issues were raised that could impact upon adherence.

“I’m wondering whether a lot of people stop taking it just because of no one chasing you up. You don’t see anyone any time you know; it’s very much on you to make sure you get those drugs.”

- Survivor_12

Side effects were, of course, a concern; not only from the cancer medications themselves. Several of the survivors also experienced side effects from concurrent medications, such as steroids or pain killers. Polypharmacy was also an issue, leading to complicated treatment regimes brought about by taking medications to manage the actual or potential side effects of other medications.

“You must take this drug every day and take this other drug for the side effect of that one, and then...’ I thought ‘Gosh, this is a lot to go through!’...They’re covering everything off, saying ‘this drug to strengthen your bones could give you indigestion so let’s not chance it. If you take it, it’s going to be fine.’ So you’re OK with that and they just literally like line me up with all these different things they have.”

- Survivor_02

Another, perhaps more surprising issue, was that a few of the survivors had little idea why they were prescribed their endocrine therapy.

“So that is what you hear from everybody – we don’t really know why we’re on it, do we? ... And I really don’t know why I’m on it; I mean I know people take it because they’ve had breast cancer so that’s why I take it every night, but otherwise...”

Medicines-related problems, although a concern, are issues that could be managed by community pharmacists. As experts in medicines optimisation, this could provide an ideal opportunity for them to utilise their skills and knowledge to better support breast cancer survivors.

In addition to the medicines-related problems experienced, survivors reported negative experiences of care when seeking advice or treatment for these problems; these concerns are discussed in the following sections.

2.2.1.3 Information provision

The overwhelming feeling amongst the majority of survivors was that they hadn't been given enough information on a range of topics. This lack of information provision was not confined to a small number of similar occasions, but seemed to overarch the whole of their treatment journeys; coming up in conversation again and again in different contexts.

2.2.1.3.1 Lack of clinical information

Most notably, survivors reported receiving insufficient clinical information on their condition and treatments. From diagnosis and throughout the treatment, there was a general sense of fear and confusion brought about by a lack of knowledge of their treatment plan,

what various treatments and procedures involve, what side effects or after effects there might be, and whether there was any aftercare advice they should follow.

“...there was quite a lot of confusion as to when to start the tamoxifen; I remember that. I remember going back to see someone at the hospital and they said ‘Oh, you really should start it!’ I said ‘What, before I do radiotherapy or after I do radiotherapy?’ I wasn’t very clear on that. I was quite scared of the radiotherapy, I’ll be honest. And I remember with the radiotherapy, going to the hospital for the first time; like your initial visit to tell you what’s going to happen, and it was only then that they told me that I’d have 3 or 4 weeks and then the fourth week would be intensive treatment. And that really upset me because I didn’t realise I was having different types of radiotherapy, so I found that quite hard, that wasn’t made clear.”

- Survivor_12

Several of the medicines-related problems (section 2.2.1.2) experienced were also related to a lack of information provision, such as survivors being unsure whether they should be taking endocrine therapy, why they are taking it or how long it should be taken for; whether the symptoms they are experiencing were a side effect of a particular medicine and how this could be managed.

“Yeah the whole journey has been a lack of knowledge of services. You know the whole scene from being told this thing, and then you know, this is going to happen to you to the very end really, it’s all

you're being led by other people; medical people. And whatever they say I've followed like a little sheep and I've had it done. I haven't questioned anything anybody's ever said to me, you know 'you've got to have this' so I've had it. I didn't question why I was having it; 'why am I having these pills?' I just took them."

- Survivor_11

Despite the general lack of information during the majority of healthcare-related interactions, a few examples of positive care experiences were also brought up; where information levels met survivors' expectations or needs at the time. In some cases, the issue was that information provided was overly complex and survivors were therefore unable to understand or process it.

"But the main negative that I felt all the way through was this thing where I never knew, I didn't understand what was going on. Even though they'd told me and I could take it on board, I couldn't translate it because it was meaningless to be until I'd been there, done that, and learnt it. I don't know whether it could have been dealt with in a different way, so I didn't want to know all the ins and outs of it, but I just wanted to, if somebody asked me a question I just wanted to not have to say 'Well I don't know!'"

- Survivor_09

2.2.1.3.2 Initial information overload

In addition to the general lack of information provision, discussions highlighted that most participants had experienced an initial overload of

information immediately following diagnosis. In order to provide the best chance of recovery, it is often important to commence treatment as soon as possible, but survivors are often in shock and overwhelmed during this time. Despite following instructions many had little idea what was happening and were unable to remember or process any information that may have been provided.

“I think when you’re going through your initial diagnosis and treatment, you’re so in a bubble because you’re going from consultant to consultant...it’s so bewildering!”

- Survivor_04

“I think to start off with when they’re telling you you’re going on these drugs, these are the side effects...You don’t take it all in when you’re in front of the oncology people. Because you cherry pick the bits you want to hear and don’t actually take in the full picture of what they’re saying.”

- Survivor_11

2.2.1.3.3 Lack of information on sources of support

In addition to a lack of clinical information, another key concern was a lack of information provision on sources of support, such as charity events; support groups; exercise classes; sources of emotional support such as creative therapies or counselling services; or practical support such as returning to work. Discussions did acknowledge that in some

cases, particularly for those in more rural locations, the reasons behind this could be that such sources of support did not exist in the local area. Indeed, those that managed to locate support services often had to travel to access these (see also section 2.2.1.7). In most cases however, survivors found themselves having to be proactive in researching the support they needed. Often they would find out about services too late or come across them by chance when chatting to fellow survivors.

“Anything I wanted I had to push to get. I had to pick it up and run with it, which is difficult if you’re not feeling on top of the world, if you’ve got cancer, I mean, even for a wig, I never did find out where the NHS wigs were; never did!”

- Survivor_05

2.2.1.3.4 Conflicting or unreliable information

The perceived lack of access to information often caused survivors to seek out information themselves. This led to several experiences involving potentially unreliable sources, such as online forums and websites. Several survivors voiced their concerns about the content of certain forums and websites, having had bad experiences. Whilst the internet and online forums can be a good source of information, survivors noted that it can be difficult to sort the reliable and evidence-based information from the “scaremongering”. Many said they now

avoid such sources altogether. Similar comments were also made of some books and magazines.

Fellow cancer survivors were also a popular source of information. Whilst many found talking to those who had been through similar experiences to be comforting and a good source of support, multiple examples of potentially incorrect information were described.

“I’d got specific things that I wasn’t allowed to eat and I was well aware of that, but then I thought ‘ooh this will be good’ and then somebody out of the blue; somebody who’s not a professional but obviously knew it, said ‘Oh no you can’t have that!’, or I’d said ‘I can’t have that’ and they said ‘No, you can!’”

- Survivor_09

Some examples of receiving conflicting information also involved advice provided by healthcare providers themselves; which varied between settings.

“I think the other thing I’ve also picked up is that you get different advice from different hospitals. And you know, that’s only when you speak to people that you find out...”

- Survivor_07

“A GP suggested something to me that I then went to the consultant and said ‘There’s a load of hormones in that. Why would I take that

when I'm taking something to knock my hormones down?!' And he just said 'No I wouldn't take it!'"

- Survivor_07

The potential dangers of misinformation were well discussed and many of the suggested improvements to care involved a service where survivors could opportunistically seek reassurance and clarification on the accuracy of any rumours, concerning anecdotes or conflicting information that they'd come across.

"When you find out about your cancer, you're tempted to go and look everywhere and although you know there's an NHS website, you don't know the others and you can go to wrong ones. And if there was some advice around which ones were the most interesting or the most validated ones, that could be interesting as well and you don't get that from your GP, or your oncologist, or..."

- Survivor_06

2.2.1.4 Lack of support from community healthcare providers

Whilst survivors gave several examples of positive experiences of care provided by a range of community healthcare providers, there was an overwhelming feeling of a lack of support provided within the primary care setting.

2.2.1.4.1 Post-discharge care

One of the first and most common responses from survivors when asked about the care they received for community practitioners after being discharged from hospital was that there was none at all.

“You don’t have to come back for what, 3 months, 6 months? Well you come out - great, haven’t got to go back! You get home, you sit down and you think my comfort blanket’s gone! I’m on my own; there’s nothing.”

- Survivor_04

Upon exploring the issue, most survivors were able to recall some positive experiences and provide examples of effective support in the community setting that they had perhaps forgotten, but for most, the overwhelming feeling was that of suddenly being “abandoned”, “isolated” and “cast afloat”. The issue of being unsure where to go for support and the need to therefore be proactive in seeking care has been raised previously in regard to the lack of information provision on sources of support (section 2.2.1.3.3). Although this is a recurrent issue throughout the cancer journey, it was of particular concern at the post-discharge stage since survivors were experiencing a major change, and believing they were over the worst of it, most found this time far more challenging than expected.

“Because you’ve very vulnerable aren’t you? And you lose a lot of confidence. I think you do need...that was the big thing with me was

once I'd finished my treatment I could not get going again and I couldn't get any help"

- Survivor_09

2.2.1.4.2 Perceived lack of expertise

Of those who were more proactive in seeking care, for example due to intolerable side effects, depression, or concerns about recurrence, the general perception was that community healthcare providers, unlike the specialist healthcare providers in the hospital setting, most likely lacked the expertise to deal with cancer-related issues.

"I can't really fault them for the GP service that they're providing, but they really have a lack of understanding about additional support for someone that's had breast cancer, they really do."

- Survivor_01

Unfortunately, several participants had come to this conclusion after trying to seek help and being turned away by various healthcare providers. Community pharmacists often immediately signposted back to GP, and GPs likewise signposted back to the oncologists. With consultants' appointments often being months apart, this perpetuated the feeling of being abandoned. Some felt that perhaps community healthcare providers did not have the power to make any decisions about care related to their breast cancer.

Survivor_01: *"I have tried [seeking advice from community pharmacists] but that's what I mean, there's that kind of feeling of yes they'll acknowledge that that's some of the side effects of the medication you're taking, however 'I suggest you go and discuss that with your GP'. You know, there's no steps for them to tell you what to try, even if it is just the exercise or changing the diet, whatever. It's always just 'You need to refer back to the GP to discuss that'."*

Survivor_05: *"And then when you talk to your GP, it's like 'Oh you've got to talk to your oncologist'."*

2.2.1.5 Accessing support in later years

Survivors very much felt that it was important to have continued access to care in the later stages of the cancer journey. With late effects from chemotherapy and recurrence always being a concern, many spoke about the need for support several years after being treated. One survivor: also founding member of a local breast cancer support group and someone who also had personal experience of the issue, spoke of her experiences:

"We've got some ladies that come to the group and it's twenty years since they had breast cancer but they still like to pop in. Sometimes you know, you just...it doesn't go away. There's a little bit there in the back of your head all the time...and sometimes it comes to the fore so you come along and you think 'I'm ok, I don't need this' It's...in fact it's a comfort blanket."

- Survivor_04

There was a lot of confusion and worry amongst survivors about whether there was a cut off time after which they were no longer able to contact their assigned breast care nurse

“And really it’s just a case the hospital discharge you and ‘Well you’ve got the breast care nurse’s number, phone her!’ You know? And you think, well how many years can you keep phoning?!”

- Survivor_08

Whilst several survivors speculated on what that length of time might be, one participant contacted her breast care nurse during a recurrence scare and was redirected back to the GP as it had been more than 5 years. Another participant voiced concerns about her care when her breast cancer did return. Despite finding the experience even more traumatic the second time around due to the knowledge that the cancer had spread, she found there was no support.

“And then I find out again that it came back, and again you come back in this world, it’s just all come down on you. And the support...because you had it once it’s expected that you know where you’re going and what you’re doing. And because it’s the same thing, although it’s more serious, but you still go through the same phase but without the same support you had the first time because it’s a recurrence, so it’s a bit different.”

- Survivor_06

2.2.1.6 Poor continuity of care

A major barrier to care for the survivors was the poor continuity of care they experienced. Over the course of their long-term treatment, they found themselves coming into contact with numerous different healthcare providers. This presented a difficulty for most as it usually meant that, with each new encounter, they'd have to 'start from scratch' to get that individual up to date. Even where there were processes in place to provide continuity of care, they often found these processes were not sufficient.

"It's like departments don't talk to each other – there's that one over there, there's that one over there and you're in the middle. It's like the GP, the pharmacist, the consultant, the oncologist, the surgeon, and nobody talks"

- Survivor_05

Continuity of care seemed to be an issue not only between settings, but also within them. Part of this issue was linked to the frequent use of locums and therefore not being able to see the same practitioner.

"It was only while we were talking I realised that the GP didn't even know I'd had [breast cancer]. Hadn't read the notes or anything. But our surgery's had a lot of problems with keeping doctors and locums and that, so they don't have the time. But to have to sit there and tell them what had happened, and my husband was really angry. He said 'shouldn't you have read the notes on your computer before we came in?!'"

2.2.1.7 Travelling to access care

The lack of access to healthcare and support services within the local area was a concern for all participating survivors. For some, this distance made it impossible to access the support they would have liked. For others, the need to travel far or frequently created stress over financial concerns. Mobility issues following surgery, or feeling too unwell to drive were also a concern. Survivors often relied upon family and friends to provide lifts.

“To get to [the support services], it was probably a 30 mile round trip. But not being able to drive at times because I had a PICC line in, I couldn’t always drive because it kept getting inflamed and stuff. And the bus was once a day and it didn’t coincide with the times of anything. And when you’re feeling rubbish, the thought of being out the house virtually all day and how are you going to get back when you don’t feel well? So I didn’t access a lot of stuff that I would maybe have enjoyed.”

“The best thing for me was when I was told I had to go every day for four weeks to Coventry for my radiotherapy. I just thought, ‘this is going to be awful!’ And then one of my friends she decided, she told me, she said, ‘you won’t be doing that every day on your own; someone will go with you.’ And she arranged, out of all of my friends, she co-ordinated a set of drivers and every day someone new picked me up and took me to Coventry, which was absolutely

amazing and I'll never forget. It was just... Yeah, everyone just rallied round."

- Survivor_12

2.2.1.8 Perceived pressures on healthcare providers

A recurring issue for survivors was how busy the healthcare providers and services are. As one survivor summarised:

"I think there's always this stigma though of putting more pressure on the NHS so it's always at the back of your mind; 'Do I call on somebody, do I bother them? Am I putting more undue pressure on?' Because you know you've got a condition that's being dealt with, so you think 'oh I shouldn't really bother anyone else'."

- Survivor_01

It became obvious that this was a considerable issue in both the hospital and primary care settings and although survivors were sympathetic to this issue, they felt it prevented them from getting the care they needed. Breast care nurses were perceived to be particularly overworked and survivors often found them difficult to contact and unable to provide the service they advertise, despite their role as the main point of contact with the hospital throughout treatment and post-discharge.

"...the breast care nurses- it's an absolutely brilliant concept. When you get introduced to them they're so nice. Well, mine was. And

they explain the service they're there for, but they just can't deliver to that service because they're under so much pressure, so much pressure; so many people."

- Survivor_01

In primary care, the majority of survivors reported struggling to get appointments at their local GP surgery. Accessing care was particularly problematic for those being treated with chemotherapy since, due to a lowered immune system, they had been advised to avoid visiting when the surgery was busy.

"But I couldn't get hold of her - my GP, and I said 'I can't come to see you when you're busy; I've been told I'm not to mix, you know, in those circumstances...so have you got a quiet time?' And the girl said 'Oh hmm...we'll get back to you', which she never did"

- Survivor_09

Experiences were also shared on the difficulties of accessing psychological support when needed due to long waiting lists. For example this participant received no support, despite being referred for counselling by her GP:

"...then I got a letter from the hospital saying 'We're absolutely snowed under; if you seriously think you really do need this support then please ring this number but please be aware it's like an 8 week waiting list!'"

- Survivor_12

Conscious of the pressures on NHS services and unsure where best to access care, survivors discussed numerous health concerns for which they did not seek care, believing their concerns to be too trivial. Such complications included long-term constipation caused by antiemetic medication; an undiagnosed ingrown toenail resulting from post-chemotherapy nail regrowth; and confusion about appropriate aftercare following a mastectomy.

“There are just things that you wouldn’t go to the doctor and ask, but you need to ask somebody.”

- Survivor_01

Survivor perspectives on community pharmacy in terms of pressures on the NHS were varied. Whilst participants commented that they were put off by how busy their local pharmacies were, they also appreciated the accessibility of community pharmacies and suggested that the development of new services could ease the workload of other NHS services.

“Yes I think it would, I think it would be good. I think people need... And it does take the pressure a bit off the doctors then”

- Survivor_12

“...you need to get a good pharmacist, because otherwise, you know they’re busy and they don’t all seem to have as much time to give you.”

- Survivor_02

2.2.1.9 Lack of privacy in community pharmacy setting

In addition to being perceived as very busy, a key concern amongst the survivors about the community pharmacy setting was the lack of privacy.

“I don’t really want to have a discussion about side effects, particularly personal side effects, in that kind of open environment. So that isn’t conducive I don’t think, to having an opportunistic conversation. Because sometimes you might not necessarily plan you’re going to say it, but sometimes it’s just ‘oh I’ll just mention it because it’s on my mind’ but...”

- Survivor_07

In order to provide certain services such as MURs, community pharmacies must, by law, have a clearly signed private area where pharmacists and patients can sit together for private conversations without being overheard by anyone else on the premises.¹⁶⁶ However, the majority of participants either were not aware of such a facility

existing within their local community pharmacy, or were not aware that they could ask to speak to the pharmacist confidentially.

“My local one is quite small in the village, so I don’t think they have a room; they never offer me anything like that anyway.”

- Survivor_06

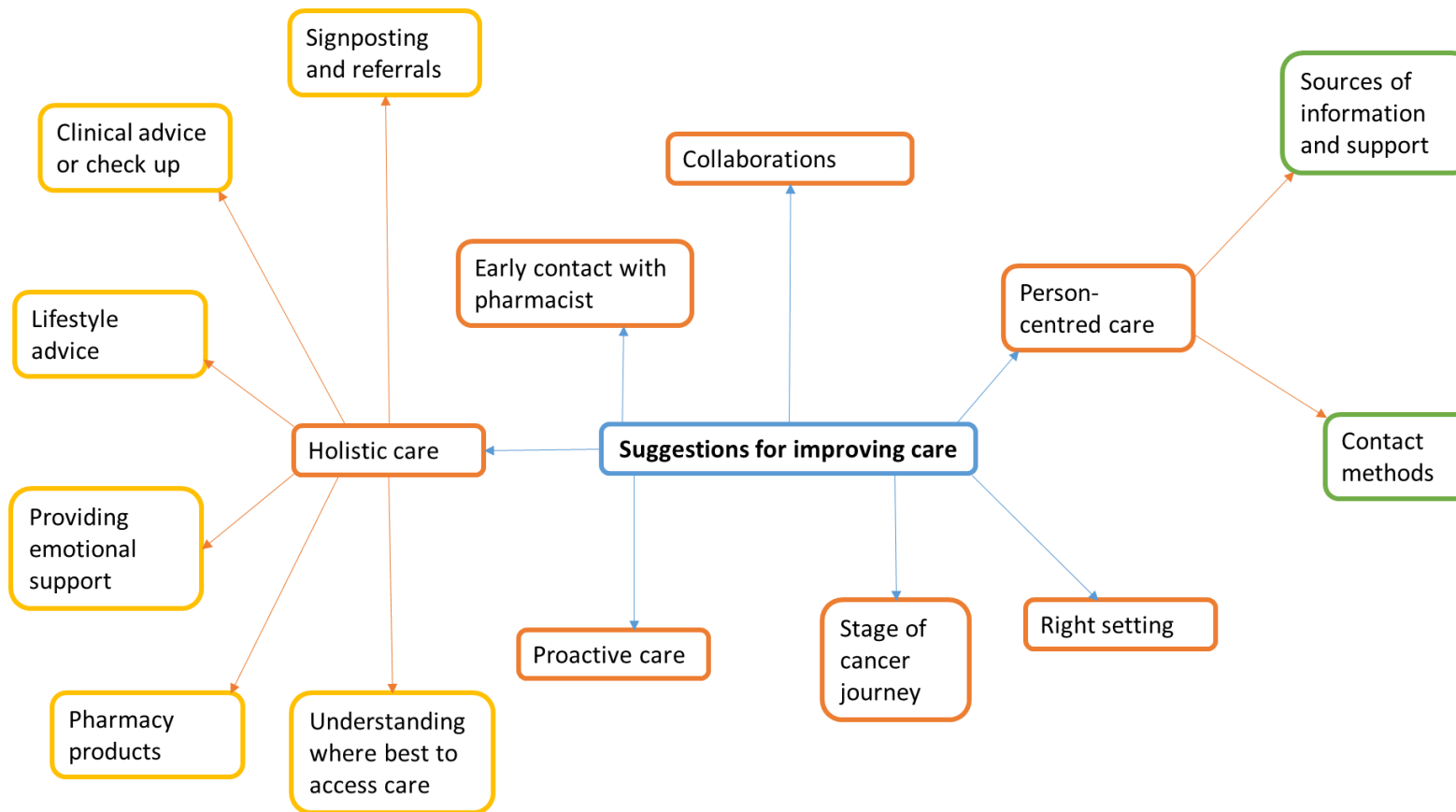
2.2.1.10 Summary of concerns and barriers to care

As this section has demonstrated, the conversations exploring survivor experience within the community setting highlighted several key concerns for the survivors; impacting on both health outcomes and quality of life. The wide variety of issues raised included everything from general concerns (such as lack of clinical information, lack of information on sources of support and lack of support from community healthcare providers post-discharge) to physical and mental health issues (such as medicines-related problems and emotional burdens) to procedural factors affecting the quality of healthcare received, (such as lack of continuity of care, pressures on NHS, lack of privacy in the pharmacy setting and needing to travel to access care).

2.2.2 Suggestions for improving care

The second overarching theme to emerge from the survivor data was *Suggestions for improving care*, the content of which is summarised in Figure 10.

Figure 10: Diagrammatic representation of the Suggestions for Improving Care theme



In considering their concerns and the barriers to care, survivors came up with numerous suggestions and ideas on improving the experience for breast cancer survivors in the future. Although many of the concerns raised were related more generally to the provision of healthcare and support in the community setting as a whole, survivor attitudes towards new support services or interventions in the pharmacy setting were very positive. Some had, throughout their cancer journey, already experienced some examples of excellent care from their local pharmacy, and therefore felt the expertise of pharmacists could be further utilised. Others who were perhaps less familiar with the potential role of pharmacists could see numerous advantages of additional support services and appreciated the convenience of the setting.

2.2.2.1 Right setting

Survivors voiced negative associations with the hospital environment; linking it to memories of being ill, and not wanting to return there. Some survivors were also deterred seeking care from other places with a similar clinical atmosphere, such as the Maggie's Centre. Maggie's is a cancer charity with centres based within NHS cancer hospitals. Its aim is to provide emotional, practical and social support.¹⁶⁷ Community pharmacy on the other hand, seemed to be a more appealing location; being away from the hospital and with more of a community feeling, it did not carry the same negative connotations. Since travel had created such a barrier to seeking out support services, being local was seen as

a huge advantage. Despite some disadvantages of community pharmacy being raised (such as being busy and lacking privacy, along with the perceived lack of expertise in breast cancer amongst pharmacists) survivors responded positively to the idea of care and support being provided here, acknowledging its accessibility and lack of need for appointments.

Survivor_08: *“Even just going through those hospital gates. It fills you with dread.”*

Survivor_07: *“Exactly. Even now there’s so much association. My local store, I don’t have that. So to have that kind of community support, be it understanding what else is out there within the community, what groups where women can come and chat; because I never really did that. But it might be a few years down the line you want to do that. Would I go back to the hospital for that? No way. I only go there when I really need to! But community pharmacy, I wouldn’t feel like that about, so maybe there’s a space.”*

To address the lack of privacy, there were several suggestions around promoting the presence of consultation rooms in pharmacies. Survivors felt that having more obvious signage to advertise the room’s purpose and invite customers to use it would encourage more opportunistic conversations. Likewise, any service offered would need to be sufficiently promoted to encourage use and make busy pharmacists appear more approachable, for example through signage, leaflets, and by pharmacy staff.

2.2.2.2 Collaborations

In order to combat the lack of support from community healthcare providers, the lack of continuity of care and the lack of information on sources of support, many suggestions for collaborations were suggested, between community pharmacists, other healthcare services or providers, and local support services such as charities.

In terms of interdisciplinary working with healthcare professionals in the hospital setting, survivors were keen for pharmacists to be involved in the care pathway. Suggestions included being asked by the hospital pharmacist which community pharmacy they would like to use. The hospital pharmacist could then contact the selected community pharmacy to hand over. Alternatively, community pharmacists could be sent a copy of the discharge letter.

“But I think if you did it right from the beginning, so when you first went; like the time you get your results...And then part of the spread from the oncologist was the pharmacy so that they were aware that you’d be going in and getting this medication, and then they kind of like just...The first time you went in, they could say “Well just step into the little consulting room” and just have a little chat with you and get to know you, basically. And then you get to know them. You know, on a chat level, kind of thing. I think that would be nice, and then that would build up. You could build up from there, couldn’t it?”

- Survivor_09

Collaborations with the hospital pharmacy teams and breast care nurses were also suggested as a means of reducing pressure on existing services and facilitating information sharing. The latter would enable community pharmacists to better support survivors; answering any questions they might come up with, or going over procedures and treatment plans to provide reassurance. It would also enable them to provide relevant advice about aftercare and side effects. Radiotherapy burns, for example was something that survivors felt they needed more support with.

“You just have to write everything down because you can’t remember everything; you literally can’t remember everything. And I remember when I had my first chemo and stuff, they kept me in hospital and you sort of sat there and you think “what’s going to happen to me then?” because it’s scary. And maybe if the pharmacy knew about me and knew I was going to go in, she could maybe, or he ...could talk a little bit about the side effects and the treatment and how it would progress, and ‘If you feel this, this and this, maybe come and see us and we can have a little chat’ or ‘Those feelings are all fine!’”

- Survivor_11

In addition to being referred into the community pharmacy from hospital, survivors also favoured the idea of community pharmacists having the ability to formally refer them into other healthcare services, such as counselling services. Collaborations between community pharmacies and local support services (such as charities) also came

up; this would encourage survivors to attend relevant events or get the type of support they need without having to be proactive in seeking out these groups and making first contact with them.

“And refer you to [support services] as well so you don’t have to find them and phone them; they phone you because the pharmacy has given the information to them...obviously, if you’re happy to do that. But personally I would have liked to do that because I’m still in the case of my Macmillan nurse says to me ‘you have to go to the Maggie’s centre, you have to contact [them] and try to see a counsellor.’ And I’m just...I’ve never been to the Maggie’s centre [locally]; I’ve never been to the hospital [locally]; I don’t know where to go or what to do. It’s very stressful...”

- Survivor_06

2.2.2.3 Proactive care

Survivors felt that one of the key ways that community pharmacists could better support them was by talking on a more proactive approach to care. This could be achieved through a number of actions; it was important to survivors that pharmacies actively advertise and promote the services they offer to eliminate any confusion about the expertise of community pharmacists in terms of breast cancer survivorship care and encourage survivors to seek out care when they need it, regardless of how busy the pharmacy may seem. Additionally, survivors felt they would benefit if, when they come in to collect their prescriptions, pharmacy staff could be more proactive in building up a relationship

with them; offering any relevant advice about their medication or reiterating that they can pop in opportunistically if they had any questions or would like further support.

“You don’t want to bother people with your problems and so you would go to see or speak to some only if it’s really serious. I don’t think you would go for a little thing, so having someone telling you ‘If you have anything just come [in].’ That would be nice.”

- Survivor_06

Whilst the survivors acknowledged that pharmacists may not be able to help them with all queries, showing more of a willingness to try and help would have made a big difference.

Survivor_04: “And if that person says, ‘Well I don’t know enough about that particular problem but I will go and find out and then I’ll get back to you.’...Knowing that they will get back to you...”

Survivor_01: “...Instead of just leaving you with the stock answer ‘You’ll need to go to your GP.’”

A more proactive attitude would help build a rapport between survivor and pharmacist and foster a productive and supportive relationship. For those who already had such a relationship with their community pharmacist, this was invaluable to them and acted as a lifeline back to ‘normality’ for when they felt otherwise isolated. Survivors spoke about being treated differently by others who felt sorry for them or did not

know how to talk to them and suggested that pharmacists and pharmacy teams could do more to provide that friendly face and normal conversation by asking “how are you?”

“So yeah, you want them to keep a little bit of contact with you to make sure you’re alright because you want that friendliness; just that little bit of friendly contact...You know sort of normal; a normal conversation that didn’t involve anything to do with being ill.”

- Survivor_11

2.2.2.4 Person-centred care

The importance of tailoring care to suit the needs of the individual was something that was often pointed out by the participants. Although the term ‘person-centred’ was not used directly by survivors, it is used here to encompass all codes relating to what survivors described as ‘individualised’ or ‘personalised’ care or services. In a more general context the meaning of the term ‘person-centred care’ describes the importance of considering the needs of an individual accessing a healthcare setting and working to build a good collaborative relationship between the healthcare provider and the individual. The concept is popular across modern healthcare settings and was first introduced by Carl Rogers as early as 1942 in an effort to move away from traditional imposed healthcare when providing psychological counselling.^{168, 169}

In this context, 'person-centred care' was selected to summarise the theme since it seemed to encapsulate the survivors' messages on the importance of being empowered to take control of their own care; the need to consider many factors such as the stage of the cancer journey, how they best absorb information; and importantly, acknowledging that everyone is different and therefore every cancer journey is different.

Whilst the participants shared several common experiences, they equally acknowledged the many differences in cancer journeys; recognising that each individual's needs in terms of care and support are likely to be different.

"What would have affected you didn't affect me and what affected me... Because everybody's different aren't they? Everybody's journey is completely different."

- Survivor_10

Some survivors, for example, hated the thought of attending a support group whilst others found it useful. Similarly, amongst those struggling with the emotional impact of cancer, some felt antidepressants were the right course of action for them, whilst others would have preferred non-pharmacological treatment options for their low mood.

It was important to the survivors that the idea of person-centred care should also extend to the provision of support for any friends and family members who need it.

“When you’re told that you have cancer and it can’t be treated or whatever, it’s just such a shock for you, for your husband, for your kids you know. Someone to just...you can speak to because you can’t speak to your husband about after; he can’t speak to you about after. The kids - they understand there’s something wrong but they don’t know all the things so they’re worried. I think having someone to speak to, or just walk in and say ‘Can you help me today?’ would be nice.”

- Survivor_06

The concept of a more individualised or person-centred approach to care is interlinked with many of the identified strategies for improving survivor experience. Whilst it is not an intervention in itself, the approach can potentially be adopted by any healthcare provider to support delivery of an intervention. It simply requires the healthcare provider to be more cognisant of the needs of a survivor as an individual; tailoring the care provided accordingly to support their needs, rather than adopting a standardised approach for all. Strategies to improve continuity of care through information sharing, for example, would facilitate a more person-centred approach.

2.2.2.4.1 Contact methods

In providing more individualised and person-centred care, having a variety of options to contact the pharmacist was important to survivors. Although survivors agreed that a private consultation with the pharmacist would be of benefit, opinions differed on appropriate means

of contact. Some suggested that the pharmacist could be proactive and telephone to see how they were getting on, whilst others felt emails were a more appropriate means of reaching out since emails could be ignored as required and may provide an easier way to discuss emotional issues. Conversely, others were not familiar with using emails so it was agreed that perhaps the pharmacist and survivor could discuss contact options between them and agree how best to reach each other.

“Sometimes it’s easier to say stuff in an email back, rather than verbally, face to face, because you can break down; you can start crying and then sometimes you get the sympathy vote and you don’t always want that. You want someone to be practical and go ‘Pull yourself together; stop being stupid. This is what you need to do’ or ‘This is what we can do’.”

- Survivor_11

Alternatively, some participants commented that would prefer if the pharmacist just spoke to them when they came into the pharmacy; this is another consideration that would need to be taken into account for any future service.

“Obviously I’m never going to forget I had it, but I want life to get back to normality and I would hate to be getting my head in a space and suddenly an email would pop in or the phone would ring and it would be this person who wanted to talk about my cancer again. Because having just gone through my six month check, to get

yourself back into the frame again, I found that quite difficult so I wouldn't want those calls."

- Survivor_01

2.2.2.4.2 Sources of information and support

Similarly to the issue of contact methods, the survivors expressed varying views on their preferred formats and sources of information or support. One of the most popular methods of communication was through written information; such as leaflets, posters, booklets, treatment timetables, information sheets, and other written sources. The benefits of these really resonated with survivors since they are passive means of communication and can also be returned to when needed.

"Well if you have a leaflet you can point to the other things anyway, can't you? You can point to the videos, access them and things like that. And that is quite impersonal; you don't have to speak to anybody, you can just go in and pick it up and go. So if you were somebody that didn't really like to talk about it and things, that would be a good opportunity to just get it, go, and then look at it at your leisure."

- Survivor_08

As a result of some negative experiences of using websites and forums, one group suggested that information on reliable and evidence-based websites would be of benefit.

“Maybe as well, something around websites, because you know when you find out about your cancer, you’re tempted to go and look everywhere and although you know there’s an NHS website you don’t know the others and you can go to wrong ones. And if there was some advice around which ones were the most interesting or the most validated ones, that could be interesting as well and you don’t get that from your GP, or your oncologist, or...that could be...Or I don’t know, on the pharmacy website there could be a link that goes to the good websites or something like that.”

- Survivor_06

Survivors were generally keen on the idea of using support groups as a source of information and of course, support. Pharmacies could help organise these groups where none existed locally; bringing people together who were interested or putting them in touch with any existing groups. Event days such as pampering days and other events to promote wellbeing were also suggested.

Although some disliked the idea of group activities, most acknowledged that perhaps at a different point in their cancer journey they might find it useful. They therefore felt it would be beneficial to be kept informed about support groups and events available.

“It would be nice if somebody in the community would just say to you - even like me when I’m just saying ‘no, that’s not for me’ if they’d just said ‘just sit down with somebody and talk to them about what [the support group is] going to give you.’ But there’s just none of that, so very much you feel on your own because – I’m sure

you've all been the same with your families -you get to the point where you think 'I can't keep worrying my family with it...so you keep it to yourself and you dwell on things.."

- Survivor_01

Overall, it was recognised that in order to cater for individual's needs, there would need to be a selection of sources available to ensure people got the information and support they needed in a way that was meaningful to them.

2.2.2.5 Stage of cancer journey

Survivors very much found that their care needs changed as they progressed through their cancer journey. In addition to the more obvious changes to their condition and treatment, their needs in terms of the levels of information they were able to process and the types of support they felt they would benefit from also changed. Additionally, there was a dramatic contrast between their initial experiences of information overload, and experiences of feeling abandoned post-discharge or into the later years. In order to address this issue and ensure a person-centred approach, community pharmacists (or any healthcare provider delivering an intervention) should therefore consider where an individual is in their cancer journey and ensure they provide appropriate levels and types of information, care and support to suit that individual.

Survivor_07: *“I always think talking is helpful and it might not be that that time is the right time to talk, but later on you still might not have processed all your emotions and how you’re feeling about it and that might be more helpful later on.”*

Survivor_06: *“And there may be some times when you are more supported, and some other times when you are less supported and therefore having someone telling you ‘come to this group and hear about whatever’ could be interesting.”*

2.2.2.6 Early contact with pharmacist

Given that each individual’s experience of breast cancer is different and their care needs change throughout the cancer journey, the survivors felt that in order to ensure they get the care they need, it was important to build better relationships with healthcare providers. A popular suggestion was having early contact with their community pharmacist. This can also help to promote good survivor-pharmacist relationships, and promote person-centred care and continuity of care. Many survivors commented that their journey would have been far easier if they’d been aware earlier on of the roles and expertise of community pharmacists.

Interestingly, several participants had never had a conversation with their community pharmacist about their cancer medications and therefore would not have thought to go to them for help with anything cancer-related. Instead, they perceived community pharmacists simply

as being the experts in minor ailments; visiting them for only advice on issues such as coughs, colds, rashes or wound care.

“I never spoke to the pharmacy about the drugs at all. Whereas if you’d, I don’t know, a sore, a burn or something, you’d speak to the pharmacist about different types of things to put on it wouldn’t you? But I haven’t had a conversation with the pharmacy at all about cancer drugs.”

- Survivor_11

Others had originally shared these views, but since progressing through their cancer journey they had come to realise that their community pharmacist could be an excellent source of support and advice. As noted by the survivors, if they do not have any pre-existing conditions when they’re diagnosed with breast cancer, they most likely would not have had reason to visit the pharmacy for anything other than minor ailments so would not be aware of the services available.

“All the little side effects... I wished I’d known her, it sounds terrible doesn’t it? I wished I’d known her before. The fact that I didn’t know her was because I was in good health so I didn’t need to know her! Because I would have gone to her with some of the side effects that I’d had that I wasn’t expecting; the one that stuck out to me this morning was losing the skin off the soles of my feet.”

- Survivor_10

“Knowing what your pharmacist can do earlier on, it probably makes sense in terms of who to contact, because you’ve got your

oncologist, and you've got your GP and you've potentially got your Macmillan breast cancer nurse. But that's it really, in terms of introduction at that point of diagnosis."

- Survivor_07

Suggestions to promote early contact with the pharmacist were related to improving continuity of care; either being referred into community pharmacy from the hospital setting or being informed about the services they offer through other means, such as leaflets or being signposted by other healthcare providers.

One of the focus groups came up with the idea of some kind of introductory pack that the pharmacy could offer. Suggestions for its contents included information about the services offered in the pharmacy, opening hours, and a list of recommended products; such as a thermometer to monitor for signs of fever (something which is vital during chemotherapy treatment).

Survivor_07: "Even just a kind of list of things that you might want to get in because suddenly you're getting a thermometer, when you didn't have a thermometer, suddenly and you're taking your temperature every day. Just a little pack of stuff that's useful to have; buy it so you've got it in. If you feel in the middle of the night suddenly you've got this; your temperature is up and whatever..."

Survivor_06: "A kit or something"

Survivor_07: *“A kit of some sort and that then gives you that first point of entry with your pharmacist potentially.”*

One survivor also suggested that this could be provided through a voucher system; likening it to the bounty packs offered free of charge to new or expectant mothers. As well as being enthusiastic about the idea of a free pack, survivors were passionate about the importance of establishing the early contact with the pharmacist and highlighting them as a key source of potential support.

“And maybe the pharmacist; you know when you have a baby and you get your new baby little bag? You know, if you could take you token or whatever, and get your little information and products bag...”

- Survivor_08

2.2.2.7 Holistic care

A holistic approach to care was important to survivors. This can be defined as *“comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person; his or her response to illness; and the effect of the illness on the ability to meet self-care needs.”*¹⁷⁰ As is clear from many of the concerns voiced by survivors, the important issues to them concerned not only their physical health, but also mental health and many other aspects of their general wellbeing. Whilst the previous section of suggestions primarily explored considerations for the delivery of a future service, this

one focuses in on suggestions surrounding the specific content and topics that are important to survivors, and how the suggestions fit into a holistic approach.

2.2.2.7.1 Clinical advice or check up

Whilst holistic care takes many aspects of health into consideration, physical health is, of course, a key issue. The participants raised many issues that affected their physical health, such as medicines related-problems, side effects and late effects of their treatments, and a lack of clinical advice. Unsurprisingly, many of the suggestions made involved regular check-ups aimed at assessing for these potential issues and providing any relevant clinical information. As previously discussed, participants had some differences of opinion regarding the use of telephone or email, but most agreed that in going to collect your prescription every month, this provides a convenient opportunity for such a conversation.

“You’re going in there every month to collect this prescription, you say what it is, we know the pressures on GPs for appointments. How nice would it be for them once a quarter to say, ‘Can we sit down for five minutes and we’ll just review everything you’re taking, make sure you’re fine with it?’ I didn’t know about taking calcium, so now I’m thinking should I be doing that? Is that not something the pharmacist could’ve sat me down and said ‘Other ladies have found this is of benefit, you may want to do it?’ Just a bit more of that personal touch, rather than just, ‘Your prescription is ready to collect, here you are’; that kind of thing.”

Whilst community pharmacists do currently offer a check-up in the form of a MUR, most of the participants had never been offered one and were not aware of it. Due to the requirement for targeted MURs and the need to be on two or more long-term medications, many survivors may not be considered eligible. However, a clinical check-up of some description was something they felt was needed. Additionally, survivors felt that more regular check-ins with the pharmacist, either at pre-agreed intervals, or whenever they pick up a prescription, or opportunistically to suit them when they have a query would be more beneficial to meet their changing needs.

In addition to supporting with medicines-related problems, other clinical interventions could include going over what to expect from treatment plans and various procedures, discussing any risks involved (including common or long-term side effects), providing advice on recovery and aftercare, and advising on preventing or managing recurrences or scares.

“One big thing that the pharmacist could offer is if you’re prescribed tamoxifen, I don’t know how many people are aware of their risk of thrombosis goes up, especially when flying. So the use of flight socks and things like that. I would never have used flight socks in the past, but I did actually, whenever I fly I do, if I do a long journey I do wear them now. I don’t know whether people are general aware of that. That could be something that, you know, if you were going to

be doing a check-up or something with women who are taking tamoxifen, as a pharmacist. You know 'How are you feeling? Have you got any side effects? Are you going on holiday? We recommend that you would do this...' And also give them the warning signs for thrombosis, so clotting, if they got any swollen ankles, swollen limbs or any painful lumps, they would not ignore it. You know, take it seriously, especially if they're on tamoxifen."

- Survivor_12

2.2.2.7.2 Lifestyle advice

Survivors stated that would like lifestyle advice to feature in any future intervention. They saw their lifestyle choices as an area of their life they could have some control over, even when their health is poor. Being able to make small lifestyle changes and have a positive impact on their health was very empowering. As one survivor summarised:

"Getting back to health is so important, as it is for everybody."

- Survivor_01

Specific suggestions for improving care involved the provision of dietary advice and perhaps a more detailed meal plan. Survivors also felt they needed more advice on useful exercises, for example as a means to alleviate joint pain caused by anastrozole, or regain arm movement after breast surgery. The concept of a personalised lifestyle plan, taking

into account the individual's medical history and current lifestyle, was a particularly popular suggestion to help them get back to being well.

*“Exercises! That was the one thing. Remind me about that later...
Yeah that's the one thing, that's the massive thing that's lacking; the exercises to rehabilitate yourself after a breast operation. I just seem to remember that was the one thing that really drove me insane, just the [lack of] advice on what to do.”*

- Survivor_12

2.2.2.7.3 Providing emotional support

In this chapter we have already seen the weight of the emotional burdens experienced by the survivors. Their need for improved support in this area was likewise evident. In addition to the suggestions on support groups and the need to provide support to family and friends as well as survivors, several other suggestions were raised.

Since the types of emotional support needed varied amongst the group, survivors agreed that an ideal intervention or service should be able to cater for a range of requirements. The need for a proactive approach to care was seen to be particularly important when considering emotional support and it was felt that pharmacists need to regularly be asking survivors how they are, reminding them of the services available, and inviting them to pop back for a chat whenever they need.

“Because you’ve very vulnerable aren’t you? And you lose a lot of confidence. I think you do need...that was the big thing with me was once I’d finished my treatment I could not get going again and I couldn’t get any help. So, I think that would be a good thing that could be done locally.”

- Survivor_09

In cases where more formal counselling was needed, survivors recognised that this was perhaps not something a pharmacist could offer, but they were keen for pharmacies to provide support with accessing these services, for example by contacting relevant organisations on their behalf, or arranging referrals.

“I never had counselling and I think that would have been really helpful to put everything into order in my mind. Because you come out the other end and this happened and that happened...Guilt, all sorts of things...which are nothing to do with the counsellor, but because of the counsellor you are able to help yourself. So I think counselling would have helped me get rid of a lot of guilt that I still carry around with me now.”

- Survivor_11

2.2.2.7.4 Pharmacy products

When discussing living with and managing side effects or late effects of cancer treatments, the topic of pharmacy products was often raised. Here, the term ‘pharmacy product’ was used by survivors to describe

products other than medicines that are usually available to purchase in pharmacies. Survivors felt they would greatly benefit from advice on which pharmacy products would be safe to use given their condition, treatment and symptoms; or recommendations on products that may support their recovery.

“There are also for me some side effects that you get from the drugs that your oncologist or your GP aren’t really treating. Like you get very, very dry skin for example; or I don’t know...yeah very, very dry. And the GP can give you some creams that are not very effective because it’s very basic cream, and maybe a pharmacy could have a range of products that could help with the side effects? The little side effects like dryness or itchiness, or I don’t know...mouthwash for example. Because it’s easy to say ‘Oh I’ll just go and buy mouthwash’ but when you have a cancer you don’t know if you get sensitive to any of the components in the products because obviously you’re more sensitive due to the treatment you get. So it could be interesting to have a range where you can go because you know it has been developed for people who have cancer and therefore they can tolerate better.”

- Survivor_06

Examples of products they would like more information and advice on included shampoos, conditioners and hair dyes that were suitable for use during chemotherapy, along with any products that could promote strong and healthy regrowth. Similarly, advice on products to strengthen damaged nails was also suggested. Moisturisers, creams and other skincare products to soothe irritated and dry skin would also have

helped; as well as advice on safe underarm products to use following surgery.

“When I had my lymph nodes removed, you’ve got, it sounds really stupid, but you’ve got the problem of like, what can you use for hair removal? ...What deodorants do you use and things like that? That was really, really difficult.”

- Survivor_08

In terms of more therapeutic products, many survivors, having suffered terribly with post-radiotherapy burns suggested that perhaps specialist wound care advice could be made available in the pharmacy, along with recommendations for creams and dressings to provide relief.

Additionally, to incorporate the idea of the introductory pharmacy kit (section 2.2.2.6) it was suggested that the pack could also include some advice on products and perhaps some free samples. Another suggestion was that pharmacists could proactively recommend any relevant products based on the survivor’s experiences.

“You know, you look on the medication and you read it once, and you forget about it in the hope that you’re not going to get any of that. But maybe a few months down the line, you might find, ‘oh my skin is a bit dry’. And then if there was, I don’t know, something proactive where when you were getting your drugs, ‘These are really common and these are drugs that you can take, or over the counter things that will be helpful and safe.’”

2.2.2.7.5 Understanding where best to access care

This chapter has explored several issues that have culminated in a great deal of confusion amongst survivors about where best to access care and support. Along with a general lack of support and information provision from community healthcare providers, survivors attempting to seek care have been deterred by signs of pressures on healthcare providers, or have experienced a culture of being automatically signposted on to other healthcare providers. The resulting uncertainty about where to seek care has perpetuated perceptions of a lack of breast cancer expertise within the community setting (section 2.2.1.4.2). Many survivors perceived the role of the pharmacist to be limited to handing out prescriptions and providing advice on minor ailments, and there was also the issue of a perceived lack of privacy in the pharmacy, which acted as an additional barrier to care.

In response to these issues, survivors reported the need for a better understanding of the expertise of community healthcare professionals in regard to managing breast cancer. In addition to taking steps to promote pharmacy services and collaborating with other healthcare professionals and local support services, it was agreed that community pharmacists should take on a role of helping survivors understand the sorts of cancer-related issues that each healthcare provider has the

expertise to assist with, and in doing so, empowering them to confidently seek care.

Survivor_01: There's not kind of a 'This is our service; this is what we can provide; this is what we're happy to talk to you about' so you're not really aware of what they know and don't know...You think that's not their area of expertise so I won't bother them with that.

Survivor_04: So maybe there should be a big campaign about 'This is what pharmacists can do'.

2.2.2.7.6 Signposting and referrals

In conjunction with empowering them to seek relevant care, survivors felt pharmacists could also support them by signposting or referring them to other relevant healthcare or support services. The idea was simply that the pharmacist could listen to their problems, then signpost them to the most relevant sources of care; be it sources of emotional support, healthy living advice, financial support, nursing care, or any other relevant service.

Survivors were also keen to be referred wherever possible; suggesting that pharmacists could contact various charities or healthcare services on their behalf, or pass on their details so the relevant people would contact them rather than simply signposting which would require the survivor to take on a more proactive role.

“And refer you to [various support services] as well so you don’t have to find them and phone them; they phone you because the pharmacy has given the information to them - Obviously, if you’re happy to do that. But personally I would have liked to do that.”

- Survivor_06

One survivor mentioned the Beacon of Hope; a former Welsh charity designed to support people with progressive or advanced illnesses and maximise their quality of life. One of the ways the charity achieved its work was to put individuals in touch with various other sources of support, depending on what support the individual needed. It was suggested that perhaps pharmacists could take on a similar sort of role.

“If the pharmacy could take on that role of Beacon of Hope, and point you in all directions, and they were the ones that did all the ‘Right, you need to see this person; she’s in dire straits’ And they were the ones that contacted me, I didn’t do anything! Literally all I did was answer the questions and they did everything, and I signed a few forms giving them the permission to do it on my behalf, and that was it, job done. Yeah it was brilliant! Absolutely it was a lifesaver; a financial lifesaver!”

- Survivor_11

3 Chapter Summary

3.1 Key findings

The aim of this study was to explore the requirements, attitudes and opinions of breast cancer survivors towards new community pharmacy-based services. Findings have been divided into two overarching themes; concerns and barriers to care from the survivor perspective, and suggestions for improving care.

Survivors experienced information overload during initial hospital treatment but felt abandoned post-discharge; even years later they had difficulties accessing any occasional care they required. A general lack of support from community healthcare providers was also reported, along with a need for more information on a whole range of clinical and general wellbeing issues throughout their journey.

Additional key concerns for survivors included dealing with the emotional burdens associated with living with and after breast cancer (such as body image issues, fears of recurrence, and concerns for the emotional wellbeing of friends and family); medicines-related problems; a perceived lack of expertise in the community setting; concerns about travelling long distances to access care; and perceived pressures on healthcare services.

Despite their concerns, the survivors shared several positive experiences of care. They were able to come up with many ideas about

how support for breast cancer survivors within this setting could be improved, particularly in the context of potential opportunities for community pharmacists to expand their role. Key strategies included collaborating with other healthcare providers and charities to improve continuity of care and access to support; and providing proactive, holistic, person-centred care, which also incorporated signposting, helping survivors to understand where best to access care, and advising on a range of issues.

Chapter 3 reported early discontinuation and frequent switching of ET. These were indicative of underlying medicines-related problems and raised some potential care needs for survivors that were investigated further during this phase. Although the survey data showed that, in contrast to the phase one cohort, early discontinuation of ET was not common for participants (a discrepancy most likely due to the small sample size); switching between ETs was common. Additionally, the qualitative aspect of the study confirmed the hypothesis from phase one; providing evidence that medicines-related problems are indeed a concern for survivors. This was demonstrated for example, by the large number of experiences of side effects, or the reported lack of follow up with community healthcare providers to address adherence amongst ET users.

Several of the identified issues could be potential causes or contributing factors of medicines-related problems, further precipitating the issue. A

clear lack of clinical information and support from community healthcare providers, together with poor continuity of care and a need for improved understanding on where best to access care, have left survivors ill-equipped to manage their condition. Alongside coping with physical and emotional burdens of living with and after cancer, it was clear that many survivors lacked knowledge on their condition or treatment and had little idea where they could access such information or find support. Without an understanding of why they are taking ET, how long it needs to be taken, or support with optimising treatment and managing side effects, it is explicable that early ET discontinuation is such a significant problem amongst England's breast cancer survivors.

3.2 Next steps

The research so far has identified survivors' requirements for improved care in the community setting and highlighted potential features of a new service or intervention from their perspective. As described in Chapter 2, each of the phases of this research were iteratively developed. The following phase will therefore go on to investigate community pharmacist perspectives on how to address the reported survivor care needs, including considering survivors' suggestions for improving care and formulating their own ideas about interventions or services to achieve this. It will then go on to explore potential opportunities and barriers surrounding implementation of the intervention strategies within a community pharmacy setting.

Current evidence suggests that community pharmacists are well-placed to offer support to breast cancer survivors.^{37, 47} However, some of the concerns and barriers to care reported by the survivors could likewise act as barriers to service delivery; including their perceptions of the lack of privacy in community pharmacies, the role of the pharmacist, or the lack of cancer-related expertise in the community setting. Therefore, in order to successfully develop future interventions or services, it is important to consider how these issues can feasibly be addressed. Some of the suggested strategies for improving care reported in this chapter could provide a solution, including promoting the use of the consultation room, taking a more proactive attitude to providing care and reaching out to survivors during the early stages of their cancer journey. The remaining phases of this research project should consider the feasibility of these suggestions, along with any other potential solutions from the perspectives of community pharmacists and stakeholders.

Given the apparent importance of medicines optimisation to breast cancer survivors, it is vital that subsequent study phases consider how this could be incorporated into any future intervention whilst taking into account potential barriers; such as a lack of expertise in community setting, and lack of understanding about the pharmacist role and where best to seek care. Additional consideration should be given to the accuracy of survivor perceptions on the roles and expertise of pharmacists and other community healthcare providers, along with the

lack of privacy in the pharmacy setting. A key priority to facilitate the development of medicines optimisation interventions could be challenging public perceptions of these issues. Alternatively, if survivor perceptions are in line with community pharmacist and other healthcare provider perspectives, the priority may be developing further training to address any underlying lack of knowledge amongst community pharmacists when interacting with breast cancer survivors.

Whilst the findings of this study will primarily inform the remaining phases of this ongoing research, alone they highlight some practice-based action points that can be undertaken in the shorter term. The study informs on significant care needs for breast cancer survivors in the community setting and based on the reported lack of support from community healthcare providers, it is unlikely that community pharmacists and other primary care practitioners are aware of these. Whilst subsequent study phases will explore this further, raising awareness of these findings in the short term can enable healthcare providers to improve their individual practice by simply being more aware of the extensive care needs of this patient group during their day-to-day practice.

Chapter 5: Pharmacist & Stakeholder Perspectives

1 Introduction

This chapter, which reports on the final two phases of the research project, aims to build on existing findings by considering the views of both community pharmacists and stakeholders surrounding opportunities to develop the role of the community pharmacist in breast cancer services.

The previous chapter reported on the concerns experienced by breast cancer survivors in terms of the breast cancer care they received in the community setting. It then went on to explore what the survivors felt community pharmacists could do to help improve their care, including various requirements for a future pharmacy service or intervention. Findings were used to iteratively develop the final two phases of the research through providing discussion points for the topic guides, which informed the content of the community pharmacist focus groups.

Building on this, phase three of this research project aimed to investigate community pharmacist views on introducing a service or intervention to meet the care needs identified by survivors. Additionally, participants explored the potential opportunities and barriers surrounding implementing the strategies identified by both the survivors and themselves, within a community pharmacy setting.

Meanwhile, in order to maximise the impact of the research, the final phase aimed to explore the views of any relevant stakeholders towards the introduction of a new community pharmacy-based service for breast cancer patients; including what data would need to be captured in order to commission the proposed service. This final stage was crucial in ensuring the findings were positioned within the current context of community pharmacy and wider primary care service provision.

Although these phases were completed sequentially, the stakeholders took on the role of commenting on the findings of the entire study: using their knowledge and experience within their respective fields to provide further context for the findings, as well as considering how these could inform further research, and eventually, changes to practice. As such, the data gathered here was very much linked to the findings from the community pharmacists (and by extension, the earlier phases). In order to avoid repetition, and in an attempt to ensure findings are presented in a logical order, it was considered more appropriate to present these community pharmacist and stakeholder perspectives concurrently.

This chapter will therefore be presented in the following sections:

Findings, reporting on the qualitative themes from both the community pharmacist and stakeholder data; and the Chapter Summary, which will review and conclude the chapter.

2 Findings

In total, nine community pharmacists participated in the study. Two focus groups were held with four and five participants respectively. Between them, participants had a wide range of experience from different settings across England; from very rural areas to large cities, and from independents to large multiples. The focus groups took longer than originally anticipated due to the need to type all messages; lasting 3 hours 3 minutes and 3 hours 54 minutes, but the participants engaged well and the discussion generally flowed.

Five stakeholder participants were interviewed; a Macmillan GP, a hospital-based oncology pharmacist, a representative from a cancer charity, a LPC chair and a stakeholder within pharmacy commissioning. Four of the five interviews were conducted face-to-face and for practical reasons, the final interview was held over the telephone. The length of the interviews, including the presentation, ranged from 1 hour 14 minutes to 2 hours 31 minutes, with most taking around 1 hour 30 minutes.

There were four key themes that emerged from the data – Approaches to improve survivor experience, Accessibility of setting, Barriers affecting the feasibility of future interventions, and Proposed interventions. These are summarised in Figure 11.

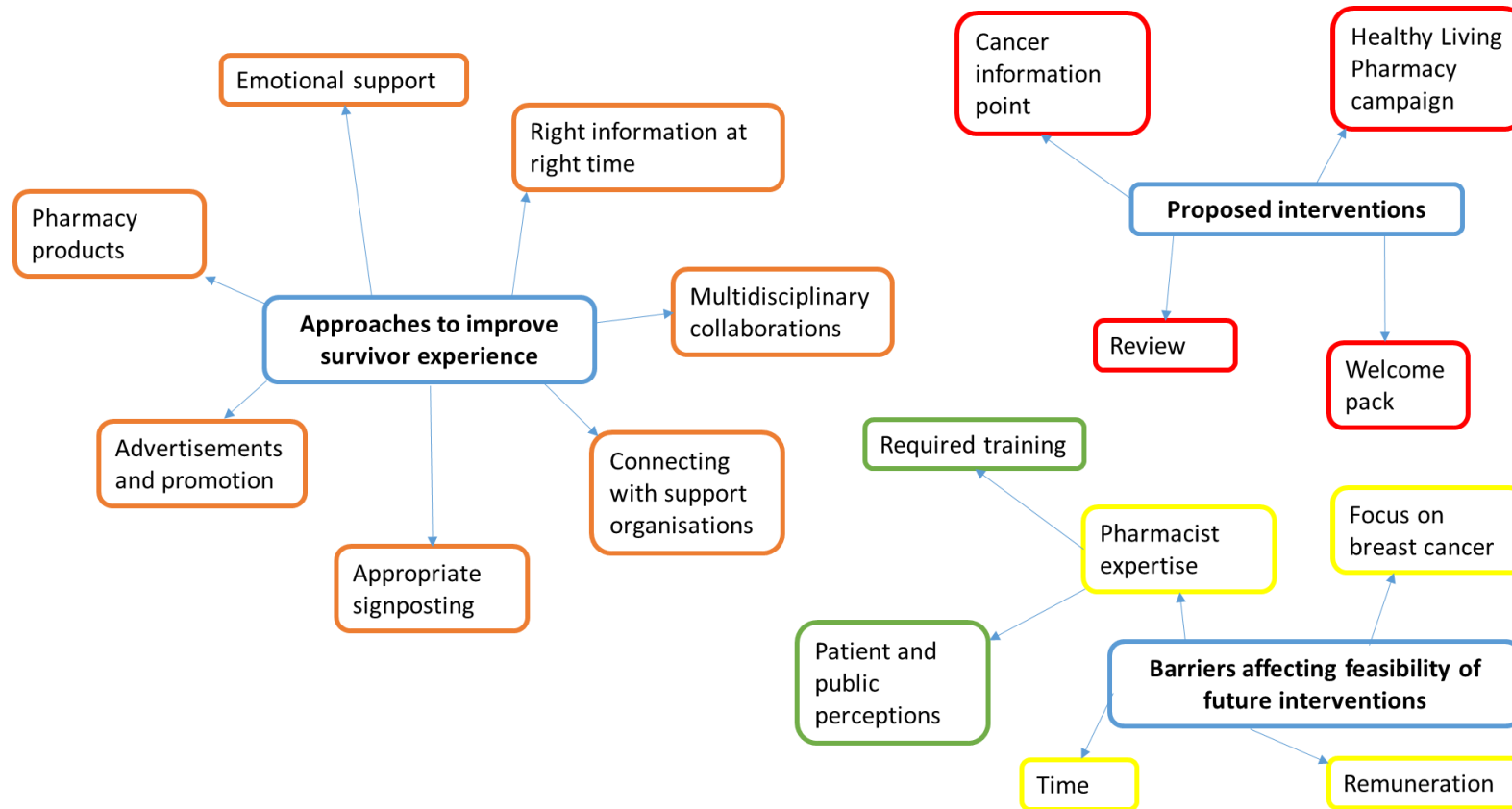
2.1 Approaches to improve survivor experience

2.1.1 Appropriate signposting

Community pharmacist participants confirmed the need for better signposting practices. In line with the survivor findings, they felt it presented a key opportunity to improve breast cancer care.

Acknowledging that signposting to the GP is common practice in community pharmacy (primarily due to a lack of knowledge about support available for breast cancer survivors), the pharmacists started to consider other potential options such as Macmillan GPs, nurses, information managers or other sources of support offered by the organisation; support groups and other services locally, or the patient helpline service provided by the hospital. In order to deliver the holistic care called for by survivors, appropriate signposting was recognised as being essential to ensuring care needs are met where pharmacists lack the resources or training to provide the required support themselves. Pharmacists felt they would benefit from training on where to look for services, or a portal to collate information.

Figure 11: Diagrammatic representation of the themes that emerged from community pharmacist and stakeholder data analysis



CP_02: *"GPs again are not specialists in this area and probably, like us have limited knowledge - maybe multi-disciplinary face to face training so we learn together and develop wider networks"*

CP_03: *"That's something worth knowing because I will now avoid referring to the GP and consider alternatives - Macmillan Nurse? Be worth making contact with the local Macmillan GP?"*

The stakeholder participants shared similar views on the importance of appropriate signposting in improving care; agreeing that community pharmacists are well-placed to assume this role provided they have the relevant knowledge about possible signposting options.

Several stakeholders were able to provide further insight into the role of the GP in breast cancer; confirming that they are usually less involved in breast cancer treatment than they would like to be and may not get to see patients until the post-treatment phases of their journey. Given their limited exposure as a profession to providing breast cancer care, community pharmacists should use their judgement when signposting survivors on, considering the needs of the individual.

"GPs are disempowered especially when breast cancer patients have their treatment because we don't get involved at all. They're so busy going to the hospital; they don't come and see us, even if they have hypertension. You're trying to get them in for a review or an asthma check and it's really hard just to do that. So I think GPs feel disempowered, they feel disconnected and then actually when you come back in... 'Oh, oh yeah...' And unless you had a pre-existing

relationship with an individual, conjuring a relationship is quite difficult at that time.”

- Macmillan GP

The stakeholders noted the importance of networking locally with support services and working towards multidisciplinary collaborations when seeking to improve signposting practices. They likewise felt that developing consultation skills and striving to provide the right care at the right time (see also section 2.1.4 Right information at right time) would be key to achieving this.

One stakeholder acknowledged that, in some instances, signposting may also be appropriately carried out by other members of the pharmacy team and their skills should be utilised where possible. Additionally, as the use of technology increases in the community pharmacy setting, it could provide a useful tool to support appropriate signposting by the pharmacy team.

“I would hope in the next year or so, we'll start to see more technology use in pharmacies as the digital relationship develops between pharmacy patients and the pharmacy. So it could be the counter staff that have the conversation about an issue and say ‘Well actually I know there's a Macmillan leaflet available on this. I've got my tablet here; I can show it to you but I can also send you a link to it, by email or whatever’ and we start to support people to use what is available on the internet and wider appropriately, so it's

kind of more of an electronic signposting role rather than just saying 'Go and see the GP'."

- Commissioning stakeholder

2.1.2 Connecting with support organisations

Collaborating or networking with other cancer support services locally was identified by the community pharmacists and stakeholders alike as being beneficial.

As discussed, an awareness of locally available services would enable community pharmacists to more appropriately signpost to these services.

"Yeah, so pharmacists would be good at that because they could say 'Oh yeah, I know about this breast care support group that meet; I've got a leaflet about it.'"

- Hospital oncology pharmacist

Connecting with charities or support workers could also potentially help the community pharmacists and pharmacy teams expand their own knowledge and could lead to future collaborations on events that would benefit survivors, such as healthy living pharmacy campaigns (see also section 2.4.2 Healthy living pharmacy campaign).

One stakeholder from Macmillan suggested that, in terms of networking locally, community navigators may be able to provide support. They could also be a useful resource in raising public awareness of community pharmacist roles.

“If you're able to be proactive and find out if there are things like community navigators in your area, and building those relationships between them so that navigators know the pharmacy exists and what the offer is and vice versa.”

- Macmillan representative

In a broad sense, a community navigator is someone who helps people access useful services or support within their community. The role can take many forms and can, for example, be linked to a healthcare service or a charity. Macmillan, in collaboration with Imperial College Healthcare NHS Trust have developed their own similar version of the role: Macmillan Cancer Care Navigators. Although not based in the community, they provide a single telephone contact to support people living with and after cancer. Their role involves providing both clinical and non-clinical support. They work with Cancer Nurse Specialists in the hospital setting and also help people access local organisations and services in the surrounding community. The service can also be contacted by non-patients, such as GPs or carers.¹⁷¹ Although this service only operates in London currently, it could be a useful point of contact for community pharmacists. It is also worth considering that

other healthcare services or charities may have their own version of the role at local level, with which community pharmacists could potentially connect.

One key advantage of local collaborations, acknowledged by the pharmacists in particular, was to ensure that standardised information (and access to information sources) could be provided across the community; thus avoiding confusion or mixed messages to survivors. Regarding this requirement, the stakeholders noted that there are potentially plenty of resources available, such as those from national cancer charities.

The task of building relationships with support services in the community setting is important for the community pharmacy profession as a whole. As acknowledged by some of the participants who were trained as BMIPs, there may be opportunity for collaborations - such as the partnership between Boots and Macmillan - on an organisational scale. However, the community pharmacists also felt this was an issue they could equally tackle on an individual level; with several participants resolving to go away and contact their local hospice, Macmillan Information Manager and other local groups after the focus group.

“Informally, I think there is a lot more pharmacy can do, although it would be down to individual pharmacists to source the information required and keep knowledge up to date, aided by specific well written training and building local networks.”

When considering this research project itself and how it could benefit from connecting with local organisations, the Macmillan representative expressed the value of this research in forwarding the organisation's own agenda. From a Macmillan perspective, further details of this work would potentially be of benefit to the organisation; allowing them to better understand the scope of community pharmacist roles and the support survivors would like from community pharmacies. Macmillan could potentially then look at its own roles as an organisation to see whether there might be any ongoing projects or roles that could be utilised to support community pharmacists in delivering survivorship care. Alternatively, this research may also highlight potential opportunities for Macmillan to expand their own roles in order to better support healthcare providers and survivors within the community setting.

2.1.3 Multidisciplinary collaborations

In addition to connecting with local organisations such as charities, the participants also saw value in collaborating with other healthcare providers across and within settings. With continuity of care and information provision causing such concern for survivors, the importance of working towards multidisciplinary collaborations was recognised by survivors, community pharmacists and stakeholders alike. As one participant summarised:

“Primary care needs to sort itself out in terms of utilising all the healthcare professionals that we have at our disposal and not think that we can or need to do it all on our own. But yeah, it comes back to trust, comes back to relationships, I think.”

- Macmillan GP

In line with the findings from the survivor data, community pharmacists were likewise keen for those being treated for breast cancer to be referred to them from the hospital setting and agreed that survivors should be able to nominate a chosen pharmacy, who should then be contacted as part of the discharge procedure. The idea of a named pharmacist was seen as being potentially very effective since it resolves another issue raised by survivors of being unsure about pharmacist expertise or which pharmacists were trained as BMIPs, for example.

CP_03: *“I love the named pharmacist idea; I think pharmacists in general are left out of the ‘team’ and side-lined”*

CP_02: *“Agree”*

CP_03: *“Or a pathway so that they take a named Pharmacist seriously if they did have any concerns without saying see GP!”*

Using their knowledge of the healthcare system, the community pharmacist participants were able build on the survivors’ initial idea further. Suggestions included ensuring that the nominated pharmacy was sent a copy of the hospital discharge summary or treatment plan.

"[Continuity of care] has always been an issue. But I will say the hospital pharmacists can help on that front by referring patients to the community pharmacists....Also asking patients which pharmacy they use and contacting the pharmacy to inform them about the patients' diagnosis and medication. Also GPs can help with this because they get the letter from hospital about diagnosis and meds"

- CP_08

Additionally, it was pointed out that since the importance of early contact with the pharmacist had been identified, it would be useful if towards the beginning of the cancer journey, the breast care nurse could recommend the named pharmacist as a potential source of early non-urgent support, as well as referring upon discharge. However, in practice, system level changes such as these might be harder to implement.

CP_02: "A named pharmacist from the beginning of journey as well - doesn't have to be at discharge or when medication starts"

CP_01: "Through treatment, the nurses could recommend talk[ing] to a named Pharmacist, queries with medication, side effects, etc. When mentioned with nurses they also said we were open weekends and so they could tell patients to phone the Pharmacist if not an urgent problem"

The community pharmacists recognised that improving continuity of care would not only require action on the part of their profession but

would need to be a collaboration amongst community pharmacists, GPs and healthcare providers in the hospital setting. Adequate transfer of care to the community setting would be a useful starting point. For example, the GP could contact a patient's named pharmacist upon receiving the discharge summary to provide an update.

"I would agree with most of the issues they pointed out especially the lack of continuity of care. I am sure pharmacists can have a significant role in bridging this gap [...] The lack of continuity of care I think has to be a joint effort between hospital/GP/community pharmacies. I don't think pharmacists can help on that front alone."

- CP_07

During the stakeholder interviews, the participants agreed that continuity of care was indeed a priority for healthcare providers as a whole. Several of the participants were already considering how to tackle this issue as part of their roles. Much enthusiasm was expressed for this strategy of transferring care to a named community pharmacist.

"One of the things that we're working on as Macmillan GPs is about the recovery package for all patients living with and beyond cancer and the idea of getting a full treatment summary from the hospital secondary care team. I think this is really helpful actually from an information point of view to say actually, there are other healthcare professionals that want this too - this would be helpful for them to do their job"

- Macmillan GP

The hospital oncology pharmacist agreed that hospital pharmacists could potentially take on the role of referring to nominated community pharmacists. An electronic referral form could potentially be a good way to achieve this, for example using a system such as PharmOutcomes. PharmOutcomes is a website designed to support community pharmacies to deliver services. Developed jointly by the PSNC and Pinnacle health partnership, it enables pharmacies to keep the required records of any services they deliver; helping them to effectively manage their time and finances. The website can also be used to gather local and national data on pharmacy services, providing evidence of the patient benefit of the services.¹⁷²

Although implementing a formal referral process would require hospital pharmacists to devote time to this activity, the hospital oncology pharmacist stakeholder felt that they would be willing to do that since this collaboration with community pharmacy would be of great benefit to patients and could also free up some of the breast care nurses' time.

Building on the idea of a formalised referral pathway, both the community pharmacists and stakeholders picked up on the potential for the process to work both ways; also allowing community pharmacists to refer an individual back to the hospital where required.

“So at that point of discharge; so at the hospital: 'You're now fine, continue as you are. You don't need to keep seeing us but we will refer you to your local community pharmacist and they will be able

to follow up appointments.’ Then potentially if that pharmacist then picks up a particular problem, they could then link in with the hospital, maybe. Oh yeah, this is wonderful.”

- Hospital oncology pharmacist

Some of these initial ideas for a referral pathway developed further, sparking an interest amongst participants around how this might be incorporated into a review; these ideas will be discussed further along with the other proposed interventions (see section 2.4.1 Review).

In terms of sharing confidential patient-specific data, the stakeholders were able to offer insight. Whilst all were supportive of community pharmacists having access to patient data and therefore being able to offer improved patient care, some potential practical issues were noted. A couple of the stakeholders came up with the idea of ensuring the patient has a copy of their treatment summary, or discharge record. This way, they could take it to the pharmacy of their choosing.

“I think from a data sharing thing, there would be difficulties between all patient treatment summaries always going to the pharmacist. But I think if we change who is at the centre here, and change it from being professional referring to professional to putting the ownership with the patient or their carer [...]and then actually they’re the ones that own their treatment summary. They have their treatment summary therefore they are then able to share that with whomever they like. And so actually that I think that changes then what the goals are almost, because actually that empowers the patient to say you’re the one with the information to hand and you can then share

it. By them doing that and giving that and giving that information to the pharmacist, there is almost a consent thing going on there. They're saying 'Actually, I'm giving you this information; this is personal information to me about my healthcare, therefore I am entrusting you'. So there's a definite consented transaction, I think, going on there that would empower the pharmacist. Interestingly; more than if the treatment summary came from the GP 'for your information'”

- Macmillan GP

One theme that emerged from the professionals' qualitative data was integrated care. Within this it was proposed that more prescriptions for breast cancer medication could be issued as FP10s; this would provide another way to ensure early with community pharmacy and reduce the burden on healthcare providers in the hospital setting. It was acknowledged, however, that this idea may not be entirely feasible for high-cost medications.

Formal referral pathways between the hospital and community settings were acknowledged as being valuable in improving continuity of care. They would enable closer monitoring on ET use, and may provide an excellent solution to the problem of frequent early discontinuation identified in the first phase of this research project.

“Your point about discharge information, I think, is absolutely right; as you know there's an awful lot of work going on across the country to try to improve the provision of discharge information to community

pharmacists. The AHSN is clearly doing a lot of work on that. But it does strike me that this in particular would be a good way of making sure that if the patient has a regular community pharmacy and that information is shared. It could be another way to ensure the ongoing long term use of the hormonal treatment for the whole duration”

- Commissioning stakeholder

The aforementioned Academic Health Science Networks (AHSNs) were introduced by NHS England in 2013 to “*identify and spread health innovation at pace and scale*”. Working at a local level, their purpose is to facilitate collaborations amongst academia, charities, local authorities and the NHS that explore opportunities and challenges to improve patient outcomes through innovative research.¹⁷³

The community pharmacists highlighted that multidisciplinary collaborations would also be beneficial in facilitating information sharing. Whilst the findings from survivors had previously revealed that they require a better understanding of healthcare professional expertise, other survivor concerns, such as lack of information provision and inappropriate signposting, led the community pharmacists to consider how well healthcare providers themselves understand the roles and expertise of other disciplines. In order to improve communication, collaboration and information sharing amongst healthcare providers, awareness of colleagues’ roles would need to be increased.

“...hospital [-based healthcare providers] and GPs need to be made more aware of the importance of community pharmacies and the potential they have on reducing the burden on them”

- CP_07

The stakeholder participants expressed the same views, suggesting that unless healthcare providers had been proactive in developing interdisciplinary relationships, a lack of knowledge was likely. The Macmillan GP, for example felt that many GPs probably have similar perceptions of community pharmacist roles as the general public. She explained that general practice is much more reliant on locums these days and therefore developing those relationships and understanding of roles and expertise is less likely.

“General practice is changing; so many GPs are retiring, so many are getting fed up and leaving the profession, or changing. And because every service is stretched, continuity within general practice is tricky.”

- Macmillan GP

The community pharmacists were keen to undertake further training that would enable them to take on an expanded role in survivorship support (see also section 2.3.3.2 Required training). Combining this with the need for a better mutual understanding of healthcare provider roles, they saw opportunity for multidisciplinary training programmes or events that would facilitate networking and provide an opportunity for

healthcare providers to learn from one another as well as learning together. This suggestion was very well received by the stakeholders; several of whom had previous experience of attending, running or assessing the need for multidisciplinary training events. They saw it as very feasible, as well as being an effective way to support the effective management of breast cancer as a long term condition going forward.

Some of the stakeholders suggested that shared training between community pharmacists and GPs would be particularly beneficial since their levels of knowledge in terms of breast cancer management is probably similar, but with different areas of expertise they could collaborate effectively, which could be useful in their future practice.

“Whilst GPs have experience, typically the GPs' work around cancer will be to refer to specialists. So they're in the same position as pharmacists in that we've got the basics; certainly some pharmacists might need a little bit of a refresher or a build on their background knowledge for the basics of cancer, how it's managed, how it's treated and is that current? But I think in terms of the detailed knowledge, they're probably on a par with GPs”

- LPC Chair

“And I guess if they've gone through the process together, then if the pharmacist has a query and contacts the GP and says ‘I've got this patient, what do you think?’ They could sort of, because they've done that training together, they could sort of hash it out between them, which is quite satisfying.”

- Hospital oncology pharmacist

One stakeholder had recently collaborated with GPs and community pharmacists at a local level to organise a training event for community pharmacists on supporting those living with and beyond cancer. Having community pharmacists involved in organising the event meant they were able to maximise attendance by linking it in with the healthy living pharmacy initiative; something that the GPs were not aware of. The event was very well-received and feedback from it has led to further events being organised to meet the needs of healthcare professionals in that local area.

“A couple of things came out from it, so some secondary care colleagues came to the meeting - and that was a ridiculous thing in the room - that community pharmacists had no idea what secondary care pharmacists really did, and vice versa. And the thing about shared learning; that was also brought up that they need shared learning together just to help them understand each other's roles and things. So I thought that was really interesting. And off the back of that, we have actually, Macmillan are going to be funding a communication skills based training event”

- Macmillan GP

In addition to training events, the stakeholders also suggested that a shadowing scheme may also be beneficial in terms of learning how other healthcare professionals work and fostering future collaborative relationships. One participant noted that Lewisham CCG had previously carried out a successful project that aimed to do just this: Walk in my Shoes. This initiative provided the opportunity for GPs and staff from 42 practices to visit community pharmacies and learn more about the day

to day processes. The 45 participating community pharmacy teams likewise had the chance to visit GP practices. The aim of the project was to challenge misconceptions about roles and encourage better collaboration in the future.¹⁷⁴

Another participant who had worked closely with community pharmacists to explore their potential role in cancer management, reported that, in addition to training, the community pharmacists felt they would benefit from experiencing the roles of the hospital-based healthcare providers working in oncology.

“They said they’d want to come and visit to shadow us in the clinic to see how we interact with patients and to understand the patient journey. So I was thinking I’d take them on a tour of where the patient goes and then they’d sit with us in the clinic”

- Hospital oncology pharmacist

Whilst a better understanding of roles was key to information sharing, in terms of the content of the information shared, the community pharmacists felt it was very important to ensure they provide the same messages as other healthcare providers. Standardising information provided across healthcare settings would be beneficial to healthcare providers, as they could be more confident with their recommendations, but also to survivors since they reported receiving incorrect, conflicting or a lack of information. Participants suggested that they would benefit

from access to the formularies and signposting information used by hospitals.

“Do the hospitals have a directory of services they refer to, which they could share with pharmacies, so we are all giving the same messages?”

- CP_02

Whilst shared training events would go some way towards achieving more standardised care messages, the stakeholders were keen to share information with community pharmacists wherever possible. The hospital oncology pharmacist felt that hospitals could look into providing information such as treatment protocols and formularies. The Macmillan GP felt that in the future there might be the possibility to share the outcomes of the Cancer Care Review or Health Needs Assessment with the community pharmacist. Meanwhile, many alternative sources of information in the form of training were also identified, such as through Macmillan and CPPE (see also see also section 2.3.3.2 Required training)

“Most hospitals either have their own medicines information department, or have access to another hospitals' medicines information department. And patients can call that as well as community pharmacists, GPs can call it. I don't think community pharmacists are aware they can call it, but they can.”

- Hospital oncology pharmacist

In addition to facilitating a better understanding of healthcare professional roles and more appropriate signposting, sharing information and developing good working relationships with other healthcare providers locally was also identified as a way to reduce workload across healthcare settings.

*“Can they [community pharmacists] pick up the phone and ask a question to at least shortcut that referral back to the GP?
‘Actually I’ve got the contact details of the breast cancer nurse at the local hospital so I’ll just go and phone him or her and get the advice direct so that the GP doesn’t have to do that.’ But again, like I was saying earlier on, that’s easier if they’ve had that outreach role and have been out and met pharmacists, but ideally do it in a multidisciplinary way.”*

- Commissioning stakeholder

2.1.4 Right information at right time

“Right information from the right person at the right time”

- CP_01

When reflecting on survivors’ concerns surrounding the lack of information provision, many of the participants noted that whilst it could be the case that other healthcare providers are not having these conversations with survivors, it could equally be that survivors are just not processing the information they are given.

“There is probably information overload and hard to absorb information due to lots of information and of course emotions.”

Indeed, the survivors themselves had reported experiencing information overload. This, along with survivor concerns surrounding post-discharge isolation, difficulties accessing care in the later years and lack of continuity of care, led the community pharmacists to identify that part of their role needs to involve providing the right information and the right time. They felt that, due to the accessibility of community pharmacy and the lack of need for appointments, they were ideally placed to take on this role. To put this into practice, pharmacists would need to ensure they make early contact with survivors and raise awareness about their role in survivorship support. They would also need to be involved in the care pathways. Potential ways of incorporating the provision of the right care at the right time into interventions will be explored later on in this chapter; see also section 2.4 Proposed interventions.

Stakeholders were very positive about the potential for community pharmacists to provide the right information at the right time and were able to offer further insight into the importance of this role and how community pharmacists might achieve it.

"I think that's an element of effective consultation, effective information giving and signposting, in that actually you have to address the needs of the patient at the time the when the patient wants those rather than, 'you're at diagnosis stage therefore

we're going to give you information on your diagnosis...We're providing you with treatment; here's information on your treatment.' People aren't always ready at those stages to hear that information so I think that's an important thing and for me that's probably one of the crucial elements of the pathway in which community pharmacy can get involved."

- LPC chair

In line with the findings from the survivor focus groups, the hospital oncology pharmacist had several examples of patients who had experienced information overload or felt they'd been abandoned by their consultant at the hospital after being discharged. She acknowledged the importance of having someone to contact as needed at every stage of the journey, and also noted that in her experience, even if the patient has a regular community pharmacy, the pharmacy often do not find out a patient has cancer until they are a quite far into their cancer journey, or even palliative; this is particularly true for cases where patients are not on cancer medication prescribed in the community. Therefore making the community pharmacist aware that their patient has breast cancer as early as possible is highly important. The hospital oncology pharmacist also reported that providing the right information at the right time can sometimes be difficult to judge, even for cancer specialists since patients are not always aware of what they need to know. However, with experience she felt community pharmacists will be well-placed to help the patient find out what information they need.

“Oh community pharmacies would be really good because they could reiterate the information at a later date, once [the patient] had come to terms with the fact that they were palliative, or they're changing treatment or whatever. Once they'd come to terms with that, then the pharmacist can reiterate the information that's already been told to them”

- Hospital oncology pharmacist

Meanwhile, the Macmillan GP delved into the examples of patients discontinuing their endocrine therapy early and some not being sure why they are taking it. Providing context on when patients are given ET information, she confirmed that this usually happens as soon as their histology results come back; so before they start their treatment. Understandably then, such a long delay before initiating treatment coupled with the overload of information during this time results in patients forgetting the details on the importance of this medication. These findings, she felt, could be of great interest to breast care nurses, who could then consider how to make improvements to their practice.

One of the stakeholders also raised the point that information giving should be a continuous process or reiterating and reinforcing key messages as required.

“It's not a one-time thing, and I think that's the point and that's what we've got lots of feedback about information provision and how it's given. We know people don't process when people have just been told they've got cancer or when they're going through

treatment and so actually it's those repeated periods of time when you can go 'Do you need any more information? We went through this stuff; do you want to go through it again?' Yeah, definitely; it's not a one-off 'Here's your information', it's a 'When do you need it?' and led by the individuals, definitely.'

- Macmillan representative

2.1.5 Emotional support

The issue of providing emotional support emerged very early on in the community pharmacist focus groups, and interestingly, views on their roles here varied. Those with previous experience of supporting cancer survivors, (such as through the BMIP service) described the importance of the emotional support aspect of the pharmacist role.

"As a pharmacist I feel I am only able to provide emotional support or refer to Macmillan"

- CP_02

"One gentleman actually came back to thank me for asking how he was. He took the time to have a coffee and think about himself after I spoke to him."

- CP_01

Conversely, other community pharmacists felt that the provision of emotional support was outside of their profession's expertise and this

role should therefore be left to those healthcare providers with relevant training in this field, such as those qualified in psychological counselling.

Findings from the survivor study had revealed that *emotional support* had a wide variety of meanings to different individuals; potentially referring to anything from a friendly chat to a formal counselling service. This range of definitions could likewise explain the difference of opinions conveyed amongst the community pharmacists. For example, one pharmacist described how it could be incorporated into other aspects of care through providing reassurance about their concerns as well as information.

“Sometimes patients can be concerned that they can’t do certain things or take certain medicines while they are on their cancer medication. They need information on what side effects are normal. Also patients respond to ‘cancer scares’ in the newspapers in different ways, breast cancer is a big issue that is often sensationalised by the media and we need to be the voice of rationality when people are concerned.”

- CP_09

A major concern raised by the survivors had been the lack of emotional support available for their family, carers and friends. The pharmacists likewise acknowledged the need for more support for this group; with

several confirming that the conversations they have currently are primarily with family members or carers.

“Think I probably talk to more carers/ family than survivors. I always ask how the carer is and sometimes I think that is a shock that somebody has actually asked how they are.”

- CP_01

When discussing emotional support with the stakeholder participants, the general consensus was that the importance of even the smallest attempts to provide emotional support is often overlooked.

“I think [emotional support is] really important and a lot of people don't realise the impact that emotional support can have on patients. So a [community] pharmacist saw one of our patients yesterday and he rang me and he was like ‘I spent about 45 minutes with her. I don't know if I really helped’. And I was like ‘Trust me, you did! If you just listened to her for 45 minutes, you would have done a world of good!’ But he didn't really see...because he wasn't obviously giving her advice or helping her in the way he helps other patients. So I think emotional support is important and it's underrated by healthcare professionals. They just think it's not required.

- Hospital oncology pharmacist

The stakeholders also discussed the apparent lack of confidence amongst some of the community pharmacists to provide emotional support, emphasising that the role does not necessarily require a lot of

specialist training and often good consultation skills are all that is required.

"I would say if you have confidence in your ability to listen and your confidence in empathy and connecting with individuals, and not to be scared when somebody says something that's major or emotional, or starts crying, or gets cross, or starts ranting about how the hospital's shafted them about something, and not being drawn into that whole emotional experience but actually being able to be an active listening in that. I would suggest you don't need knowledge or expertise, you just need knowledge and expertise in communicating and then actually the rest of it is ok because you can confidently say "I don't know the answer to that question, but you know what? I've heard you today and this is clearly causing you distress or a problem so I'm going to find out a bit more to help you and support you." And suddenly you didn't need to have the answer, you just need to know where to look for it and the confidence to do that really. And that again helps with patient perceptions really.

Sometimes that emotional support is just asking 'How are you? It's ok to feel like that.' And just reassuring people that when you're going through a difficult time with cancer it's ok to get upset, it's ok to feel frustrated, angry and all of those things and then signposting to people who are experienced and have that counselling skill. Because I think what we're not trying to do is create an army of 45,000 community pharmacist counsellors; that's stretching it a little bit. But actually there's certainly some basic elements of training that can help pharmacists who want to step forward and do a little bit more of that emotional support that might just be enough for some patients. So that material is there; things like Sage and Thyme, even baseline consultation skills where you start to develop that a little bit further, can really help to understand what is it the

patient wants? What is the real issue? Have they come to me today to talk about their medication, or is it actually they're just really upset, or angry or concerned, emotional about their cancer journey at that point?"

- LPC chair

A few stakeholders mentioned additional training courses that may support community pharmacists in providing emotional support; these included 'Sage and Thyme' and 'Hope'.

Sage and Thyme is an evidence-based model for conversations with people who are worried or distressed. It was originally developed by University Hospital of South Manchester NHS trust in response to the 2004 NICE guidance 'Improving Supportive and Palliative Care for Adults with Cancer'. The initial training involves a workshop that teaches how to listen to patients effectively and respond in a way that will empower them. It is widely used in the NHS for both clinical and non-clinical staff.¹⁷⁵

Hope is a programme of group sessions provided by Macmillan that stands for Help to Overcome Problems Effectively. This programme is designed for cancer survivors; giving them the skills they need to effectively cope with emotional, psychological and practical issues of living with and after cancer. Health and social care professionals, such as community pharmacists can train to become a programme facilitator themselves.¹⁷⁶

Finally, one stakeholder also suggested that providing emotional support should not necessarily be the sole responsibility of the pharmacist. Where appropriate, other members of the pharmacy team may also be able to support here, particularly in cases where they have a pre-existing relationship with the individual.

“And I suspect also their wider teams as well because its often said, but I think it's true: If I reflect on the pharmacies I've managed in the past where yes, I live locally and I also knew people but a lot of my counter staff had lived in and around that area for years and years and you know, had their kids grown up with other patients who came in...And so that long-standing knowledge of people and hence confidence just because interpersonal relationship, is really quite important”

- Commissioning stakeholder

2.1.6 Pharmacy products

The community pharmacists were very receptive of the survivors' suggestions on providing more information about which pharmacy products are safe and effective for use during breast cancer treatment.

“I think as pharmacists we underestimate the support we can provide, often it's very simple like dry skin or vitamin/dietary advice.”

- CP_03

Some had experienced queries about such issues themselves and had spent time calling manufacturers or the local hospital to establish which products to recommend.

“We’re in the position to give proper evidence based information where there is a lot of misinformation- cancer and deodorants, hair colours etc.”

- CP_09

It was also noted that in the larger Boots stores, some of the beauty advisors had undertaken training to enable them to recommend suitable beauty products to cancer survivors. For pharmacies situated within these stores, this could be a valuable source of information, and an opportunity for collaboration or appropriate signposting.

“Most pharmacies are now health and beauty so referring patients to the beauty part as well, like make up and how to cover the scars, makeover to help them look and feel good as well. I know No 7 does this with cancer patients”

- CP_08

From a stakeholder perspective, recommending pharmacy products for the management of cancer-related side effects was a very well-received suggestion. The importance of this role and the existing knowledge gap surrounding this practical information was something that resonated with the participants, who agreed that it was something that could

feasibly be addressed on a national level. The LPC chair noted that if a patient comes in for advice on a minor ailment and they require something that is safe to use whilst receiving radiotherapy or chemotherapy for example, it can be very difficult to find that information quickly or know who to contact to find out. Without access to this sort of information even recommending suitable shampoos or deodorants suddenly becomes very complicated.

“That I think is an area that's amenable to national action. So it could be CPPE training, it could be pharmacy bodies, or one of the pharmacy publications could work with Macmillan or other charities to develop guidance about appropriate products to be used. Because what I wouldn't want to have is a degree of reinvention of the wheel at a local level where it doesn't really need to be, or where people don't have time to do that. So that would strike me as appropriate action that could be taken nationally.”

- Commissioning stakeholder

The Macmillan representative also added that she felt this is something that could be covered by some of the work they were currently undertaking in partnership with Boots, alongside the BMIP and Macmillan Beauty Advisor roles.

Although the community pharmacist participants had voiced some concerns about ensuring they make the same recommendations as the hospital, the hospital oncology pharmacist expressed a different view.

She was particularly enthusiastic about the potential role of community pharmacists here; explaining that in the hospital setting, product recommendations are restricted to those listed on the formulary. Community pharmacy however has access to a much wider range of products and therefore a greater opportunity to find a product that is both suitable and effective for the individual.

“So if I shared our formulary, or our recommended products, if someone got a rash because of whatever, ‘this is what we would try with the patients’ so that the pharmacist is aware of that. Then obviously if the patient comes in and says ‘I’ve tried it, it’s not working’, they can be a bit more exploratory and say ‘Well we’ve actually got this product available that the hospital doesn’t have available. It’s similar but it’s got a slightly different ingredient. Maybe have a go with this and see if this works?’ Because then they’ve exhausted the first line things that we would recommend but because they’ve got more access to other stuff, they could try second and third line things.”

- Hospital oncology pharmacist

2.1.7 Advertisements and promotion

The pharmacists felt that several of the survivors’ concerns could be addressed through improved advertising and promotion.

Advertisements placed within the pharmacy, as well as more widely within public health campaigns, could effectively raise awareness of pharmacist roles and expertise; helping to address public perceptions

of the role and, as survivors recommend, help them to understand where best to access care.

“There is a general lack of understanding and misconceptions about the pharmacist role and what we can do- I think it is due to the changing roles of pharmacists over the last decade or so. Hopefully with media campaigns and promotion of the profession this will change”

- CP_02

Some pharmacists are already tackling this issue; using in-store signage to notify customers that cancer support is one of the services offered or promote the availability of the consultation room for discussing private health matters (see also section 2.2 Accessibility of setting).

“It seems to be a big ongoing issue; trying to help people to recognise [consultation rooms] are there. And actually to encourage them to ask to use them; as well as pharmacy staff offering their use.”

- Commissioning stakeholder

The Macmillan television adverts explaining the role of cancer-trained beauty advisors were commented on by some of the community pharmacists who were also keen to see similar adverts that raise awareness of the BMIP role, particularly since BMIPs which appeared

to be relatively unknown, even within the community pharmacy profession. It was likewise acknowledged that more needs to be done to ensure BMIP-trained pharmacists are easily identifiable, to service users and other pharmacists.

“Yes, a lot of the advertising has focused on beauty advisors, be nice to see a pharmacist in a positive light.”

- CP_03

The Macmillan representative likewise recognised that more needs to be done to showcase the role of BMIPs, and not just in terms of national television advertising campaigns.

“Whether or not it's something in the window that says ‘there's someone here’ and not just our advertising. And then maybe a picture of them, you know, as in ‘I look like this’; absolutely.”

- Macmillan representative

The community pharmacists reflected on the possibility that within their respective pharmacies, they could make an effort to advertise and promote any relevant services or events available within their community. One such method of achieving this would be through posters and leaflets, or as part of the Healthy Living Pharmacy initiative (see also section 3.4.2 HLP campaign). This in turn would also aid them in networking with local support organisations and signposting appropriately.

“Signposting is one. Also getting ourselves familiar with all the support groups in your own local area would be helpful. Maybe put up posters or leaflets about them?”

- CP_04

2.2 Accessibility of setting

Throughout the focus groups, accessibility of setting came up several times; in terms of both the accessibility within individual pharmacies and of pharmacies within communities.

The community pharmacist participants felt the widely accessible nature of the setting and the ‘relaxed’ atmosphere (particularly in terms of the ability to opportunistically seek care) were features of community pharmacy that make it particularly well-placed to provide additional survivor support.

“I think community pharmacists would be great at providing a service like this. More accessible and it’s a relaxed setting.”

- CP_04

The community pharmacists also commented that the location of the pharmacy might potentially affect the uptake of any future service or intervention; with one pharmacist recognising that she’d been dealing with a lot more cancer-related queries since working a city pharmacy. In contrast, one of the pharmacists located in a rural village said she had

little experience of dealing with these types of queries, despite having a lot of patients taking medication for breast cancer.

Adding to this, the hospital oncology pharmacist also voiced a concern that despite the abundance of community pharmacies across the country, the distance an individual would have to travel to get to the pharmacy may create an issue; for example if an intervention or service was not available at their nearest pharmacy. This could then potentially lead to some conflict between pharmacies if patients were switching pharmacies to access additional services and taking their prescriptions with them.

Accessibility of setting in terms of factors within the pharmacy primarily came up in connection to the use of consultation rooms. Since one of the concerns voiced by survivors was the lack of privacy in community pharmacies, much of the discussion in the community pharmacist focus groups was linked to whether the use of consultation rooms was being optimised.

“With reference to lack of privacy - pharmacists in general are poor at using the consultation room and perhaps should make more of an effort to use it more frequently - then awareness will increase”

- CP_02

The pharmacists acknowledged that sometimes the positioning of the consultation room within the pharmacy can be an issue; with some

consultation rooms being tucked around a corner and not visible. One participant who worked in a large store explained that her consultation room was actually near the main store tills, over the other side of the store from the pharmacy. Despite these issues, the participants did note that pharmacists need to do more on an individual level to make use of the consultation room, ensuring they look out for signs that customers may want to speak privately, as well as advertising that it is there. One participant said they have a sign on the counter promoting that the consultation room is available if required.

“It's a case of spotting the signs that someone needs a bit of privacy”

- CP_03

A few of the stakeholders likewise noted that optimising the use of consultation rooms is an ongoing issue, but improvements are being made. Whilst one of the suggested solutions from the community pharmacists was to make use of advertising (see section 2.1.7 Advertisements and promotion) one stakeholder argued that there are already overwhelming amounts of posters, signs and other advertising in some community pharmacies, therefore may not be the best solution. Instead, pharmacy teams could be more vocal about the availability of the consultation room.

“I think that's been highlighted in some recent comments from the GPhC in terms of what they're focusing on now when they're doing inspection visits, is actually looking and listening around perceptions of privacy and actual, the reality. I think there is still an element of the consultation room is used for services or incredibly delicate conversations rather than actually being used routinely to offer patient care and support. Certainly in some of the pharmacies in which I've worked, the consultation room is not visible to the patient; it's out the back behind the door so they're not aware that those facilities exist. So I can understand how that perception is there. But I think even where those facilities aren't potentially available, making sure the patient feels that they're being treated in confidence and in a private area, even if it's just moving to one side and recognising that they might be overheard. It's something that has room for improvement, but actually has improved significantly over the last 10 years.”

- LPC chair

2.3 Barriers affecting feasibility of future interventions

When considering the feasibility of potential interventions, the community pharmacists were enthusiastic about expanding their roles to provide improved care for breast cancer survivors and felt there was considerable scope for the profession to make a difference. However, they did have some concerns surrounding the feasibility of introducing a new service or intervention. The stakeholders provided further insight into how far, from their perspective, these issues would be likely to affect the feasibility of future community pharmacy services or interventions.

2.3.1 Remuneration

Whilst the community pharmacists were all willing to take on additional roles in order to provide better survivorship care, they equally acknowledged that a potential barrier to taking on new roles or delivering new interventions could be issues surrounding remuneration.

The community pharmacists reported carrying out a variety of activities as part of their professional practice for which they do not receive payment. Several noted that they often give up their free time for these additional roles because they find their job rewarding or because they care about providing good patient care, and therefore would not be concerned, at least on an individual level, about being paid for taking on a more active role in survivorship care. It was also noted that many of the strategies to improve care could be carried out as part of a pharmacist's current day-to-day role; for example, appropriate signposting and advising on pharmacy products, so remuneration would not be such an issue.

On a wider scale, the pharmacists believed that despite their feelings on remuneration as individuals, there may be some concerns from their employers. Pharmacy businesses would need to consider how new interventions or additional roles may affect workload or incur costs for the business.

“I wouldn't want [remuneration] to be an issue, I don't think any of us come in to the profession for financial gains it's about patient care, but in reality it may be - stores, staff, etc. cost money and the payments we are receiving currently are tight and don't give much room for extras.”

- CP_02

In order for a new service or intervention to have an attached payment, it would, of course, require funding. The community pharmacists shared their concerns about where this payment could feasibly come from. In October 2016, the Government cut community pharmacy funding by £113 million, which resulted in the need for many community pharmacies to reduce their staffing levels and become more reliant on remuneration for pharmacy services.¹⁷⁷ In light of this, the pharmacists noted that ideally, any intervention would need to be commissioned by the NHS, either locally or nationally. However, some pharmacist participants voiced concerns about the current lack of funding available for community pharmacy services.

“Whether or not it'll be funded is the real question especially in the current climate.”

- CP_07

One community pharmacist suggested that another potential source of funding could be through cancer charities, such as Macmillan. She had previously worked on several local projects that had been awarded

Macmillan funding and therefore suggested that if a small amount of funding could be secured for a local pilot, this could be enough to prove the importance of the pharmacist role, and may eventually lead to a commissioned service with attached remuneration.

“Maybe we need to get some funding from somebody (Macmillan), give evidence of the need for service, set up a specific service and show that pharmacists can play a part in cancer pathway- hence commissioned service and payment”

- CP_01

During the stakeholder interviews, the issue of remuneration was touched upon. Some of the stakeholders felt that the most viable solution was to expand upon pre-existing interventions such as HLP campaigns or MURs (see also section 2.4 Proposed interventions).

“This is about recognising that if a pharmacist is doing this service, they are potentially not doing something else. [...] We'd love to do everything and sit down with every patient for 20 minutes. Practically, time is finite, money is finite so some decisions have to be made about what is feasible. I still think there's a lot of scope for it and I still think it's highly feasible to do, but wrapped up within things like the current MUR framework in England and Wales and the Chronic Medication Service in Scotland. How can you say, well actually let's build it into part of that so the funding follows that patient.”

- LPC Chair

2.3.2 Time

“Time is always an issue!”

- CP_06

Closely linked to the concerns about remuneration, various time-related issues were raised by the participants when considering the feasibility of a future intervention. As one community pharmacist summarised when considering the many potential ways to better support survivors;

“[There’s] so much we could do. A role in itself without doing the day job!”

- CP_01

When taking on any new roles or delivering any intervention, one of the most important considerations is the time it would take time to complete the task. The community pharmacists explained that they already have a large workload and are expected to deliver many other services, so they felt that a time-consuming intervention may act as a barrier to service delivery. In addition to detracting from the time pharmacists could be spending delivering paid services, they noted that spending more time away from the dispensary would require them to have appropriate staffing levels in place to ensure the safe running of the pharmacy. If extra support staff were required, this would create an

additional cost for the business, therefore increasing the need for remuneration.

“Obviously we know staff levels in the pharmacy is an issue these days as seen in the news lately. So time will be an issue with everything else that is happening in the pharmacy but with sufficient staff levels, it shouldn't really be a problem.”

- CP_07

One of the stakeholders likewise acknowledged that without a second pharmacist, providing opportunistic support without using pre-booked appointments might not be realistic.

“If you a pharmacy where there's only one pharmacist, time would be a massive issue. If you're just having drop ins, footfall sort of thing, then most of the time I imagine the pharmacist might not be available to speak to that patient there and then so it might have to be an appointment based thing, which might be better. Because I think if the patient comes in and the pharmacist is busy they get turned away. If that happens so many times, the patient is not going to go back. So that is an issue.”

- Hospital oncology pharmacist

The community pharmacists reasoned that in order to take on additional roles they would also require further training (see also section 2.3.3.2), which would once again create an issue in terms of time. Whilst the focus group participants were generally open to completing any

required training during their own free time, one pharmacist noted that this is less likely to hold true for the general population of community pharmacists. The selection bias alluded to here is of note since many of the participants volunteered to give up some of their free time to be involved in this study due to a pre-existing interest in cancer support.

“Company restrictions may play a big part rather than personal limitations. I think most pharmacists would get on board and provide services etc. if they could do it within working hours - it’s the extra work in their own time that would put a lot of pharmacists off”

- CP_02

As with the remuneration issues, the pharmacists felt that whilst on a personal level, they were enthusiastic about expanding their roles; their employers may not take the same view. The participants also acknowledged that in order for the role of the community pharmacist to develop in terms of breast cancer support, it would be the responsibility of the individuals to be proactive; taking an interest in the opportunities, and taking on any required training or increases in the workload. Whilst there were concerns about the feasibility of a formal service, pharmacists felt that there were many changes they could make to their practice on an individual level at least, such as having proactive conversations with breast cancer survivors and networking with local support services to obtain information and enhance their signposting practices.

2.3.3 Pharmacist expertise

As established during the survivor study, perceptions of pharmacist roles are varied, and may not always be accurate. This section considers pharmacist views on patient and public perceptions of their expertise, as well as their own views of their expertise in terms of the training they feel they need, and how both of these considerations could potentially affect the feasibility of any future intervention to support breast cancer survivors. Information on pharmacist learning needs is required when designing an intervention, ensuring it is feasible and the necessary training is in place. Meanwhile, in order to successfully implement an intervention in the community pharmacy setting, potential service users and members of the public must have an understanding of the expertise of the community pharmacist and be willing to take part in the service.

2.3.3.1 Patient and public perceptions

The survivor study revealed a vast range of experiences in terms of the breast cancer care provided by community pharmacists. Whilst some survivors reported very positive experiences of care, others felt there was a lack of expertise amongst community pharmacists (and other healthcare providers) in relation to breast cancer support (see Survivor Perspectives chapter, section 2.2.1.4.2 Perceived lack of expertise). In response to these findings, the community pharmacists agreed that they could do more to ensure that all survivors receive the support they

need; both by assuming new roles and taking steps to ensure that survivors and the public have an accurate understanding of the expertise and services available in community pharmacy.

The survivor study had highlighted many issues that survivors felt could be tackled by community pharmacists. As part of the community pharmacist focus groups, much of the discussion revealed the community pharmacists' views on these perceptions and whether they seemed realistic in light of current expertise of the profession. The pharmacists agreed that they would be ideal candidates to tackle issues such as lifestyle advice, supporting with pharmacy products, and common side effects and aftercare concerns. However, views were divided on whether survivor perceptions of community pharmacist ability to provide emotional support were accurate (see also 3.1.5 Emotional support). Likewise, pharmacists felt they had additional strengths that were overlooked by survivors, such as the importance of their role in cancer prevention and supporting with long term conditions.

The participants noted that some public confusion about pharmacist expertise could be due the differences in the levels of care provided to survivors depending on the cancer support experience of individual community pharmacists.

“I think in a lot of pharmacies, where the Macmillan training is not required, when patients come with cancer-related queries, they mostly get referred because the pharmacist probably doesn't have

the training required. These regular occurrences I'm sure contribute to patients losing confidence in seeking advice from the pharmacists and automatically assume they wouldn't be of any help"

- CP_07

In terms of the wider picture of healthcare provision, the participants acknowledged that the roles of community pharmacists are continually evolving; perpetuating misconceptions or confusion about expertise within the profession. They agreed that in order to ensure sufficient uptake of any future service or intervention, public perceptions of community pharmacist roles would need to be updated accordingly, for example through advertising and promoting the support available (see also section 2.1.7 Advertisements and promotion).

"I don't think [the lack of understanding of community pharmacist expertise] is limited to cancer care/advice/survivorship. There is a general lack of understanding and misconceptions about the pharmacist role and what we can do- I think it is due to the changing roles of pharmacists over the last decade or so. Hopefully with media campaigns and promotion of the profession this will change."

- CP_02

Whilst recognising that there are things that can be done to address the perceptions of their profession's expertise, the community pharmacists also acknowledged that this is an ongoing issue affecting many aspects of the community pharmacist role. This is therefore something that

needs addressing on a national level as well as by individual healthcare providers.

“It’s the 6 million dollar question, I’ve been qualified for 22 years and we’ve been trying to change public perceptions for a long time before that. I don’t think I have the answer. We are experts on medicines; how many patients know this?”

- CP_09

For example, in the months preceding the focus groups, there had been a national media campaign encouraging the public to visit their community pharmacist as a first port of call before making an appointment to see their GP. This was something that some of the pharmacists reflected on, with mixed opinions on how this affected public perceptions of their roles. Some felt the campaign was beneficial, as it publicised community pharmacy as a source of healthcare and encouraged people to visit. Meanwhile, it was also noted that this can cause problems if the public does not fully understand the expertise of the pharmacist and therefore when to seek care from the pharmacist and when to go directly to the GP.

“In some respects it is increasing our profile and we are helping quite a lot of patients and saving GP appointments, other patients are just frustrated because we can’t help”

- CP_02

Whilst the community pharmacists acknowledged the importance of their role in shaping public perceptions of their profession, it was also noted that achieving a shift in perceptions also requires the co-operation of the public; including being proactive in seeking care and educating themselves on where best to access care depending on the type of concern they have.

“But they need to ask pharmacists the questions first before assuming that they might not know. Most of the time if we don’t know something we tend to signpost patient or tell them to come back when we get more information”

- CP_08

2.3.3.2 Required training

The community pharmacist participants unanimously agreed that in order to better support breast cancer survivors, one of the most important factors would be the provision of relevant training. Since the scope for multidisciplinary training has already been discussed (see section 2.1.3 Multidisciplinary collaborations), this section will focus on discussing the training needs of community pharmacists specifically.

Stakeholder participants likewise identified some learning needs for community pharmacists from their perspective, and noted that community pharmacists as a profession are particularly receptive to new learning opportunities.

“We do always find though, that the profession tends to be a ‘I always want more training’ profession and I suppose, I think that probably is positive, but sometimes it can be seen to be a weakness, perhaps in the eyes of other people who perhaps don’t understand the pharmacist mind-set of eagerness to always learn more.”

- Commissioning stakeholder

Differences in levels of survivorship care provided in the community pharmacy setting were evident in the data from both survivors and community pharmacists. This was largely down to different levels of experience and training; some pharmacist participants for example, had completed the BMIP training whilst others felt they had very little knowledge of cancer. The pharmacists recognised that in order to introduce an intervention, it was important that everyone delivering the service complete appropriate training to ensure that potential service users would all have access to the same levels of care.

“...we need to be sure that we're prepared and adequately trained for the questions we may receive; we need to be an integrated part of the team so everyone's giving the same message”

- CP_03

A few of the stakeholders likewise raised similar concerns, emphasising the need to ensure equity of care across community pharmacies.

“How do you ensure that the quality of care you get from all community pharmacies is the same? Can they expect to receive the same level of care across all pharmacies?”

- Macmillan GP

Regardless of their experience in cancer support, the community pharmacist participants all felt they would require further training in order to deliver any future service or intervention. A general lack of confidence in providing advice on breast cancer was expressed and pharmacists reported receiving little to no formal training on cancer; in terms of both the content of their MPharm degree, and the availability of postgraduate training.

“Seriously I think cancer is not taught properly at undergraduate level, it’s a hard going part of medicinal chemistry and pharmacology and not covered well in the clinical aspects as it is thought of as being highly specialised. I think a lot of community pharmacists are daunted by oncology pharmacy”

- CP_09

Whilst lack of confidence was touched on by community pharmacists, the issue featured heavily across the stakeholder interviews. From the stakeholder perspective, there was a strong belief that, whilst community pharmacists may require some training to expand their knowledge and expertise, the main barrier to expanding the roles of the profession was actually the lack of confidence to do so.

"Looking at oncology as a topic it is incredibly complex and a specialist area. So I think there is, in primary care, a potential for that knee jerk reaction of "I can't help you because you've got a complex problem." Whereas sometimes we know that that problem might be something really straightforward such as "the medication I'm taking makes me feel unwell, is that normal? How long will it last?" And absolutely those are things within a community pharmacist's understanding to say "Yes I can help you with those things and here are some options." Sometimes it's just some reassurance they're needing and I think when you start to look at just even slight advanced cancer support like the Boots Macmillan Information Pharmacist where you're not looking at any clinical change or clinical knowledge, more about how to manage and signpost a patient properly and listen to their needs, that changes that whole approach. So that for me, there is a potential for some improvement in the skill set of community pharmacists to address that, and give them the confidence rather than technical knowledge but it's there and I think it's helping people to understand what questions can be answered in the primary care environment and what questions absolutely would need to be referred to their oncology team."

- LPC chair

"I think pharmacists in general don't have enough confidence in themselves and they feel like they should know the answer to everything so some people may mumble out an answer and look at their feet when they say it, which obviously doesn't fulfil confidence for the patient. But I think it's ok to not know the answer; I think that needs to be clear. [...] I've been doing oncology for the last 6 years of my life, but I don't know every answer to every question; it's more about knowing where to find that information and being comfortable to admit your limits. It's

so much more respectful to say "I don't know the answer, I'll contact this person." Or "I'll give you a call tomorrow with the answer" if it's in a community pharmacy setting. "I'll find out, I know where to find out". I often if I'm in a consulting room, I'll have the screen and generally it will be facing the patient and I'll be like "Let's have a look together" I'll know what website to look on; generally it's the SPC, and I'll show them where to look and I'll read it out to them to show them the information, if it's like an interaction or a side effect or something [...] And then it means I've learnt with the patient; we've learnt together. And I think the patient then will respect me for that going forward."

- Hospital oncology pharmacist

In order for community pharmacists to feel confident enough to support breast cancer survivors, the stakeholders reported that improving consultation skills would be vital. Those without a background in community pharmacy themselves were surprised by community pharmacists' lack of confidence in interacting with cancer survivors. Additionally several noted that until recent years, the MPharm degree lacked a requirement to teach consultation skills.

"[One community pharmacist who was preparing to interact with cancer patients] said 'I don't even know how to behave!' He even said something as simple as 'should I cock my head or is that really patronising when I'm talking to a cancer patient?' That was how like...specific and nervous he was. That was how much detail he wanted to know, which I found absolutely fascinating."

- Hospital oncology pharmacist

“The barriers are that FEELING of lack of knowledge and expertise. And I would go even a step back from that actually it’s not about lack of knowledge and expertise. I would say if you have confidence in your ability to listen and your confidence in empathy and connecting with individuals.”

- Macmillan GP

In 2014 consultation skills practice standards were announced for pharmacy professionals in England. Prior to this, formal consultation skills training for pharmacists were not considered essential. The standards included managing patient-centred consultations, using up-to-date and evidence based information, understanding local needs, empowering patients in self-management, undertaking appropriate clinical assessments and referring as required.¹⁷⁸ Following the introduction of these standards, there has been a lot of ongoing work to support community pharmacists and all pharmacy professionals to improve their consultation skills in general. As part of their day-to-day practice, community pharmacists routinely engage in one-to-one consultations with patients; providing advice and support on the management of many conditions. However, the stakeholders reported that, in their experience, community pharmacists still lack the confidence to support those individual living with and after cancer; it is generally not thought of as a long term condition and there is still a fear surrounding providing care.

One of the stakeholders, who had done a lot of work on improving consultation skills in the community pharmacy setting, explained that whilst general training packs are available, consultation skills are, for most people, something that need to be practice and developed with time and experience. Pharmacists should therefore consider whether they actually need as much training as they think.

“I think where they ask from training, we need to be mindful that perhaps it isn't training, sometimes it's about professional development; reflection, reflective practice, feedback, and all those elements that build up that development, rather than here's a package or a course I can go on that will suddenly make me brilliant at consultation skills.”

- LPC chair

The community pharmacists, meanwhile discussed a vast range of topics that they felt they would need further training on; these included everything from information about breast cancer as a condition; various treatments and side effects; aftercare; when to refer; how to improve patient outcomes; and communication skills to support with discussing sensitive issues.

“Maybe something like common side effects - tips or management strategies, maybe helping pharmacists understand patients' journey more, maybe link to guidance on why drugs chosen above others. Communication tips as well as could be sensitive topics/questions”

In terms of the way the community pharmacists preferred to learn, they favoured the idea of some sort of training pack, similar for example, to those offered by the Centre for Postgraduate Pharmacy Education (CPPE). However, they also raised several issues concerning the feasibility of such training. Given the amount of research surrounding cancer globally and the subsequent advances in treatment, one of the most common concerns was the issue of information going out of date. In order to ensure the latest information would be available for them, the pharmacists reasoned that developing online training such as e-learning could be a potential way to ensure it could be updated regularly.

In terms of learning resources, the stakeholders suggested that organisations such as Macmillan or CPPE might have existing training materials that might be appropriate; or that future collaborations could perhaps be arranged. The topics they felt should be covered include how cancer develops and work within the body, how the treatments work, common treatments, side effects and how to manage them, when to refer individuals to other healthcare providers, general information on radiotherapy and chemotherapy, information on pharmacy products and practical advice, how to provide emotional support and how to find additional sources of information.

“I do think that knowledge gap is there for a lot of pharmacists and I don’t know what kinds of resources are more generally available, so what CPPE for example, have in their portfolio at the moment, what would provide some of those practical aspects. Because you know, you can have a brush up on your pharmacology and treatment of different cancers, but as you were describing, some of the practical knowledge about use of emollients being used post-radiation and things like that. It’s very practical but in some respects the most important element to have knowledge of to be able to help”

- Commissioning stakeholder

The Macmillan representative explained that Macmillan offer a wide range of learning and development materials, designed for both healthcare professionals and people living with and beyond cancer. The Cancer Awareness training for example, might meet some of these learning needs and is available to all healthcare professionals.

Although the pharmacists acknowledged that they had a lot of requirements in terms of training, they felt strongly that in order to be feasible to complete, any information pack would need to be concise and limited to key information to facilitate easy completion. Additionally, pharmacists noted that due to busy working schedules, they would need to be more proactive and take part in self-directed learning in order to build up their confidence and knowledge.

“To be honest if the training pack is too detailed it will prevent a lot of people from doing it. But something compact with patient

frequently asked questions and the treatment options and side effects and how to manage it will be good enough”

-CP_08

Despite the obvious need to support community pharmacists to improve their confidence and knowledge in terms of supporting breast cancer survivors, the potentially vast amounts of training required to prepare them for any future intervention, and the concerns over the feasibility of delivering the training; interestingly, several of the pharmacists commented on how much they had learned from participating in the focus groups. They were enthusiastic to use what they had learnt and felt there were several small changes they could easily make to their practice to make a difference to survivors.

“I didn’t realise how much support [breast cancer survivors] actually genuinely need. So I have learnt a fair few things today and will try and read up a bit more”

- CP_04

“I’ve definitely taken some ideas on board - avoid referring to GP unless I’m sure they can help, introduce myself, reconnect with local hospice team.”

- CP_03

2.3.4 Focus on breast cancer

Some of the community pharmacist participants expressed a concern about limiting interventions to support only those survivors with breast cancer, feeling it would result in insufficient uptake to make the service worthwhile. They believed all cancer survivors should have access to community pharmacy-based support services.

CP_06: "I think it is feasible and would be beneficial to patients to develop a new pharmacy service tailored to cancer survivors in general and not just breast cancer patients but whether or not it'll be funded is the real question especially in the current climate"

CP_05: "I agree with [CP_06]. If the service was widened to include all cancer survivors it could be offered in all pharmacies but if it were just for breast cancer survivors I'm not sure there would be enough patients to make it worthwhile to offer the service in every pharmacy."

Additionally, some of the community pharmacists felt there was potential opportunity to expand their roles into other stages of the cancer journey, rather than just focusing on survivorship support. The importance of the pharmacist role in prevention and early diagnosis of cancers, for example was recognised, linking in with the recent public health agenda set out in *Prevention is better than cure*.³⁹

"To be perfectly honest I think we should be dealing with cancer as a collection of diseases rather than breast cancer especially-

there are many medication-related issues and public health opportunities if we widen the focus”

- CP_09

Stakeholder insight into this question revealed a general consensus that breast cancer is a focus for prospective intervention. Due to its high prevalence and long-term management in primary care, there is significant opportunity to make an impact. It was also seen as good choice to study due to the availability of information and the well-defined treatment pathway, which perhaps some other cancers lack. Additionally, the findings from this research itself highlighted some key care needs that community pharmacists, along with other healthcare professionals, can feasibly address.

“The overall thing that strikes me is that as cancer treatment has improved over the last 20 years, I suppose we are moving to more of a situation particularly in the case of breast cancer because of the ongoing treatment period, it’s almost moving to be a long term condition. I mean it’s a long term condition hopefully without the condition, but it’s moving into that chronic relationship with primary care. And maybe there’s a mind-set change that’s required across primary care overall and not just community pharmacy about that.”

- Commissioning stakeholder

Stakeholders generally favoured the idea that after testing proof of concept with one cancer, any future intervention would eventually expand its scope to include other cancers also largely managed in the community setting, such as prostate cancer. Beyond this, all cancers could also be included.

The hospital oncology pharmacist, as the expert in cancer types, felt that it would be highly feasible for community pharmacists to support survivors with all cancers. She felt that any training provided could be kept general and the difference between cancer types in reality were not as complicated as people imagine.

“It depends on what area of the journey you're looking at. If you're focusing on survivorship, again I think that's still quite general. I don't think it needs to be tumour specific because most patients would have received IV chemotherapy, they may or may not have received radiotherapy, and they probably would have received some sort of oral treatment afterwards - it may not be endocrine, but an oral treatment afterwards. And then they're still in that position where maybe they've been discharged by the hospital, they're potentially on long-term follow up where they're seen every six months to a year maybe. But they're all in that boat. So yeah, I don't think they would need specific tumour group. So I think having a general overview of how cancer works and an understanding of how the different drugs work, is enough initially. And then I think you have to give the pharmacists... They have to take responsibility for their own learning.”

- Hospital oncology pharmacist

Whilst the specificity of breast cancer may affect uptake, it was likewise noted that uptake may also be affected by the characteristics of the population at local levels, such as age, social deprivation and health literacy. However, having a formal referral process in place would facilitate uptake:

“I think when any service starts [insufficient uptake] is always a risk. The background scoping, I think from a cancer perspective is that we can see clearly for women, you've got a significant proportion of the population who are diagnosed with cancer will have breast cancer. So I think the scope is there. Coming back to that element of if you're referred into a service, then actually you're much more likely to ask questions.”

- LPC chair

2.4 Proposed interventions

Despite the acknowledged feasibility issues, the community pharmacists welcomed the idea of new interventions. In response to the findings of the survivor study, they came up with several possible ideas that they felt could feasibly meet survivor requirements, whilst incorporating the identified strategies to improve care. The stakeholders were then able to offer further insight as to the feasibility of these proposed interventions from their perspectives.

2.4.1 Review

The participants largely felt that concerns surrounding the lack of remuneration and time to carry out new interventions could be feasibly addressed through providing survivorship care as part of existing services. The survivors had expressed a requirement for a formal review with the pharmacist in which they could discuss any concerns about their medications or treatment plan as well as receiving emotional support and advice on various aspects of their general health and wellbeing. The pharmacist participants likewise saw the value in such a check-up or review; reasoning that many of the survivor-requested topics could be provided as part of the MUR service.

“Could expand targeted MUR to include cancer patient - general chat about understanding/compliance with any treatment, signposting to local cancer support, healthy living advice”

- CP_03

“The targeted medicines list has been added to over time anyway. There was no additional training, no profession-wide consultation other than people who have a knowledge base saying ‘Yes, that sounds like a sensible approach, let's add that one in.’”

- LPC chair

Having already highlighted the importance of multidisciplinary collaborations in improving care and considered how referrals between community pharmacy and secondary care or access to survivor medical

information (such as treatment plans and discharge summaries) might improve survivor experience and outcomes (see section 2.1.3 Multidisciplinary collaborations), much of the discussion for both the pharmacists and stakeholders turned to how these approaches could be implemented in the context of a MUR-style intervention. This would provide an ideal way to ensure pharmacists connect with survivors early and that survivors are aware of the expertise of community pharmacists and the support available in the community pharmacy setting.

“Yes, MUR is a good platform to make patients aware that us as pharmacists are available for all their needs and if we don’t have the answer then we will try to find one or find someone that can help them”

- CP_08

In terms of referrals, it was also suggested that if GPs and community pharmacists were to work together to agree their roles, it might be possible for GPs to refer patients for breast cancer-specific MURs. This would allow them to share the medicines review workload; providing better care for patients and saving healthcare professional time. As part of this, CCR information could also be shared with community pharmacists to support the individualised and person-centred approach to care provision.

“We have pharmacists’ MURs sometimes come in and I think GPs sometimes go ‘I don’t know what to do with this. Has this

been a holistic review? Has this been about asking about their relatives; how they're managing caring for their mother with dementia, or actually is it just about the side effects based on their medication?' And so as a result of that it becomes 'Perhaps I ought to see them again?' Whereas actually if there's a bit more joined up thinking of what expectations should be, and what expectations are, for the reality of what the community pharmacists provide and what the GPs provide, and a vice versa [...] that's where I think a more formalised cancer care review by the GP for all patients living with and beyond cancer would be a real enabler for pharmacists to know 'Actually this is what I can expect from GPs under the recovery package'; that GPs, or someone within primary care - because it could be practice nurses - this will be being covered at this annual cancer care review. Therefore I can say "Ooh how did it go with this? How are you getting on?" Do you know what I mean? So there's a communication between the two.

- Macmillan GP

Another aspect of the aforementioned Recovery Package recognised in NHS England's Five Year Forward View, was the e-HNA, developed by Macmillan. This is a questionnaire completed online by the survivor and used by healthcare providers to support with care planning.¹⁷⁹ Although it is part of the national agenda for the NHS, it is not clear whether many survivors are being offered this service currently. One of the suggestions from the community pharmacist focus groups was therefore that community pharmacists could carry out the e-HNA for breast cancer survivors as part of their review.

Amongst the stakeholders, the experience of HNAs varied. Whilst the hospital oncology pharmacist confirmed that within her hospital the role is routinely undertaken by the cancer nurse specialists, the Macmillan representative explained that this was not the case in all settings and felt that enabling community pharmacists to take on the role would be a possibility in the future.

“Currently we know that it's not even happening in the acute sector and we're trying to also look at how we develop it in the community sector around community navigation support through the practice care nurse for example. And so the view would be that in the future if you've got a co-ordinated network of fully trained individuals it might not matter who does it because obviously you could do it as an individual, in theory.”

- Macmillan representative

The MUR service structure would support the holistic approach to care that survivors requested; incorporating medicines optimisation and managing medicines-related problems as well as considering any comorbidities and providing relevant healthy living advice. Several of the stakeholders likewise acknowledged the importance of a holistic approach to care; recognising for example, the importance of healthy living in reducing the risk of secondary cancers and recurrence.

“In the current contract, it might be easy if pharmacy looks at it as says ‘Well actually I can't make any of the changes I'd like to make, all I can do is help manage their medicines’ When you

start to link that with holistic care and say 'actually what I can do is give you advice at this stage; we can discuss your medication, we can review that again in 12 months' time; we can discuss lifestyle changes; we can talk about the late effects of cancer treatment and what that means.' Those are things which don't necessarily need intervention from a prescriber or another healthcare professional, but the pharmacist can own in entirety with the patient."

- LPC chair

When considering the findings of the quantitative phase of this research, the stakeholders suggested that the MUR service had potential for addressing the issues of early discontinuation and frequent switching of endocrine therapy. Through teaching survivors about the importance of their medications and empowering them to make informed decisions about their treatment, pharmacists may be able to support with improved adherence and medicines optimisation.

"I think the review part for me certainly is the one that piqued my thinking, especially when you look at the elements around medication adherence and patients discontinuing treatment early or having to change treatment four or five times. Actually what role could the pharmacist play in understanding that actually this treatment is going to be a long-term thing? 'How are you getting on, is everything still ok?' And then when the patient may come in and say 'I'm thinking of stopping taking these, it's been two years', understand 'how long should you be taking these for? What are the benefits?' And giving the patient the confidence to have a really open and honest discussion where they're both

equal partners in the conversation, and the patient then can make a choice and say 'I'm going to continue it' or 'Actually I'm going to stop it, but I'm stopping it from an informed position.' So I think there's a lot of scope for the pharmacist to be involved in those reviews and that would sort of eke out some of the other potential concerns that patients have around the late effects of cancer that may go unmentioned or unreferenced until a later date, or they just assume that this is what happens when you have cancer and not recognising that there may be treatment that can help relieve the symptoms or actually that that's not the normal process and therefore we need to refer you back in. So I think as experts in medicines that's probably the biggest area of review. So if we look at the current MUR structure it looks at high risk medicines, it looks at patients' respiratory conditions, hospital discharge...cancer's missing from there completely. So actually just putting it in there would simply make it much more likely for people to say "Well let's have a conversation".

- LPC chair

Given the medicines-related problems that the survivors experienced (such as side effects, adherence-related issues and lack of information or understanding about their medicines – see also Chapter 4, section 2.2.1.2 Medicines-related problems) the pharmacists also suggested that another possibility to provide a review could be to target breast cancer medications through the existing New Medicines Service (NMS). Stakeholders similarly saw the potential benefits of extending the NMS service; suggesting that if it were not for funding limitations, the service would ideally be carried out for all new medications as an essential service. Although the NMS focuses on a specific list of medicines and therefore take a less holistic approach, expanding the service to include

adjuvant endocrine therapy would still ensure the patient was made aware of the community pharmacy as a potential source of care. As with the MURs, patients could be referred into the community pharmacy; from either the hospital or their GP, facilitating continuity of care.

“It fits with the evidence that patients often leave hospital without having received adequate information about their medicines or at least, they're stating that. It could be that they've received it and it's not been absorbed, but either way it's a health services issue to solve, not the patients issue really. But yes you could also pick that up in the MUR or similar type care plan service as well. So yeah I think that does make sense, and in that more focused service you could then also make sure that you have the appropriate healthy living discussions as well.”

- Commissioning stakeholder

Whilst the community pharmacists were enthusiastic about their ideas to incorporate breast cancer survivorship support into the existing advanced services, they reasoned that in order for this to become a reality, further research would be required to pilot these and prove that there is a need to further develop the MUR service or NMS. The stakeholders added that since so many long-term conditions and medications could potentially benefit from being targeted by these services, evidence would need to be included to show that it would be more worthwhile to focus on breast cancer in place of other alternatives.

“If you can prove there is a need, then perhaps there could be targeted cancer NMS/MUR”

- CP_09

“But everybody ought to get some support, so taking NMS and making it an essential service. And it really ought to be used for all new medicines; the restrictions at the moment are related to funding.”

- Commissioning stakeholder

Stakeholders meanwhile, were able to provide further insight into future plans for these national pharmacy services, acknowledging that whilst extending the scope of these services to support breast cancer survivors would likely have been both feasible and worthwhile based on current service models, following the recent Murray Review of Community Pharmacy Clinical Services and the work that followed, changes to these models may be imminent over the upcoming years.¹⁸⁰

“[The Murray Review] came out with a recommendation around changing MURs so that rather than them being the once a year annual thing that applies to some patients but not all, that you have more of a longitudinal approach so you perhaps have more frequent conversations and interventions, but maybe not as long; spread out more evenly across the year of care. So that fits with something that we'd thought for a while and has been experimented with in a piece of work called the Community Pharmacy Future Project. [...] So the CPF2 project; the second one, was undertaken in West Yorkshire and it's been described

as a pharmacy care plan service, so providing this regular interventions for people with long-term conditions. And that would work as well for breast cancer survivors, I think, as anything.”

-Commissioning stakeholder

The Community Pharmacy Future project is a joint venture amongst community pharmacy companies Well, Lloyds Pharmacy, Boots UK and Rowlands Pharmacy, aiming to develop new community pharmacy services.¹⁸¹ As explained by the commissioning stakeholder, one of the initiatives they have been working on is the Pharmacy Care Plan service, which aimed to conduct a medication review whilst incorporating more holistic, person-centred care.

Although changes to advanced pharmacy services are currently being considered and progress in this area is likely, at this stage it is difficult to predict exactly what the changes will be or when they will happen. However, the incorporation of breast cancer support into either existing or future advanced services seems potentially very feasible.

“So I think taking this forward, the most sensible step would be building this into existing medication-related service frameworks. The challenge would be that they're under review at the moment to actually move from the current view to ‘do we start to step those up and remove MURs completely and replace it with a medicines optimisation service?’ So one where actually, you start to look at the clinical indications for those drugs rather than just how the patient is managing them; looking at true optimisation where you're stopping some medicines, you may be

changing some others, even if it's via recommendation from the GP. So those are ongoing discussions that will continue to happen by actually have a much stronger patient outcome. That being said, for me these could easily be dropped into the current frameworks of New Medicines Service, and Medicines Use Reviews, and Chronic Medicines Service in Scotland. Because actually by just saying 'let's add this drug to the list of targeted patients, or this class of patients'... patients receiving endocrine therapy for breast cancer, it's a fairly discrete patient group, they're easy to identify, the links with referral would be straight forward. It gets over the time/funding setting because it's delivered as a professional service. The gap would be how do we build that training and knowledge in? The reality is when we've added the targeted groups for other conditions there's been no additional training. There is available training from CPPE for pharmacists in England around targeted MURs and it wouldn't be too difficult to add in a section on breast cancer and endocrine therapy. But generally where pharmacists have got those things, they've used it as part of their ongoing professional development so it's your responsibility and accountability to make sure that you are competent in having those conversations."

- LPC chair

Finally, a suggestion for a different type of review intervention was put forward by one of the stakeholders who saw value in a clinical audit designed to review ET users in the community setting and ensure they understand the importance of ET and continuing its treatment for the full 5 years. As part of the Community Pharmacy Contract, pharmacies are required to undertake two clinical audits each year; one of these is

a national audit set by NHS England and the other can be of the pharmacy team's choosing. Ideally, the audit could be developed in collaboration with a breast cancer charity or a pharmacy body, for example, and conducted on a national level. However, this is also something that individual pharmacists could conduct within their pharmacy to raise awareness of the issue.

2.4.2 Healthy living pharmacy campaign

HLP campaigns aimed at supporting survivors were another popular suggestion from the community pharmacists for incorporating new roles into existing services. Since those pharmacies with accredited HLP status are required to run regular health promotion campaigns, the community pharmacists and stakeholders alike saw the potential of incorporating breast cancer into the HLP initiative; agreeing that engaging with the public and support organisations to promote cancer support in the local area would be very feasible and would fit well with the HLP agenda.

“You know now most pharmacies are Healthy Living pharmacies and they have to do promotional campaigns. Perhaps one or two of them could be on Cancer Support. We can get people from the local support groups to come and man the promotional desk and talk to customers”

- CP_03

Whilst one of the stakeholders noted that HLP campaigns would be more fitted to focusing on breast cancer prevention, it was felt that effectively managing life with and after breast cancer could likewise be included, particularly through linking it in to healthy living messages.

It was also noted that the wider pharmacy team can have a key role to play in championing healthy living pharmacy campaigns, therefore freeing up pharmacist time.

“In terms of skill mix usage in the pharmacy, I am very keen that we also ensure we have best use of all the team, and we don't need a pharmacist to be giving that healthy living advice. That can be given by other members of the team as long as they've been appropriately trained so that's the other aspect just to note because of effective use. And HLPs are very much driven often by the counter staff and dispensary team and the way that they've been activated to take a more focused approach in public health.”

- Commissioning stakeholder

2.4.3 Welcome pack

The survivors' suggestion to introduce a welcome pack was well-received by both the pharmacists and stakeholders as a means to encourage early contact with the pharmacy and promote pharmacist roles and services. Some felt however that the inclusion of free product

samples would be difficult to fund and organise, and deemed it unnecessary.

One pharmacist suggested that it would be particularly useful to tailor the welcome packs to detail the services offered in the individual pharmacy. Another recommended that a voucher system could be adopted to facilitate the supply of these packs; these could be issued along with the medical exemption card. Both these suggestions proved particularly appealing to the stakeholders in ensuring each individual receives the right care at the right time and achieving equity of care for all.

“Cancer patients already get free prescriptions via a medical exemption card. Could a welcome pack be provided at the same time as issuing the exemption card? [...] Or rather than the actual pack, a voucher to be redeemed at their local pharmacy.”

- CP_05

“How patients access the same level of support. Now they can choose not to, and so that's why I like the idea of a [welcome pack voucher] system, so that everybody has opportunity to be given this. The patients can still opt not to; they're permitted to not take it up. But I think that's a more robust way because all patients finish treatment. I think that's a better way than doing it from the GP because sometimes what happens is you go ‘Ok well they've finished treatment, so from a medication review point of view we'd probably need to see them within the next 6 months’, then they may do a review at the last clinic so we can

say 'Well they've been seen [in the hospital] so we don't need to see them for another 6 months.' [...] So actually there's a real hiatus [in continuity of care]"

- Macmillan GP

One of the stakeholders suggested that as an alternative to the proposed voucher system for issuing welcome packs, a better solution may be if the pack were to be issued in the hospital setting as part of a formal referral process.

"I wonder whether it's actually a more realistic approach maybe if one assumes there's a core pack of information that people would perhaps be presented with by the secondary care team when they are first diagnosed. So it's part of that information provision as you also mentioned in terms of that proactive referral from the hospital back to GP and community pharmacy care. So there's a clear obvious hand over, but at that point also, an explanation as to what one ought to expect from general practice and community pharmacy"

- Commissioning stakeholder

2.4.4 Cancer information point

The final intervention suggestion from community pharmacists involved setting up a cancer information drop in clinic that could be held at regular intervals and run by a second pharmacist with specific training. The clinic could address any questions or concerns the service users had; from advising on medication use, to fact checking cancer-related

information reported in the media. Since this intervention idea was completely new, it was acknowledged that the time and cost of running this intervention would be more of a factor. Therefore, the pharmacists reasoned that in order for it to be worthwhile, the scope would have to be widened to include all cancer types and all stages of the cancer journey, including prevention.

“It could be run as a weekly drop in clinic using the consultation room so anyone worried about cancer, be it themselves or a family/friend, current or past patients or even those who may be at risk or believe themselves to be at risk can drop in for a review or for some signposting/reassurance. For example, women on HRT hear conflicting information about risk, yet the risk associated with obesity is underplayed. If the speciality is widened, someone could come in to have their mole checked, it’s really easy to spot something that looks suspect and requires referral. We’d need the training and we’d also need to exercise proper clinical judgement as it wouldn’t work if we were too risk averse- we’d be referring everyone (this is getting back to the problems already highlighted by patients)”

- CP_09

A few of the stakeholders, meanwhile, were more sceptical about the practicalities of this suggested intervention in terms of pharmacist time and ensuring sufficient uptake. It was suggested that it might be more feasible if run in collaboration with a charity, for example, or if the service were to incorporate information on all cancers and focus on a different stage of the cancer journey each week; prevention,

recognising early symptoms, adjuvant treatment, survivorship and palliative care.

“What I suppose my recommendation would be to any pharmacists thinking about doing that is engage with your community and build that interest, and if they're up for it then do it. It's only just to prevent that waste of resource and money when actually it could be really valuable but if no one knows about it or it isn't really the way that people want their information, then it won't work. So I'd really like to push a lot of that; really engage with your communities, really get some of that co-delivery, co-design of some of these solutions. So if you start to get build ups of people asking you questions, you know, potentially ask them ‘How do you want to get involved, what would you recommend that we do?’ And really get that patient perspective in that local area.”

- Macmillan representative

3 Chapter Summary

This research has presented evidence of some ways in which community pharmacists could contribute to breast cancer survivorship services. Community pharmacists were receptive to the suggestion of taking on additional roles in here and acknowledged considerable scope to proactively support survivors and their family and friends; ensuring they have access to the right care at the right time.

Stakeholders likewise endorsed the idea of community pharmacists taking on an increased role in survivorship support. They were keen to

collaborate with community pharmacists and support where possible; acknowledging the move as both potentially feasible and worthwhile.

Collaborations at local and national level amongst healthcare providers in both primary and secondary care settings, as well as with charities or support groups were noted as particularly worthwhile; facilitating the sharing of patient data and other useful information. Importantly, collaborations could also lead to the development of formal referral pathways into and from community pharmacy; improving continuity of care and addressing survivors' complaints of initial information overload contrasted with feeling abandoned post-discharge.

Whilst time and remuneration were acknowledged as key barriers to the introduction of new interventions or services, participants saw opportunity to improve survivor support as part of existing services; such as organising HLP campaigns focusing on breast cancer, developing a targeted MUR for breast cancer, or incorporating endocrine therapies into the NMS service.

Another popular suggestion was that of a welcome pack, which would serve as a means of promoting early contact with community pharmacy; something which could potentially be vital in improving survivor experiences and outcomes. The pack would include information about the specific pharmacy and its services as well as information on living well with and after cancer, and possibly free product samples, if they could be easily obtained. Participants felt that the idea of using a

voucher provided to each individual by their breast care nurse would be the most feasible way of introducing individuals to community pharmacy and promoting continuity of care. The individual could then take this voucher to their chosen community pharmacy and exchange it for a pack, providing opportunity for the initial interaction with the pharmacy team.

In order to increase uptake of any potential service or intervention, it was suggested that expanding the service to provide care throughout the cancer journey could be taken into consideration, as well as offering the service to those affected by all cancers; not just breast cancer.

Another consideration was ensuring the community pharmacists would have the knowledge and expertise required to deliver any intervention or support. Whilst the community pharmacists felt they would need to learn a great range of information to learn in order to expand their roles, the stakeholders believed that any knowledge gaps could be easily addressed with background information on breast cancer, usual treatment options and useful pharmacy products, above all the community pharmacists needed to build their confidence in interacting with survivors; developing their consultation skills and ability to provide emotional support and learn with the service user.

The ongoing work to re-evaluate and potentially replace existing advanced services in community pharmacy may lead to the introduction of personalised care plans and the opportunity for pharmacists to take

on a more clinical role in medicines management. Whilst scope has been identified for the expansion of the existing MUR and NMS services to incorporate breast cancer and its treatments, the uncertain future of these services may make these recommendations less straightforward to implement. However, if the proposed pharmacy care plans are introduced, this could provide further opportunity for pharmacists to continue to expand their roles in breast cancer support.

In the meantime, many suggestions appeared very feasible in the shorter term and findings highlighted many small changes that community pharmacists could introduce to their practice, including networking locally; working to improve patient and public perceptions of community pharmacist roles through promoting existing services, along with the availability of the consultation room; working to develop consultation skills; and undertaking any other relevant learning activities as required.

Chapters 4 and 5 have outlined the key thematic findings from the qualitative work. The final discussion will review the findings of the research project in relation to current practice and literature, in order to make future recommendations about how community pharmacists can take on a larger role in supporting breast cancer survivors.

Chapter 6: Summary Discussion and conclusion

1 Introduction

This chapter will bring together the findings from each of the four data collection and analysis phases: 1) Treatment pathways, 2) Survivor perspectives, 3) Community pharmacist perspectives, and 4) Stakeholder perspectives, and examine the extent to which they answer the research question: *What opportunities are there for community pharmacists to develop their role to support and improve outcomes for breast cancer survivors?* The overall findings of the project will be discussed, explaining how they fit in with existing knowledge and what they contribute to the field.

The strengths and limitations of the research will also be considered within this chapter. This will build on the strengths and limitations of the methodological approaches already discussed in Chapter 2, section 7: Methodological considerations.

I will then go on explain and discuss the implications of the research for community pharmacy, current healthcare practice, healthcare policy, and future work; providing further context for the findings. Finally, the conclusion summarises this chapter and the thesis as a whole.

2 Key findings

2.1 Overview of key findings

The overall aim of this research was: *To identify the opportunities for community pharmacists to develop their role in providing support and improving health outcomes for people living with and after breast cancer.* The research began with the literature review (reported in Chapter 1), which, through demonstrating the need to focus on survivorship support, went some way towards address the objective of identifying points in the breast cancer journey where community pharmacists could support patients in their use of medicines and patient goals, to help improve outcomes and quality of life. This particular objective was addressed further through the subsequent data collection and analysis phases.

The quantitative study highlighted that the adjuvant treatment phase of the cancer journey was worth exploring further. This was confirmed by the qualitative findings (triangulation), which likewise identified medicines-related problems to be an issue and highlighted the need for more information and support following discharge from hospital. Other stages of the patient journey where survivors highlighted the need for support were following diagnosis, where information overload was an issue; and in the later years, where issues such as late effects and recurrence fears are a concern to survivors.

The quantitative phase of the research (reported in Chapter 3) highlighted the medicines-related problems associated with endocrine therapy treatment and the concerning levels of early discontinuation and switching that increases the risk of recurrence and mortalities. The initial phase of qualitative research (reported in Chapter 4) explored these further and other issues from survivor perspectives, revealing issues such as information overload during initial hospital treatment then feeling abandoned post-discharge. Medicines-related problems were once again identified as a concern for survivors. Other issues identified included a lack of information provision (both clinical and in terms of support services); lack of continuity of care; lack of services available locally; perceived lack of expertise amongst community healthcare providers and perceived pressures on healthcare providers. Suggested strategies to improve experiences included person-centred, holistic and proactive care; referral to community pharmacy from hospital; signposting to support services and advising on healthcare provider roles and expertise.

The final two qualitative phases of the research (reported in Chapter 5) went on to explore community pharmacist and stakeholder perspectives on feasible strategies for expanding community pharmacist roles to better support survivors. Feasible strategies for community pharmacists included providing relevant care at the appropriate time; signposting appropriately; advising on suitable pharmacy products; promoting pharmacist roles and services; collaborating with other healthcare

providers and local support services to improve continuity of care; and undertaking further training. Pharmacists acknowledged time and funding as barriers to introducing new services, but were particularly keen to increase support as part of existing services such as MURs or HLP services. Stakeholders were positive about community pharmacists taking on an increased role to support survivors. Whilst they identified that changes to national services such as MURs may be challenging to implement, many of the suggestions were perceived as being very feasible in the shorter-term. Stakeholders were keen to collaborate with pharmacists where possible and were enthusiastic about shared training and establishing local networks.

When drawing together the findings from each of the research phases, the findings highlight several opportunities for community pharmacists to expand their roles. Improved communication and collaboration – with survivors, other healthcare providers both in primary and secondary care, and local support services and charities - are crucial to supporting survivors. Changes in this area should aim to improve signposting practices, enhance continuity of care, and ensure person-centred, holistic care for survivors.

Training for community pharmacists is also key, ideally covering a range of topics including the condition, treatment options, aftercare advice, managing side effects and late effects, improving patient outcomes and consultation skills for dealing with emotional or sensitive

issues. Lack of confidence was a major issue for community pharmacists and therefore a key requirement for any training was to reassure pharmacists that an in-depth knowledge of the subject is not required in order to be able to support survivors and improve their care and educate them on how to effectively deal with queries that are outside of their expertise.

There is potential for flexibility in terms of the level at which many of the strategies to improve care can be implemented: Opportunity has been demonstrated for individuals to drive change, as well as scope for changes to be introduced within organisations or localities, or more widely on a national scale. In terms of developing future interventions or services to support survivors in the community pharmacy setting, the key requirements are that it should be holistic and person-centred. Early contact with potential service users is also important; for example, through referral pathways or initiatives such as the Welcome Pack. There is potential scope to incorporate such an intervention into pre-existing pharmacy services.

The remainder of this section discusses each of the findings in a more in-depth manner; considering how they relate back to existing knowledge.

2.2 Key quantitative findings

The quantitative phase of this research addressed the objective: *To understand the patient characteristics, treatment pathways and healthcare needs of service users*. Findings provide insight into current ET treatment pathways in England and highlight some key issues that could translate into healthcare needs for breast cancer survivors.

More than half of the study cohort survived for over five years after being discharged from hospital following initial treatment for breast cancer. Survival rates decreased with age; a trend which reflects the general UK population data in which over 75% of the breast cancer deaths in 2010-12 occurred in those aged over 60 years.¹⁸²

The majority of the cohort were treated with ET and initiated therapy within six months of the index date, therefore can be defined as adjuvant treatment. UK prescribing guidelines recommend adjuvant ET to be continued for at least five years.^{85, 183} However, over half of the ET-receiving cohort discontinued treatment before this period had elapsed. In addition, almost a third of individuals switched ET up to four times over the course of the study.

In general, the most commonly prescribed medications within the cohort are similar to those of the national population. Analgesics, antibiotics, statins, lansoprazole, antidepressants and medications for hypertension and heart failure all appear in the top ten most commonly prescribed

drugs and classes of drugs in England.¹⁸⁴ Hypertension, hypercholesterolaemia, osteoporosis and depression are likely common comorbidities, for which these medicines are indicated. SSRIs may alternatively have been prescribed to alleviate some of the side effects of ET, such as hot flushes, low mood or loss of libido.⁹⁸ The common use of analgesics, although frequently used amongst the general population, raises concern regarding the possibility of analgesic-associated side effects; laxatives and gastrointestinal anti-secretory drugs are often prescribed concurrently and were two of the most commonly prescribed medications within the cohort. These additional medicines, with their own set of side effects could create additional medicines-related problems. It is also important to consider any concurrent medicines that an individual might be using, such as over-the-counter medicines, or those prescribed by the hospital. Pharmacists and other primary care professionals must be alert to these issues and the importance of their own role in medicines optimisation for breast cancer survivors.

CCR data revealed many inconsistencies in the level of intervention provided; almost a third of patients have no record of receiving a CCR. Meanwhile, some patients reportedly had up to 89 CCRs during the time they were included in the study. Most received an initial CCR within the first 6 months of index date, as required by QOF, but others had no record of CCRs until years later. These findings suggest the need for a standardised delivery of this service to ensure that all CCRs

delivered are of high quality and worthwhile. This is something that has been noted in other studies and is currently being addressed by Macmillan through the publication of advice and the development of support software.^{60 185} Moreover, the findings of this research highlight a clear issue regarding the accuracy of records kept for CCRs, with over-recording being a concern in some cases. Since this intervention is in its relative infancy and there are no requirements for ongoing CCR records to be maintained, it is expected that accurate data may not be available. Healthcare providers completing CCRs should be mindful of this, and should aim to improve practice through simple measures such as accurate recording keeping to support delivery of a standardised and optimised service.

Nationally and globally, ET use is increasing, and AIs are commonly the therapy of choice. An international study investigating longitudinal trends from 2001-2012 for post-menopausal women across nine countries (Australia, Denmark, England, Finland, France, Iceland, the Netherlands, Norway and Sweden) found that similar trends were seen across all the countries. While tamoxifen had traditionally been the therapy of choice, the increase in AI use post-2003 reflected emerging evidence of its superior efficacy and updates to clinical guidelines.¹⁸⁶

In England, NICE currently recommend an AI as the first line for postmenopausal women; advising that those who have previously been treated for two to three years with tamoxifen be offered an AI.

Meanwhile, tamoxifen is recommended for premenopausal women or cases when AIs are contraindicated or not tolerated.⁸⁵ Despite the initial decrease in tamoxifen prescribing seen in the international study, it reported that by 2012, use had stabilised and even increased slightly in Australia, the Netherlands and Sweden; a trend which the authors linked to the emerging data on AI-related adverse effects, and the improved efficacy of tamoxifen when continued for ten years.¹⁸⁶ This could provide a possible explanation for the AI to tamoxifen switches seen within this study.

The high numbers of individuals that discontinue ET treatment early are concerning due to the associated increased risk of mortality and breast cancer recurrence.^{89, 90} A 2011 population-based study by Huiart *et al.* previously used CPRD to explore some aspects of UK ET prescribing.⁹⁹ Although not the main focus of the research, the study, which followed patients with breast cancer from 1998 to 2008, also reported early discontinuation, but did not find it to be as common; with 29.8% of the cohort discontinuing treatment before five years.⁹⁹ The higher rate of early discontinuation in recent years; 52.5% as seen in my study is an interesting development, although findings could be affected by differences between the two study protocols. Notably, the way in which the authors handled instances of switching between ETs is likely to have led to underestimation; follow up was censored at the time of the switch, preventing instances of early discontinuation following a switch from being detected.⁹⁹

Although Huiart *et al.* provided insight into ET use in the UK prior to 2008,⁹⁹ there have since been many changes to prescribing practice, including the move to long-term management of breast cancer in primary care; the licensing of letrozole and anastrozole as adjuvant treatments; and the 2006 update of NICE guidance for the treatment of breast cancer to recommend AIs as a first choice.^{99, 187} Our study, therefore, provides more up-to-date insight into ET early discontinuation across the country, providing further evidence of the magnitude of this issue, as well as highlighting other important issues (discussed below). In terms of this research, these findings, through iterative development, informed the qualitative phases of the project.

The high frequency of switching between ETs is also of concern. Whilst some occurrences may be clinically appropriate; due to a change in national guidance, for example; going through the menopause; or switching to an AI after two to three years on tamoxifen,⁸⁵ the link between switching and early discontinuation⁹³ could mean these women are at increased risk of recurrence and death. Previous studies have also found comorbidities to be a causal factor in switching.^{93, 188} For example, one study found that depression predisposed women to switch, suggesting that ET exacerbated the symptoms, along with depression itself acting as a barrier to persistence.⁹³

The likely causes of both early discontinuation and switching include recurrence of breast cancer and medicines-related problems.

Medicines-related problems can be defined as “*an event or circumstances involving pharmacotherapy that actually or potentially interferes with a desired health outcome*”.¹⁶⁵ These include issues such as adverse effects and medication interactions. The adverse effects of ET and their association with low quality of life and non-adherence are well documented,^{98-100, 103} making them a likely causal factor for early discontinuation and switching.

The high prevalence of early discontinuation and multiple switching amongst ET users should be highlighted to primary care practitioners and those involved in developing services. It is vital that the risks associated with these issues are recognised and any care needs, such as managing medicines-related problems, are systematically addressed to prevent any avoidable recurrences or mortalities.

The abundance of international research exploring strategies to better support survivors is encouraging. Amongst other things, many studies have highlighted the importance of better communication with survivors, effective pharmacological and non-pharmacological management of side effects,^{98, 101} and patient education.¹⁰³ In practice, however, the current lack of implemented services and interventions are notable. As the demand for improved survivorship services increases internationally, the roles of primary care healthcare providers in many countries will continue to evolve. In the US, for example, a review of breast cancer survivors recognised the need for long-term support and

better education for primary care physicians. The scope for pharmacists to expand their role was likewise acknowledged; suggesting a more active approach in patient education to combat issues such as non-adherence.⁷⁸

In England, primary care services for those living with and after breast cancer are similarly limited despite increasing demand for better survivor support. Currently, primary care roles focus on prevention and early diagnosis. As in the US, community pharmacists in England have scope to expand their role to deliver much-needed support to breast cancer survivors. Several national reports have previously noted the potential role of the community pharmacist in providing enhanced care to cancer survivors.^{2, 189, 190} Pharmacists are the most easily accessible of primary care professionals; enabling opportunistic access to advice or interventions. As experts in optimising medicines, pharmacists have the knowledge and skills to tackle medicines-related problems. Additionally, their experience in health education and patient empowerment makes them ideally placed to offer support to those living with cancer and its after-effects.^{47, 78} Through the development of new interventions in community pharmacy, pharmacists could systematically address care needs of breast cancer survivors and tackle the issues of early discontinuation and frequent switching to improve quality of life for breast cancer survivors and reduce the risk of recurrence and mortality.

2.3 Key qualitative findings

The qualitative aspects of this research addressed several of the study objectives; obtaining the perspectives of survivors, community pharmacists and stakeholders.

When attempting to compare and triangulate the data from the survivor survey to the quantitative findings, results were broadly similar. Since the quantitative cohort are assumed to be representative of England's population of breast cancer survivors, this suggests that the survivors who participated in the focus groups and interviews are somewhat representative of the population of breast cancer survivors in England, at least in terms of ET treatment. Although interesting, given the small sample size and the focus of the qualitative research, the level of representativeness of the data is not a priority here. All survey participants were prescribed ET, either currently or in the past. This is slightly higher than in the CPRD cohort, in which 82% received an ET. Almost half the survey participants had switched ET at least once, which again is slightly higher than in the CPRD cohort, of whom one third experienced a switch. Both phases identified the most common first choices of ET to be either tamoxifen or anastrozole, with anastrozole being slightly more common amongst the survey participants. This could reflect the guidance at the time of ET initiation, the date of which unfortunately was not determined in the case of the survey participants.

Overall, survivors within my study reported a lack of support from community healthcare providers (see Chapter 4, section 2.2.1.4). This finding is unsurprising since the need for primary care to expand its role in cancer is well observed and has been acknowledged both nationally and internationally.^{37, 81, 87} The findings of the most recent National Cancer Patient Experience Survey also allude to this issue (although it did not distinguish between tumour sites or explore survivor experiences of community pharmacy). The survey found that only 41% of cancer survivors felt that the GPs and nurses at their healthcare practice definitely did everything they could to provide support. Meanwhile, only 53% and 45% of survivors felt they were given enough care and support from health and social services during and after their treatment respectively.⁴⁸ These findings likewise indicate the need for community healthcare services to take on a larger role in supporting survivors.

Notably, the above figures from National Cancer Patient Experience Survey highlight that this lack of support is even more of an issue in the post-treatment phase of the cancer journey. This is also reflected in the findings from my survivor focus groups, in which initial information overload was reported followed by feeling abandoned post-discharge (see also Chapter 4, sections 2.2.1.3.2 Initial information overload and 2.2.1.4.1 Post-discharge care). In addition, some survivors had also experienced difficulties when attempting to access care in the later years of their cancer journey. Overwhelmingly, survivors continually

reiterated that their care needs changed over the course of their cancer journey. Along with this the level of information they required or were able to process fluctuated. In order to improve care, it was important to them that healthcare providers take their stage of the cancer journey into consideration when providing care and support.

In response to this, community pharmacists and stakeholders identified the importance of ensuring they provide the right information at the right time. The key message in relation to this theme is the need for community pharmacists to make contact with survivors as early as possible in their cancer journey; ensuring the opportunity to establish that supportive relationship and their role as a source of information and support throughout the cancer journey. Stakeholder input acknowledged the importance of this role in reducing the proportion of endocrine therapy users who discontinue their therapy early as well as the need for information giving to be a continuous process - information should be reiterated as and when required.

One stakeholder, however, highlighted the point that whilst the stage of cancer journey is of interest, the subject and level of information provided should primarily be dictated by the needs and preferences of the individual survivor. This is an important point, and echoes the survivors' recommendations for person-centred care, recognising that no two cancer journeys are the same. The importance of person-, or patient-centred care was also acknowledged in *Achieving world-class*

cancer outcomes: A strategy for England 2015-2020, in which measures such as the Recovery Package were introduced; encouraging healthcare providers to adopt a more personalised approach to care.²

One noteworthy qualitative study, sharing some similarities with this research, likewise acknowledged the lack of information and support following hospital discharge after completing active treatment. As part of a collaboration between the Macmillan Survivorship Research Group (MSRG) based at Southampton University and the UK charity Breast Cancer Care, a two-phase study was designed to identify the needs of women with primary breast cancer after completing their active treatment. The key difference, however, between this study and my research, was that my research explores survivorship requirements throughout the cancer journey. This study meanwhile, was designed to focus specifically on survivor requirements when transitioning back to 'normal life' after discharge from active treatment.¹⁹¹

The initial phase of the aforementioned study involved qualitative focus groups with survivors and telephone interviews with a range of healthcare professionals including breast care nurses, oncologists, surgeons, GPs, practice nurses, and survivorship academics. The second phase saw the development of a Breast Cancer Care resource pack for survivors based on these findings. This was sent out to the phase 1 participants and their opinions of it were explored in a second

survivor focus group. Views of the healthcare professional participants were gathered via telephone interview or email correspondence. Based on these findings, the final resource pack; *Moving Forward*, was produced. Although the description of the methods lacked some of the finer details, the approach to analysis was structured and logical. Efforts to ensure validity were described; including member checking, checking for transcription errors and the involvement of multiple researchers in the coding process. Out of the 12 patients and 20 professionals who participated, it seems that only one (a GP) was lost to follow up.¹⁹¹

In addition to the theme of *Isolation* that was identified in the study - consistent with the lack of support post-discharge and the resulting feeling of abandonment demonstrated in my research - they identified three other themes: *Loss of self*, *Reflection* and *Moving Forward*. The authors suggest that these four themes formed a cyclical process which they dubbed *The Cycle of Reconciliation*. Immediately following discharge, individuals seldom feel relief that their treatment is over, instead feeling scared about what happens next. At this stage, the study reports, they do not require much information as they can be easily overwhelmed. This is the Reflection stage as they spend this time looking back on their journey and thinking about how they have changed as a person.¹⁹¹

Reflection then leads to the Loss of Self. Whilst my research reported on the many emotional burdens of coming to terms with life after breast

cancer, the authors here provide additional context, describing it as a period of grieving over the unexpected loss of the person you were before breast cancer. This stage then led to isolation, which was caused not only by the severing of frequent contact (and therefore support) with the hospital, but also a perceived need to appear happy and well to others around them who were celebrating their completion of treatment and return to normality. The final element of the cycle was Moving Forward, which was the main priority for the survivors. Here, they required information to support them to adjust to their new identity and self-manage their condition as well as reassurance that they would be able to rebuild their lives.¹⁹¹

A further comparison of the two sets of findings also reveals many other consistencies, such as the need for support in dealing with side effects; late effects; body image concerns; concerns about the wellbeing of family and friends; and the fear of recurrence.¹⁹¹ These findings provide evidence that the issues identified in my research are accurate and are applicable in the wider population, strengthening the transferability and validity of the findings.

Another parallel was the recognition that everyone has a different breast cancer journey and different needs in terms of information and support, which change over time. This reflects the findings of my research in that it highlights the need to provide person-centred care and the right information at the right time.¹⁹¹

Overall, when considering how the qualitative findings from each phase of my research fit together, many of the themes centre on the need for improved communication and education. A key message to come out of the research was that despite the many opportunities for community pharmacists to expand their roles in supporting breast cancer survivors, community pharmacists cannot work alone in implementing these changes. As several participants acknowledged, communication and collaboration are key to driving change and primary care must come together as a unit, drawing on the many strengths of the variety of healthcare providers within this setting and forming stronger working relationships to achieve this goal.

Strategies to support better relationships within primary care included the sharing of information resources that might help promote more standardised advice and recommendations, sharing patient-specific information (with their consent) such as results from HNAs and CCRs, or any information sent from secondary care such as discharge letters or treatment summaries.

These ideas fit in well with current strategies to implement Primary Care Networks across the country. Through facilitating local-level collaborations amongst GPs, pharmacies, mental health services, hospitals, social care and voluntary support services, these networks aim to provide more integrated, personalised and proactive care.¹⁹² As the NHS landscape changes, new models of care such as these open

up new opportunities for pharmacists to expand their roles. This is illustrated, for example, by the role of GP practice pharmacists.¹⁹³

These pharmacists may be able to further support collaborations between GP practices and community pharmacy, as well as challenging any misconceptions about the expertise of community pharmacist.

A further suggestion on this theme was shared training events, which link the matters of communication, collaboration and education.

Community pharmacists and stakeholders alike were in favour of collaborating to support training; with suggestions being made for shared training between community pharmacists and other healthcare providers such as GPs. Training could also be led by hospital oncology pharmacists or breast care nurses, for example. It would serve several purposes; addressing the identified training needs of community pharmacists, building confidence amongst community pharmacists and other healthcare providers to enable them to proactively adopt a larger role in supporting breast cancer survivors, enabling healthcare providers to better understand one another's roles and providing networking opportunities on which to build future collaborations. Armed with a better understanding of the roles and expertise of other healthcare providers, community pharmacists would be able to signpost more appropriately. Meanwhile, raising awareness of community pharmacist roles and expertise could be an important first step in addressing public misconceptions about the role and getting breast

cancer survivors signposted to their local community pharmacist for support.

The community pharmacists' lack of confidence in survivorship support featured heavily in the stakeholder data. From an outside perspective, several of the stakeholders reasoned that the key training requirement for community pharmacists was in developing the confidence to proactively offer support to survivors. This included successfully identifying the care needs of the individual, knowing where to look up relevant breast cancer-related information and how to effectively signpost any survivors who needed further care or advice. This lack of confidence perhaps fuelled the survivors' perceptions of the lack of expertise amongst the profession and within the wider primary care setting.

The lack of confidence and knowledge amongst community-based healthcare professionals in supporting survivors has also been identified when providing care for other cancers. Research on Cancer Care Reviews, for example, has highlighted that survivors perceived there to be a lack of cancer-related expertise amongst GPs.¹⁸⁵ Meanwhile, practice nurses have reported that they lack confidence in providing care to cancer survivors.⁸⁷ This evidence is consistent with the survivors' views in my research, which suggested a lack of breast cancer expertise amongst healthcare professionals in the community setting in general.

Although not related to survivorship specifically, a study exploring new models of care in which community pharmacists assume a role in providing oral anticancer medicines, found education and communication to likewise be barriers to the introduction of new services. The qualitative study, which gathered views from community pharmacists, oncology pharmacists and chemotherapy nurses, also raised concerns about time, funding and whether GPs possessed the expertise required to routinely prescribe oral anticancer medicines. The study called for better communication and information sharing between primary and secondary care, along with the introduction of structured training programmes for community pharmacists. Participants felt these programmes should address a wide range of learning needs, including knowledge of cancer and oral anticancer medicines; organisation and co-ordination of cancer care; patient-specific information and support needs; and advanced communication skills.¹⁹⁴ Again, these concerns and requirements align with the findings of my research; highlighting that issues such as these are not specific to breast cancer but extend to more generally to cancer care provision in the community setting.

In addition to making changes that foster collaborations in the primary care setting, my research highlighted that improving communication and collaboration with hospital-based healthcare professionals as well as various charities and support services were also crucial to improving the support available to survivors. Whilst participants acknowledged that developing new models of care would be more challenging and a

longer term aim, networking locally to improve signposting practices in community pharmacy was recognised as a simple and effective first step in expanding community pharmacist roles. The pharmacists identified that this was something they could implement as individuals, but also recognised the potential for larger-scale collaborations, involving organisations locally or nationally. Collaboration is therefore perhaps something that should be addressed at all levels in order to maximise impact.

In terms of considering new models of care and formal referrals to and from community pharmacy, there are some projects already underway that fit into this. The work of the AHSNs in improving continuity of care was mentioned by one of the stakeholders. The Transfers of Care around Medicines (TCAM) project, which recently involved a trial in the North East, aims to ensure patient discharge information is shared with community pharmacy. This enabled hospital staff to refer patients they identified as needing additional support to participating community pharmacists. Relevant discharge information was supplied through PharmOutcomes, allowing the community pharmacist to provide relevant advice. The project has been shown to reduce hospital readmissions and length of stay following readmission. TCAM pathways are currently being developed across the country and the service is expected to be available nationally in 2020.¹⁹⁵

The importance of my research is demonstrated by its relevance to current work such as this. Whilst the above project is not related to breast cancer specifically, it is crucial in providing a means for community pharmacists to access patient discharge information. In the context of developing new services for breast cancer survivors, this service could be instrumental in providing community pharmacists with the information they need to effectively support breast cancer survivors initiated on endocrine therapy.

Overall, the stakeholders identified that referring patients into community pharmacy to ensure continuity of care is highly worthwhile and a lot of work has already been done on the topic. It is a strategy that could improve care for those living with a range of conditions, not just breast cancer. Whilst there is no quick or easy solution, proactive collaborations with other healthcare professionals even at local level, will be beneficial to survivors. This quote from one stakeholder summarised the issue nicely:

“ I think at transfer of care that continuity is really important and it's where there is a really big gap that I don't think anyone's got a magic wand to fix as yet, but slow and steady approaches to it could fix a lot of things and help people in the right way.”

- LPC chair

When considering the requirements of a prospective service or intervention, a great deal of importance was placed on person-centred

and holistic approaches. These findings fit into the current move towards new models of care that recognise the need to tailor care to the specific needs of the individual. Both person-centred care and holistic care for cancer survivors have been called for at policy level, and are increasingly reflected in the design of practice-based interventions, such as the Recovery Package and the Pharmacy Care Plan Service.^{2,}

37, 196

A further concept that embodies holistic, integrated and personalised care, is that of social prescribing. Whilst the concept has been around for some years, the benefits of social prescribing are becoming increasingly recognised since they link so well with the current health policy agendas set out in the NHS Long Term Plan.^{25, 197, 198} Supported by NHS England, the Health and Wellbeing Boards along with local CCGs are working towards achieving nationwide availability of social prescribing.¹⁹⁸ The schemes allow community healthcare providers to refer individuals to a variety of non-clinical support services providing social, emotional, and practical support within a local community. Whilst each local scheme may operate slightly differently, they normally involve a community navigator or social prescribing link worker, who helps the individual develop a personalised plan. That individual will then be referred to the relevant services depending on their health and wellbeing needs. These could include physical activities, befriending schemes, arts and crafts, and group learning for example.¹⁹⁷ Given the identified holistic care needs of breast cancer survivors, social

prescribing could be a valuable resource for community pharmacists, allowing them to ensure breast cancer survivors access the holistic care as part of a structured scheme.

Importantly, the demand for a holistic approach to care is also identified within the Breast Cancer Care and MSRG study, with the survivors requesting a formalised 'wellness check' that could involve drawing up an individualised and holistic care plan. They suggested that perhaps this could be incorporated into their first follow-up appointment at the hospital. The healthcare professional participants agreed that this was necessary, but reasoned that it could be carried out in the primary care setting as part of a long-term follow up plan.¹⁹¹ Whilst my research was looking specifically into the potential role of community pharmacists; something that was not addressed in this study, this finding provides strong evidence to support the need for a formal intervention for breast cancer survivors that takes a holistic and personalised approach and helps them improve their outcomes and quality of life.

Support and advice on leading a healthy lifestyle and maintaining wellbeing whilst managing their condition and its after-effects was a big issue for survivors. It was also one of the topics that community pharmacists felt well-equipped to provide counselling on. In addition to providing one-to-one advice to survivors, the community pharmacists felt that a cancer-related HLP campaign would be the ideal opportunity to raise awareness of this issue more widely. The stand-out benefit of

this intervention is that it is something community pharmacists can lead in individual pharmacies with the support of their pharmacy team. It would have the benefits of raising awareness of survivor needs amongst the team and the community as well as supporting survivors as required. Organising such an event would also provide opportunities to collaborate with local healthcare providers and support services.

An alternative model for promoting healthy lifestyles amongst survivors was demonstrated in a community pharmacy-based intervention to improve exercise uptake and cardiovascular health of prostate cancer survivors. The intervention, which was trialled in nine community pharmacies, involved a health check, fitness assessment, lifestyle prescription and a follow-up assessment after 12 weeks. Qualitative analysis showed that lifestyle-related behavioural changes could be successfully created through a community pharmacy intervention that uses a model of assessment and feedback, rather than simply providing lifestyle advice.¹⁹⁹ Whilst this study focused on participants with prostate cancer, the model could potentially be beneficial within other populations and could provide a solution to the need for lifestyle advice amongst breast cancer survivors.

Several other studies have also demonstrated the importance of healthy living advice. For example, a discrete choice study exploring preferences on follow-up care in Scotland found that breast cancer survivors would value dietary advice.²⁰⁰ Meanwhile, a US-based

qualitative study exploring the needs and perspectives of breast cancer survivors, oncology specialists and primary care providers in breast cancer survivorship care, one of the nurses described how she often gets asked questions on healthy diets, supplements, and other aspects of maintaining health and wellness after treatment. As a result, she was undertaking additional training to better equip her to provide such advice.²⁰¹ Several reviews and policy documents both nationally and internationally have also reported on the importance of health and wellbeing.^{25, 37, 39} Guidelines on breast cancer survivorship from the American Cancer Society, for example, discuss the importance of health promotion, advising on lifestyle modifications to reduce lymphedema risks, assessing for body image concerns and referring for psychosocial care as necessary.⁸¹

As part of a personalised and holistic approach, survivors expressed the need for more information on pharmacy products and over the counter medications that would be safe for them to use during their breast cancer treatment. This innovative suggestion was considered feasible and something that could once again be addressed through multidisciplinary collaborations. Community pharmacists expressed a belief that presenting consistent information across and within settings was highly important, and this was corroborated by the survivors who shared their experiences of receiving conflicting and inaccurate information. Compiling this type of information would therefore provide an opportunity for collaborating with other healthcare professionals, for

example to understand what oncology pharmacists and breast care nurses would recommend within the limits of their formulary.

Collaborating with product manufacturers to obtain information on the suitability of individual products could also be advantageous.

The welcome pack intervention idea was very well received by survivors, community pharmacists and stakeholders alike. Its key strength is of course to ensure early contact with a local pharmacy, which has a number of benefits in terms of continuity of care and bridging that gap between discharge and aftercare in which isolation and abandonment are commonly experienced. As well as ensuring survivors are aware of the potential role of the community pharmacist in their care and the types of support and services available, it would promote use of the community pharmacy more generally and could improve the uptake of any other relevant services, such as the targeted review. In terms of supporting collaborations with other healthcare professionals, it could also be a useful first step in incorporating community pharmacists into the care pathway. One of the key benefits of this intervention is that it would not be time consuming on the community pharmacist's part since the information is provided in the pack. In terms of cost, expenses would be incurred in compiling the pack rather than pharmacist time.

The most acceptable idea for an intervention or service was a review. This seemed to have the most potential in terms of meeting the

requirements of the survivors whilst retaining feasibility. In terms of the required expertise, community pharmacists are already accomplished in delivering similar services (such as MURs and NMS) and would therefore just require training in managing breast cancer specifically. In terms of time and remuneration, once the training had been completed a review service could be integrated well into existing pharmacist roles, and the idea of incorporating it into the existing MUR service was very well-received by pharmacists and stakeholders alike.

One of the initiatives of the Community Pharmacy Future project was the Pharmacy Care Plan service. This service aimed to conduct a medication review whilst incorporating more holistic, person-centred care. During a trial in North England, community pharmacists discussed beliefs and behaviours of medicines taking with service users; providing information and advice on medication and lifestyle, and finally, referring the individual to other services (such as smoking cessation) as required. The community pharmacist would work with the individual to agree health goals as part of a care plan. This was then followed up after 6 and 12 months, with interim consultations as required.¹⁹⁶

If this service were to be implemented nationally, it could potentially be very beneficial to breast cancer survivors. A personalised and holistic care plan would address many of the care needs identified in this research, and would additionally facilitate future collaborations to ensure appropriate signposting and continuity of care. My research

therefore highlights the importance of further developing this intervention and of ensuring that breast cancer survivors are amongst those to be targeted.

A further innovative aspect of the Pharmacy Care Plan service is the use of patient activation measures (PAM); a 0-100 scoring system that assesses the ability of an individual to manage their own health, based on their knowledge, skills and confidence to do so. As well as being cost-saving and improving health outcomes, higher PAM scores correlate with a positive experience of care.²⁰² This measure was highlighted by one of the participants as a potentially useful tool in improving care experiences. Indeed, it could potentially be very useful in conjunction with any new intervention as it could help community pharmacists in providing person-centred care; particularly in assessing survivors' potential for self-management.

My research, in conjunction with the findings of the above studies, creates valuable insight into the care needs of breast cancer survivors in the primary care setting; a previously understudied area of research. When considering how these findings fit into existing knowledge on the care needs of survivors, the lack of support and the requirement for proactive and holistic survivorship services within the community setting have been likewise identified by survivors of other cancers. The importance of follow-up care in the community has been recognised for all cancers. A wealth of literature promotes the use of survivorship care

planning that incorporates the physical, emotional and social aspects of wellbeing.^{81, 87} One study in Scotland for example, explored survivor preferences in relation to new models of primary care-based follow up care for various cancers. The study, which took the form of a discrete choice experiment, included survivors with a variety of cancer types: breast, prostate, colorectal, and melanoma. Participants valued continuity of care and preferred face-to-face appointments over telephone or video-based alternatives. In line with the findings of my research and the general literature on survivorship care, the inclusion of dietary and lifestyle advice was seen as important. The option to attend psychological counselling was also valued.²⁰⁰ This is likewise consistent with the findings of my research, which calls for the provision of emotional support as part of survivorship care. My research also identified a requirement for personalised care and information, including the introduction of a welcome pack. Whilst the participants of the discrete choice experiment did place some value on receiving a personalised information pack (covering their cancer type and treatment), the p-value and therefore this finding was not statistically significant.²⁰⁰

When considering how my research findings add to current knowledge of survivorship, it is also worthwhile acknowledging that survivorship is an issue that not only affects those living with cancer, but certain other conditions as well. Human Immunodeficiency Virus (HIV) for example, is a widely researched condition for which long-term survivorship care is

required. Over the last two decades, the advances in treatments for HIV have been considerable. Similarly to breast cancer, people are now surviving for longer with the condition. The population of long-term survivors now includes those diagnosed before, as well as after, the introduction of highly active antiretroviral treatments; including those diagnosed at birth.²⁰³ As with breast cancer, HIV was initially dealt with in hospital, but due to increasing demand for survivorship care, healthcare providers in primary care began to expand their roles during the late 1990s and early 2000s.²⁰⁴ Due to the shared requirement for survivorship services in the community for both these conditions, it is worthwhile considering whether similarities in care needs exist, this could provide insight to inform the development of future services for all survivors.

One UK-based mixed methods study explored the barriers to primary care providers when taking on an extended role in HIV survivorship. Researchers initially distributed questionnaires to GPs, district nurses, practice nurses and health visitors. This was then followed up with semi structured interviews. Service users and other professionals within the HIV field were additionally interviewed. Many of the themes to come out of the study were similar to the findings of my research. Healthcare professionals were generally in agreement that HIV and AIDs care should be provided in the community wherever possible. For some, lack of time and funds for treatment were concerns. Key concerns were surrounding a lack of knowledge amongst healthcare providers, along

with a lack of communication and information sharing with the specialist teams in secondary care, both of which would likely impact upon the ability to offer the required care in the community setting. The findings of this study highlight notable similarities between the care needs of HIV and breast cancer survivors.²⁰⁴

More recent HIV survivorship studies also indicate that care needs align with those of breast cancer survivors, emphasising the importance of good relationships with healthcare professionals and the need for robust emotional and social support.^{205, 206} A national UK survey found that whilst only small proportion of HIV survivors reported problems with taking their treatment regularly (4%) or their current treatment knowledge (5%), 15% reported being unhappy with their relationships with healthcare professionals. In similarity to my research many of the survivors were also concerned about self-confidence, depression or anxiety, and eating or appetite.²⁰⁶

Overall, my research adds to the mounting knowledge of survivorship care needs, confirming that breast cancer survivors often face similar issues to survivors of other long-term conditions. This information can be used by primary care practitioners when seeking to provide quality survivorship care and when developing new services.

3 Strengths and limitations

This research has undoubtedly provided some vital insights into the opportunities for community pharmacists to expand their role in breast cancer services. However, before considering the implications of these findings it is important to initially critique the strengths and limitations of the approaches used and the findings gathered.

One of the key strengths of the research was its mixed methods design, enabling the project to benefit from the combined strengths of quantitative and qualitative approaches to explore both the breadth and depth of the opportunities for community pharmacists to expand their role in breast cancer services. This was particularly essential given the lack of existing knowledge on this topic and the requirement for exploratory research. The sequential design supported the use of iterative development; another key strength of this work, enabling the findings from each phase to inform and further refine the design of each subsequent phase. Many of the considerations surrounding the strengths and limitations of the methods used in this research were discussed in Chapter 2: Methodology and Methods; these aimed to ensure the rigour of the research from the outset.

Triangulation is a key strength of many mixed methods studies. The individual phases of this study revealed some convergence of findings, which provided a more in-depth understanding of the issues at hand as well as validating the findings. For example, medicines related-

problems were initially identified as a potential issue in the quantitative phase of the research. Data from survivors then confirmed the magnitude of this issue and provided further context on survivor experiences of medicines-related problems. Another example of triangulation was seen when survivors reported a lack of breast cancer expertise amongst healthcare providers in the community setting. Community pharmacist and stakeholder data both confirmed this; identifying a need for further training for community pharmacists and GPs alike. This was needed to address both the lack of knowledge and lack of confidence experienced by these healthcare providers in supporting breast cancer survivors.

Despite the strengths of this research, there were also some limitations. Firstly, the research included only female participants. Whilst supporting men throughout their breast cancer journey is equally important, only around 300 men a year are diagnosed with breast cancer compared to over 50,000 women.⁷⁶ The extremely low prevalence therefore makes men a difficult group to study due to the lack of potential participants. The decision was therefore made to focus on female participants. In addition, any future intervention developed for breast cancer survivors is less likely to be accessed by men due to their small numbers coupled with the lack of men who access pharmacy services compared to women.¹²⁵ Regardless of these factors, it is important to acknowledge that men may have slightly different care needs to women and the research may have benefited from exploring these differences to

increase the transferability of the findings and aid the development of any future pharmacy services designed to support all breast cancer survivors.

In terms of the quantitative phase, a key strength was its cohort design, which allowed patients to be followed up over a long period. This enabled the mapping of each individual's ET treatment pathway; highlighting issues such as early discontinuation and multiple switching, which would not have been apparent using cross-sectional data. Additionally, the large cohort and use of CPRD ensured that the data is representative of the national population.

A limitation of the cohort study design is the loss to follow up. To minimise this, patients with insufficient follow up (i.e. less than two years) were excluded from the study. However, this introduces a selection bias; potentially affecting the representativeness of the cohort.

The use of HES, while enabling the accurate identification of the index date, meant that data was restricted to England rather than the whole UK. Due to the way the data is linked to CPRD, it can only be obtained from practices consenting to the linkage scheme, which may have a minor effect on the representativeness of the data. However, the 75% of practices in England that participate in the scheme equates to 58% of overall CPRD practices,¹¹⁶ minimising any effects on generalisability.

When measuring ET exposure time and utilisation, some assumptions were necessary. Since CPRD includes only primary care data, hospital prescriptions could not be analysed. Likewise, any ET prescriptions written outside the study period could also affect ET exposure. Without access to any dispensing data, actual medication consumption could not be confirmed, causing a possible overestimate of exposure. Despite this, the data provide a good indication of potential exposure and switching practices, which can inform future practice.

Over the 10-year study period, several changes in guidance occurred, possibly influencing breast cancer management and outcomes. For example, from December 2011, fulvestrant was no longer considered a suitable alternative to an aromatase inhibitor.¹⁹⁰ Although analyses did not consider the impact of this change; the number of patients prescribed this medication was minimal (n=25).

As previously discussed, the quality of the CCR data reported in this research may be questionable and could be indicative of poor recording practices. Whilst these potential inaccuracies should be taken into consideration when reviewing this data, it is still useful in highlighting the need for further research on the content and recording practices of this intervention.

When reflecting on the qualitative approaches, the use of the PPI activity helped strengthen the study in terms of ensuring the relevance

and quality of the findings by considering an expert patient's perspective during the design stages. This is good practice in studies involving patients and members of the public and strengthens the credibility of the research (see also Chapter 2, section 5.2.2 Patient and public involvement activity).

The use of focus groups in collecting the survivor data was a key strength. During the study design, focus groups were identified as the most appropriate choice of data collection due to their success in encouraging the generation of new ideas. Meanwhile, a pragmatic approach also allowed individual interviews to be conducted where required to generate maximum data. The combination of individual interviews and focus groups enabled comparisons to be drawn between the two methods. The focus group data was indeed richer, providing evidence that this method was more efficient. Whilst the individual interviews each had some points in which the participant did not feel they had anything to contribute, this was not an issue in focus groups. Hearing the ideas and experiences of others seemed to motivate participants to offer their own perspectives where they had previously remained quiet or provided a brief answer; participants seemed equally happy to agree and disagree with the comments of others.

The community pharmacist data collection further demonstrated the strengths of focus groups over individual interviews. Some of the participants commented that attending the focus groups had been

useful in raising their awareness of the support that breast cancer survivors need. Learning from the ideas and experiences of the other participants, a few pharmacists decided to proactively make changes to their practice. Strategies included connecting with their local hospice and carefully considering where best to signpost rather than automatically signposting to GPs.

Given the apparent benefits of using focus groups instead of interviews for survivors and community pharmacists, the necessity to use individual interviews for stakeholders could be seen as a limitation of the research. Whilst a stakeholder focus group proved infeasible, it is possible that it might have produced richer data. However, it is also important to consider the wide variety of backgrounds and expertise amongst the stakeholder participants, resulting in their experiences and views likely being less comparable than those of the survivors or community pharmacists. This may either have acted as an added advantage in a focus group setting, or potentially hindered the productivity of the group.

Another consideration with focus groups is how the group setting may have affected the data gathered in terms of confidentiality, honesty and privacy, for example. Whilst the online aspect of the pharmacist focus groups carried an additional benefit of anonymity, participants in the face-to-face focus groups may have decided against sharing some of the more private aspects of their experiences, or perhaps any views

that did not align with those of the group. Although this was a possibility from the start, the benefits of the focus group in terms of supporting the formulation of ideas arguably outweighed this possibility. As previously discussed, various steps were taken to ensure participants felt comfortable in sharing their experiences and confidentiality was maintained. The survivor survey was introduced to gather potentially sensitive data that participants may not have wanted to discuss as a group. In practice however, the participants were all very open and were happy to discuss negative and emotional experiences within the group. Many even seemed to find benefit in speaking to others with similar experiences. In hindsight then, the survey was largely an unnecessary addition to the focus groups, but was useful in providing initial context to initiate discussions.

The use of face to face focus groups amongst the survivors required participants to meet up in person. Since travelling distances had to be taken into consideration, another study limitation was that recruitment was confined to Warwickshire, Lincolnshire and Nottinghamshire. Despite being limited to the English Midlands, the data incorporated a wide range of experiences, and some participants also had experience of being treated in other areas of the country. However, it is important to consider that findings may not be an accurate reflection of the experiences nationwide, therefore possibly affecting the transferability of findings.

The use of online focus groups introduced many advantages (see Chapter 2, section 5.6.1 Using online focus groups). One of the major benefits was enabling the participation of pharmacists from across the country; helping to consider a wide range of experiences and maximise the transferability of the findings. In practice, the ability to take part from any location was appealing to participants, boosting recruitment and enabling them to take part whilst doing other tasks. Since the focus groups occurred in the evening, this proved a real benefit for those who were working a late shift or had small children at home. The use of typed responses in place of a spoken conversation allowed those to take part who would otherwise have been unable to contribute.

However, one limitation of this approach was the added time taken to conduct the focus group. As outlined previously, it was initially intended that the facilitator would speak and present data over PowerPoint slides. However, due to technical issues (a further limitation of online focus groups), all provided information, questions and responses were communicated in writing. Unfortunately this meant that the focus groups in reality took twice as long as originally intended. Whilst participants continued to contribute to the conversation, it was not possible to judge their interest or distraction levels. Splitting each focus group into two shorter sessions may have been a more sensible approach to ensure engagement.

Further to this, the small delays during which participants were typing responses sometimes made the conversation feel stunted and meant

that participants were not always replying to the most recent comment. Whilst the discussion therefore did not have as much flow or rapport as its face-to-face counterpart, several advantages to having a written conversation trail were noted. Participants were not only able to refer back to the information provided on the findings of the survivor focus groups, but also referred back to comments previously made, adding further context and making connections as the conversation progressed. This proved beneficial in supporting them to assess the feasibility of the group ideas. Typing responses also provided additional thinking time, which likely supported better communication and increased the relevance of the points being made. Online focus groups have previously been shown to produce more concise and on-topic responses.¹⁴⁵ Therefore, despite the additional time required for data collection, the transcripts were shorter and the data was easier to analyse than that of the survivor focus groups since each statement was more relevant.

When reflecting on the number of participants in each focus group, the optimum number according to the literature was 6-10 participants.¹³⁷ However, this study used smaller groups in both the survivor and community pharmacist data collection. The number of participants per focus group could therefore act as a limitation of the research. Unfortunately, one of the focus groups included just two participants. Whilst this cannot strictly be considered a 'group' and more participants would have produced richer data, the two participants did collaborate

on ideas. They were forthcoming in voicing opposing opinions and discussing the differences in their experiences. This made the data richer and was a better use of time than conducting two separate interviews. It therefore turned out to be beneficial that the focus group went ahead as planned.

When reflecting on the first focus group, the number of participants (five, plus myself and the second researcher) felt too large. As the facilitator, I noted several disadvantages to having so many people around a table. It made the setting feel more formal; therefore making it less conducive to natural conversation. It also took far longer to obtain the required data from that number of participants and resulted in the focus group running significantly over the allocated time. Since it was the first focus group, there were also some other difficulties, such as ensuring the group stayed on topic and ensuring no one dominated the conversation too much. Whilst this was certainly exacerbated by the large number of participants, my lack of experience as a facilitator also played a role here. Given these challenges, along with the fact that the topics of discussion were sometimes delicate in nature, I concluded that subsequent focus groups should have no more than four participants. This would create a more informal atmosphere; allowing survivors to feel more comfortable sharing personal experiences within a more natural conversational context. Based on the experiences of collecting data from survivors within this study, I would therefore argue that the optimum number of participants (particularly in cases where the subject

matter is related to personal or emotional experiences) is three to four per focus group.

As mentioned, I had no previous experience of conducting focus groups prior to commencing the data collection; this was a limitation of the research. As a result, I adapted my role slightly as I gained more experience. For example, I became better at ensuring participants contributed and keeping to time. However, I had undertaken some training in conducting focus groups and interviews and my background as a community pharmacist was also helpful since I was already used to discussing treatment experiences with cancer survivors, information gathering and actively listening; these consultation skills proved useful. As a researcher, I tried to remain as objective as possible and be reflexive in order to limit the bias introduced by my background.

The presence of a second researcher at the survivor focus groups proved to be another strength of the study. As an observer, she was able to offer additional insight into the data gathered as well as advise me on how to refine my facilitator technique, enabling me to be more reflexive. The additional field notes aided accurate transcription, particularly when it was hard to decipher from the audio-recordings what was being said or who was speaking. The field notes also supported familiarisation with data and the facilitation of future focus groups through the iterative development process.

In terms of data analysis, each of the qualitative phases employed the same iterative thematic analysis approach recommended by Green *et al.* (previously described in Chapter 2 section 5.5.2 Focus group and interview data) to code, categorise and identify themes.¹³⁹ The use of an established framework together with the iterative analysis was a strength of the research, increasing its credibility and dependability. A further strength of the research was the involvement of a second researcher, who reviewed a proportion of the data, along with the codebook and agreed the final themes.

In terms of preparing the data for analysis, this research is interesting in that each phase adopted a slightly different approach to best suit its methodological design. The survivor data was audio-recorded, fully transcribed then analysed. In contrast, the community pharmacist data was collected using typed online responses. This meant that a full transcript of data was automatically generated as the focus group progressed and no further transcribing was required.

Finally, the stakeholder data collection was audio-recorded as with the survivor data. However, since the discussions were informal and a great deal of each recording consisted of the presentation provided to stakeholders, fully transcribing the audio-records would have been an unnecessary use of resources. Additionally, since the stakeholders were discussing the themes already identified, a more sensible

approach was to code directly from the audio files then transcribe only the required quotes.

When reflecting back on these approaches, there are strengths and limitations to each of them. In terms of my own professional development I have benefitted greatly from experiencing this variety of methods since it gave me a better appreciation of the strengths and limitations of each. In terms of the appropriateness for the research in question, I am satisfied with the methodological choices but acknowledge that these methods would not have been as successful if carried out in a different order. For example, fully transcribing the survivor data, although very time consuming was effective in supporting familiarisation; an important stage of the analysis process. It also aided the iterative aspects of the analyses; making it quicker to review and reorganise categories and themes as required. If I had used audio-coding from the outset, the process would have been extremely difficult, time consuming and most likely ineffective.

Audio-coding only worked so well for the stakeholder data because I already had a deep understanding of the data and no new themes emerged. Although the advantages and disadvantages of this method have been discussed at length previously, I feel that the usefulness of this approach is highly dependent on how you think as a researcher and how you visualise themes. Another factor to consider is the importance of emotions in the data and to what extent the lack of this

information might affect the interpretation of findings. In this particular case and taking into consideration the aims of this research, a loss of emotion in the translation from audio clips to written quotes was not a key concern.

In contrast, the typed transcripts from the online focus groups provided a good middle ground; whilst their use lacked the immersive experience, there was no risk of transcribing errors and they proved a highly efficient use of time and resources. Of course, the strengths of this method must also be weighed up against the usefulness of online focus groups compared to face-to-face settings, as outlined previously.

4 Implications

4.1 Implications for community pharmacy

Since this research focuses on the opportunities for community pharmacists to expand their roles in breast cancer survivorship services, many of the implications focus on community pharmacists to help shape the future of their profession. These implications range from smaller actions that can be completed by individuals to larger issues that should be adopted nationally or at organisational level.

In the short term, raising awareness amongst the profession about the need for survivorship care and support for breast cancer survivors in the community setting is an important first step. Likewise, through

disseminating the findings of this research as widely as possible, educating community pharmacists about the care needs of survivors and what they can do to take on a supportive role is key. As well as the usual routes of dissemination such as conferences and journal publications, other routes of dissemination could include pharmacy magazines or websites; any newsletters or information updates circulated within large multiples (such as Boots 30-minute tutor or similar formats), or through short presentations at community pharmacy training events (such as CPD events, pre-registration training days). Professional organisations such as the Royal Pharmaceutical Society may also have a role in supporting with this.

These activities should aim to encourage individual community pharmacists to make small changes to their practice; such as having proactive conversations with survivors to ensure they have all the care and support they need, connecting with support services and healthcare providers in their local community to improve signposting practices and begin to build collaborative networks, undertaking training and organising in-store events such as HLP campaigns.

One of the biggest impacts community pharmacists can have on an individual level is to tackle breast cancer recurrence and mortality through ensuring they conduct regular MURs (or have consultations) with those being prescribed adjuvant endocrine therapy. Ensuring they understand the purpose of their treatment, understand the importance

of continuing for five years, and are effectively managing (or ideally not experiencing) any adverse effects from their treatment could potentially have a huge impact on survivor quality of life as well as reducing NHS costs through reducing the risk of recurrences. This fits in with current national policy agendas outlined in *Prevention is Better than Cure* (see also Chapter 1, section 3.1.1 Prevention of cancer).³⁹ Providing advice and support on healthy lifestyle changes is also a simple and effective way for individual community pharmacists to improve survivor experiences and prevent further ill-health.

In terms of the training pharmacists can undertake, CPPE provide a general training pack on Cancer, as well as e-learning on Cancer in Community Pharmacies: Raising public awareness (although the main focus of the latter is early diagnosis).^{207, 208} There are also company-specific training courses, such as the BMIP training, available to Boots pharmacists. Meanwhile, Macmillan offers information for healthcare professionals and the public on a wide variety of potentially relevant cancer-related issues, such as Cancer in Primary Care, Communicating with Patients, Late Effects, Nutritional Care, and Promoting your service.²⁰⁹ Whilst these suggestions are not specific to breast cancer or survivorship, the background information may provide some context and improve confidence. A further option is more self-directed learning, to address any individual learning needs.

In terms of collaborating, community pharmacists should aim to work together within their locality, supporting one another to expand their roles. Building relationships with their local surgeries or hospices will be useful for signposting and raising awareness of their potential to support survivors. Contacting any local charities, services or support groups as well as Macmillan GPs, Macmillan Cancer Care Navigators, and breast cancer nurses or hospital pharmacists to discuss information sharing is also recommended.

On a wider scale, there may be opportunity for the larger pharmacy companies to help drive change on an organisation level. They could potentially support with raising awareness amongst employees, organising HLP campaigns, design training and collaborations with charities.

4.2 Implications for current healthcare practice

This research has identified some important care needs amongst breast cancer survivors in the community setting. Based on the survivor reports of a lack of support from community healthcare providers, it is likely that a variety of healthcare practitioners in this setting are unaware of the extensive care needs of this patient group. As with community pharmacists, raising awareness of findings amongst GPs and other healthcare providers in primary care can help them to adapt their practice to better support breast cancer survivors. Consultations should take a holistic approach and healthcare providers should be

mindful of the level of information required by the individual.

Counselling on endocrine therapy should be provided to all those prescribed the therapy and efforts should be made to ensure any adverse effects are managed as well as possible. Those GPs and nurses who carry out CCRs should aim to ensure they follow the advice provided and keep accurate records of the intervention.

Healthcare providers within the community setting can benefit from collaborating with community pharmacists and other healthcare professionals. Building networks to support information sharing can help individuals improve their knowledge of breast cancer survivorship support and promote a better understanding of community pharmacist expertise. The introduction of widespread Primary Care Networks will aid with this, providing increased opportunity for community pharmacists to become more integrated into the primary care workforce. As multidisciplinary relationships improve, there may be increasing opportunity for shared training events and small changes to practice that utilise the expertise of each of the healthcare professionals involved. This could enable the roles of cancer survivorship care to be shared out, therefore reducing workload as well as improving survivor experiences. Health Needs Assessments or CCRs for example, could be conducted by community pharmacists then fed back to the surgery.

In terms of secondary care, collaborations with community pharmacists may also reduce workload here. Referring patients to community

pharmacists for aftercare could help reduce the burden on breast care nurses, as reported by survivors. It is important to consider that initial workload may increase whilst setting up such a system and more paperwork may be created at the point of discharge. However, projects such as the TCAM have demonstrated the benefits and feasibility of such a service.

4.3 Implications for healthcare policy

The findings of this research are well-positioned within current policy agenda; further demonstrating the need for holistic, person-centred care, as well as considering the ways in which that could be implemented.^{22, 25} Healthy living and wellbeing support is not only a priority in terms of improving the health of the nation,³⁹ but, as this research has demonstrated, it is likewise a priority for breast cancer survivors themselves who require improved support in maintaining good general health and wellbeing. Equally, the role of medicines optimisation, particularly with respect to long-term endocrine therapy use, is key to preventing recurrence and ensuring that the significant national population of breast cancer survivors “*live well for longer*”.³⁹

Also high on the national healthcare agenda is the need to improve survivorship care and ensure primary care takes on a larger role in providing these much-needed cancer services.²² Since community pharmacists are widespread and undoubtedly the most accessible healthcare provider within the primary care setting, their potential role in

achieving these goals is clear. Despite this, pharmacists feature very little in recent policy. In order to achieve their visions, it is strongly recommended that policymakers promote utilising the expertise of all healthcare providers who could support in cancer services.

The *Cancer Workforce Plan Phase 1: Delivering the cancer strategy to 2021* sets out to ensure the NHS has the required workforce in place to deliver the national cancer strategy.⁴ Amongst other issues, the report acknowledges improving cancer experiences and supporting those living with and beyond cancer as key priorities. It emphasises that the policy aims not only include ensuring sufficient levels of staff, but also “*supporting our staff to develop new skills and enabling them to work differently*”.⁴ It goes on to describe the importance of developing new models of care that factor in the roles of non-cancer specialists and considering the perspectives of patients, who of course interact with a wide variety of healthcare professionals throughout their cancer journeys. This is something that is currently being worked on nationally and within the 19 Cancer Alliances, which focus on developing models of care locally to fit with the needs of their local population. The need to support the establishment of multidisciplinary teams was also acknowledged, which again links well with the findings of this research that call for local collaborations.

In light of these workforce strategies, this research could be particularly useful to national policymakers and the Cancer Alliances when

considering future models of care. The potential role of the community pharmacist in cancer services has been constantly overlooked in healthcare policy documents. This research however, has the potential to drive change through demonstrating the vast scope for the profession to utilise its expertise and accessibility to tackle some of the unmet care needs of breast cancer survivors. Recognition by policymakers and those involved in developing new care pathways or services could benefit the healthcare system as a whole, shaping the future of the community pharmacy profession, reducing workload and offering support for the wider healthcare workforce, improving survivor experience and outcomes, and bringing the country a step closer to achieving its visions for cancer.

Within the report, Health Education England (HEE) acknowledged the need to support the healthcare workforce in developing their skills and taking on new roles in cancer.⁴ They could therefore utilise the findings of this research to develop and deliver training to support community pharmacists in expanding their roles. Since this research also highlighted the potential benefits of a shared approach to training, there may also be scope for HEE to become involved in providing multidisciplinary training to support all community healthcare providers.

Another important implication for healthcare policy is that the findings support the integration of breast cancer into the advanced services. Given the recommendations of the Murray Review in redesigning the

MUR service, along with the successful development of the Pharmacy Care Plan service, it is likely that changes to MURs are imminent.^{196, 210}

The Murray Review highlighted the need for community pharmacists to become more involved in wider healthcare services through integrated models of care and referral pathways. The importance of prioritising long-term conditions and multimorbidities was also acknowledged, but little guidance was provided on which long-term conditions should be prioritised as part of the service redesign. The recommendation was simply to include those conditions for which strong evidence of effectiveness of interventions already exists, such as diabetes, COPD and hypertension.²¹⁰ This research provides some evidence to support the inclusion of breast cancer in these services. Although future research is required to further explore the feasibility of a breast cancer-specific clinical service, this research should be considered by NHS England when considering the possible targets of the future service. In the shorter term, consideration should be given to the feasibility of incorporating endocrine therapy into the existing NMS service.

As part of their role, Macmillan Cancer Support commissions and funds a wide variety of research. Their data is often used to inform national healthcare policy. Interest in this research has been shown by more than one Macmillan representative, with whom informal discussions about the findings have occurred. The Macmillan representative who participated in this research also suggested that the findings could be useful to them in understanding the scope of community pharmacist

roles; helping to inform their own agenda in this area. Any resulting research or initiatives to develop from these conversations could add to the body of research in supporting the expansion of community pharmacist roles and may also help inform future healthcare policies.

4.4 Implications for future research

In addition to furthering knowledge in the fields of breast cancer survivorship care and community pharmacy service provision, this research highlighted several areas where future work is important. This research set out to identify opportunities for community pharmacists to expand their role in breast cancer survivorship services. Key service requirements were identified, along with some potentially feasible interventions. The most notable requirement for further research is therefore to further develop this intervention.

The MRC guidance for developing complex interventions has been previously discussed. This research addressed the first two steps of a three-step process. Future work should aim to address Step 3: *Modelling process and outcomes*. A small-scale model of the process would allow researchers to measure the effects of the intervention outcomes alongside conducting an economic evaluation. Once completed, feasibility testing and piloting can commence. The MRC recommend using an established framework for developing and evaluating interventions, for example the Multiphase Optimisation Strategy (MOST), RE-AIM, as well as the NICE guidance on developing

behavioural interventions. They further advise that piloting will likely require both quantitative and qualitative methods.¹⁰⁴

In terms of developing a review for breast cancer survivors, what this will look like will depend on the future of the existing advanced services in community pharmacy. Future research should explore how a breast cancer-specific intervention could potentially fit into this landscape as it continues to develop and change. For example, as an MUR or Pharmacy Care Plan for breast cancer survivors, or an NMS intervention for those on endocrine therapy.

Future research should also further explore the scope for the welcome pack intervention, investigating the most useful contents of the pack, the acceptability and effectiveness of using vouchers (distributed upon discharge by hospital pharmacists or breast care nurses, for example) to invite survivors to their local pharmacy to get one, and the overall effectiveness of the intervention in terms of enhancing understanding of pharmacist roles amongst both survivors and healthcare professionals, increasing uptake of any other interventions and most importantly, improving survivor experiences of care.

Further research should also aim to develop new models of care that include community pharmacists. This research has added to demand for collaborations and care pathways that facilitate the continuity of care into the community setting. Progress in this area is already being made

through projects such as TCAM service,¹⁹⁵ which introduce referral pathways into community pharmacy. In order to help shape the future of the community pharmacy profession in breast cancer survivorship services, future work should continue to explore further ways of establishing referral and information sharing pathways with both secondary care and GPs.

A key area that requires further research is surrounding the development of training materials and courses. Findings from this study have identified the key requirements for community pharmacists in terms of training. Online training was a popular option and high importance was placed on the need for the most up to date information. Discussions also highlighted the possibility of shared training events with other healthcare professionals, or the development of training materials through collaborations with organisations such as Macmillan Cancer Support or CPPE. Future work should therefore further explore the possibilities surrounding the education and training of community pharmacists to equip them to better support breast cancer survivors. Potential areas of focus include the usefulness of pre-existing training (such as the more general cancer-related training offered by CPPE and Macmillan), the effectiveness of strategies to build confidence amongst community pharmacists, and how training needs will change along with service and intervention development.

Emotional support was one of the key requirements for breast cancer survivors. However, throughout this research it became evident that participants each assigned a different definition to the term. 'Future research could therefore explore how this differs between and amongst survivors and different healthcare professionals.

Further research is required surrounding cancer care reviews. This study has highlighted the implausible numbers of CCR records, suggesting over recording. Ongoing work to standardise the intervention and introduce supportive technological solutions may go some way to rectifying this issue. However, once these changes are implemented, future work should also explore the accuracy of recording practices in order to ensure that records can be reliably used to improve the delivery of person-centred care as well as to inform research into the wider effectiveness of the intervention. Another possibility worthy of future research is that CCRs could be undertaken in the community pharmacy. Macmillan have already identified that the intervention need not be undertaken by a GP; creating scope for other community-based healthcare professionals to take on this role. Research should initially explore the acceptability of this move to GPs, community pharmacists and survivors, before carrying out a pilot to evaluate any potential improvement in survivor outcomes or experience.

In terms of further observational studies, it is important to establish the causes of early discontinuation and frequent ET switching. This data

will be of importance to healthcare professionals when setting out to minimise these issues. Further analysis of the quantitative dataset used in this research, (or an exploration of CPRD data using similar methods), could establish causal links. This could be achieved through exploring any clinical events linked with switches or final prescriptions. Adherence is also likely to be an outcome of interest. The extent of adherence and the factors affecting it could provide further insight into the causes of early discontinuation and switching and highlight other medicines-related problems that may be of importance.

This research gathered the perspectives of some influential individuals in breast cancer or service development fields. However, the stakeholder interviews aimed mainly to add context and inform the implications of the research. A more in-depth exploration of stakeholder perspectives may be useful as part of future work. Since perspectives nationally and locally may vary, focus groups with local and national stakeholders could be utilised to further explore the field. Focus groups could include GPs, breast care nurses, hospital pharmacists, Macmillan Cancer Care Navigators, and representatives from Cancer Alliances and Health Education England, for example.

A final consideration should be given to the suggestion that a service or intervention targeting only survivors of breast cancer is too specific. Although there was some difference of opinion surrounding this issue, concerns were voiced about the potential lack of uptake. It was also

acknowledged that widening the service specifications to accommodate all cancer survivors would be feasible in terms of the additional training required. A longer term possibility for future work could therefore be to explore differences in the care needs of survivors with other cancer types and to establish the extent to which the long-term feasibility of future interventions and services may depend on a service that provides support for all survivors of all types of cancer.

5 Conclusion

This mixed-methods research identified several opportunities for community pharmacists to develop their role in providing support and improving health outcomes for people living with and after breast cancer. Raising awareness of survivor care needs amongst community pharmacists is a crucial first step. Survivors reported experiencing initial information overload, then feeling abandoned after being discharged from hospital. The importance of holistic and person-centred approaches to care were identified as key. The need for proactive conversations with survivors was likewise highlighted, along with aiming to start building these relationships as early as possible in the cancer journey.

Communication and education were identified as key action points; in order to improve their practice and deliver perspective interventions, community pharmacists require training in breast cancer, its treatments, and providing survivorship care. Above all, training should aim to build

confidence in providing breast cancer survivorship care, encouraging community pharmacists to consider it as much a part of their role as supporting those with any long-term conditions. In terms of communication, healthcare providers in the community setting need to work together to provide much-needed support for breast cancer survivors. Some training materials that may be useful to community pharmacists already exist; self-directed learning could provide a useful solution as well as contributing to CPD.

Other short-term actions individuals can take include working on building relationships with GPs and other healthcare professionals as well as networking with local charities and support organisations is also important in terms of enhancing signposting practices. Sharing information resources is important to build knowledge and ensure survivors are receiving consistent, evidence-based information and advice across settings. Shared training events with other healthcare professionals such as GP were hailed as an effective way of building relationships, knowledge and confidence.

Collaborations with secondary care can also be useful in terms of information sharing. National cancer policies call for multidisciplinary collaborations, new models of care and improved survivorship care in the community. This creates scope for the integration of community pharmacists into care pathways. Formal referral pathways are key to initiating survivor contact with community pharmacy whilst ensuring the

community pharmacist has access to the patient-specific information required to provide the appropriate follow-up care.

In terms of the scope for community pharmacy-based interventions, breast cancer-focused HLP campaigns were identified as an effective and feasible way of raising public awareness of the survivorship support available in community pharmacy. These services also provide crucial healthy living advice to survivors and initiate conversations with endocrine therapy users that aim to prevent recurrence.

Survivors also called for a regular and holistic breast-cancer specific medication review. A feasible solution is incorporating this into one of the advanced services – MUR or NMS – as targeted condition. Currently however, these services are being reviewed and redesigned. Future research should therefore explore the potential for breast cancer to be incorporated into the evolving clinical review service.

This research can be utilised by individual healthcare providers, particularly community pharmacists, to help them make small changes to improve their practice. At local and national levels, the Cancer Alliances and policymakers should work aim to make use of the skillset and accessibility of community pharmacists, supporting them to take on a larger role in survivorship care through involving them in the development of new models of care and services.

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Appendix 1: ISAC Protocols Approval Letter

ISAC EVALUATION OF PROTOCOLS FOR RESEARCH INVOLVING CPRD DATA

FEEDBACK TO APPLICANTS

CONFIDENTIAL		<i>by e-mail</i>	
PROTOCOL NO:	16_202R		
PROTOCOL TITLE:	Exploring prescribing patterns, treatment pathway and healthcare resources use of breast cancer patients in primary care to inform community pharmacy services for breast cancer survivors in England		
APPLICANT:	Li-Chia Chen, BSc (Pharm), MSc (ClinPharm), PhD. Email: li-chia.chen@manchester.ac.uk		
APPROVED ☒	APPROVED WITH COMMENTS (resubmission not required) ☐	REVISION/ RESUBMISSION REQUESTED ☐	REJECTED ☐
INSTRUCTIONS: <i>Protocols with an outcome of 'Approved' or 'Approved with comments' do not require resubmission to the ISAC.</i>			
REVIEWER COMMENTS: Protocol 16_202R is approved.			
DATE OF ISAC FEEDBACK:		14/02/2017	
DATE OF APPLICANT FEEDBACK:			

For protocols approved from 01 April 2014 onwards, applicants are required to include the ISAC protocol in their journal submission with a statement in the manuscript indicating that it had been approved by the ISAC (with the reference number) and made available to the journal reviewers. If the protocol was subject to any amendments, the last amended version should be the one submitted.

**** Please refer to the ISAC advice about protocol amendments provided below ****

During the course of some studies, it may become necessary to deviate from a protocol which has been approved by ISAC. Any deviation to an ISAC approved protocol should be clearly documented by the applicant but not all such amendments need be submitted for ISAC review and approval. The general principles to be applied in regard to the need for submission are as follows:

- Major amendments should be submitted
- Minor amendments need not be submitted (but must still be documented by the applicant and should normally be mentioned at the publication stage)

In cases of uncertainty, the applicant should contact the ISAC secretariat for advice quoting the original reference number and providing a brief explanation of the nature of the amendment(s) and underlying reason(s).

Major Amendments

We consider an amendment as major if it substantially changes the study design or analysis plan of the proposed research. An amendment should be considered major if it involves the following (although this is not necessarily an exhaustive list):

- A change to the primary hypothesis being tested in the research
- A change to the design of the study
- Additional outcomes or exposures unrelated to the main focus of the approved study*
- Non-trivial changes to the analysis strategy
- Not performing a primary outcome analysis
- Omissions from the analysis plan which may impact on important validity issues such as confounding
- Change of Chief Investigator
- Use of additional linkages to other databases
- Any new proposal involving contact with health professionals or patient or change in regard to such matters

* N.B. extensive changes in this respect will require a new protocol rather than an amendment - if in doubt please consult the Secretariat

Minor Amendments

Examples of amendments which can generally be considered minor include the following:

- Change of personnel other than the Chief Investigator (these should be notified to the Secretariat)
- A change to the definition of the study population, providing the change is mentioned and justified in the paper/output [NB previously major]
- Extension of the time period in relation to defining the study population
- Changes to the definitions of outcomes or exposures of interest, providing the change is mentioned and justified in the paper/output [NB previously major]
- Not using linked data which are part of the approved protocol, unless the linked data are considered critical in defining exposures or outcomes (in which case this would be a major amendment)

- Limited additional analysis suggested by unexpected findings, provided these are clearly presented as post-hoc
- Additional methods to further control for confounding or sensitivity analysis provided these are to be reported as secondary to the main findings
- Validation and data quality work provided additional information from GPs is not required

To submit an amendment of protocol to the ISAC, please submit the following documents to the ISAC mailbox (isac@cped.com)

1. A covering letter providing justification for the request
2. A completed and, if necessary, updated application form with all changes highlighted; if new linkages are required the current version of the ISAC application form must be completed. Otherwise, the original form may be amended as necessary
3. **The updated protocol document containing the heading 'Amendment' at the end of it.** Please include all amendments to the protocol under this heading. No other changes should be made to the already approved document.

Appendix 2: Codes indicating patients with a breast cancer diagnosis in CPRD

Medical code	Read code	Diagnosis
3968	B34..00	Malignant neoplasm of female breast
348	B34..11	Ca female breast
26853	B340.00	Malignant neoplasm of nipple and areola of female breast
23380	B340000	Malignant neoplasm of nipple of female breast
64686	B340100	Malignant neoplasm of areola of female breast
59831	B340z00	Malignant neoplasm of nipple or areola of female breast NOS
31546	B341.00	Malignant neoplasm of central part of female breast
29826	B342.00	Malignant neoplasm of upper-inner quadrant of female breast
45222	B343.00	Malignant neoplasm of lower-inner quadrant of female breast
23399	B344.00	Malignant neoplasm of upper-outer quadrant of female breast
42070	B345.00	Malignant neoplasm of lower-outer quadrant of female breast
20685	B346.00	Malignant neoplasm of axillary tail of female breast
49148	B347.00	Malignant neoplasm, overlapping lesion of breast
56715	B34y.00	Malignant neoplasm of other site of female breast
95057	B34y000	Malignant neoplasm of ectopic site of female breast
38475	B34yz00	Malignant neoplasm of other site of female breast NOS
9470	B34z.00	Malignant neoplasm of female breast NOS
8351	BB91.00	[M]Infiltrating duct carcinoma
30189	BB91000	[M]Intraductal papillary adenocarcinoma with invasion
39760	BB91100	[M]Infiltrating duct and lobular carcinoma
58131	BB93.00	[M]Comedocarcinoma NOS
40359	BB94.00	[M]Juvenile breast carcinoma
67701	BB94.11	[M]Secretory breast carcinoma
12427	BB9F.00	[M]Lobular carcinoma NOS

7319	BB9G.00	[M]Infiltrating ductular carcinoma
32472	BB9H.00	[M]Inflammatory carcinoma
12300	BB9J.00	[M]Paget's disease, mammary
60803	BB9J.11	[M]Paget's disease, breast
42542	BB9K.00	[M]Paget's disease and infiltrating breast duct carcinoma
12480	BB9K000	[M]Paget's disease and intraductal carcinoma of breast
45681	B83..00	Carcinoma in situ of breast and genitourinary system
7833	B830.00	Carcinoma in situ of breast
10387	B830000	Lobular carcinoma in situ of breast
18694	B830100	Intraductal carcinoma in situ of breast
18029	BB9..00	[M]Ductal, lobular and medullary neoplasms
27728	BB90.00	[M]Intraductal carcinoma, noninfiltrating NOS
21833	BB91.11	[M]Duct carcinoma NOS
62871	BB92.00	[M]Comedocarcinoma, noninfiltrating
16677	BB9B.00	[M]Medullary carcinoma NOS
47920	BB9B.11	[M]C cell carcinoma
50946	BB9C.00	[M]Medullary carcinoma with amyloid stroma
21861	BB9E.00	[M]Lobular carcinoma in situ
9956	BB9E000	[M]Intraductal carcinoma and lobular carcinoma in situ
24523	BB9L.00	[M]Paget's disease, extramammary, exc Paget's disease bone
3969	BB9M.00	[M]Intracystic carcinoma NOS
60683	BB9z.00	[M]Ductal, lobular or medullary neoplasm NOS
59251	BBM9.00	[M]Cystosarcoma phyllodes, malignant
98883	BB9D.00	[M]Medullary carcinoma with lymphoid stroma
12499	Byu6.00	[X]Malignant neoplasm of breast
105488	B36..00	Local recurrence of malignant tumour of breast
19389	B3y..00	Malig neop of bone, connective tissue, skin and breast OS
41011	B3z..00	Malig neop of bone, connective tissue, skin and breast NOS

Appendix 3: Codes indicating patients with a breast cancer diagnosis in HES

ICD 10 code	Diagnosis
C50	Malignant neoplasm of breast
C50.0	Nipple and areola
C50.1	Central portion of breast
C50.2	Upper inner quadrant of breast
C50.3	Lower inner quadrant of breast
C50.4	Upper outer quadrant of breast
C50.5	Lower outer quadrant of breast
C50.6	Axillary tail of breast
C50.7	[no description]
C50.8	Overlapping lesion of breast
C50.9	Breast, unspecified

Appendix 4: Codes indicating breast surgery in HES

OPCS 4 code	Breast surgery description
Z15.1	Upper inner quadrant of breast
Z15.2	Upper outer quadrant of breast
Z15.3	Lower inner quadrant of breast
Z15.4	Lower outer quadrant of breast
Z15.5	Axillary tail of breast
Z15.8	Specified breast NEC
Z15.9	Breast NEC
T9000	Sentinel node mapping for breast cancer with blue dye or radioactive probe alone
T9020	Sentinel node mapping for breast cancer with blue dye and radioactive probe
B27.1	Total mastectomy and excision of both pectoral muscles and part of chest wall
B27.2	Total mastectomy and excision of both pectoral muscles NEC
B27.3	Total mastectomy and excision of pectoralis minor muscle
B27.4	Total mastectomy NEC
B27.5	Subcutaneous mastectomy
B27.6	Skin sparing mastectomy
B27.8	Other specified total excision of breast
B27.9	Unspecified total excision of breast
B28.1	Quadrantectomy of breast
B28.2	Partial excision of breast NEC
B28.3	Excision of lesion of breast NEC
B28.4	Re-excision of breast margins

B28.5	Wire guided partial excision of breast
B28.6	Excision of accessory breast tissue
B28.7	Wire guided excision of lesion of breast
B28.8	Other specified other excision of breast
B28.9	Unspecified other excision of breast

Appendix 5: Codes indicating endocrine therapy prescription in CPRD

Prodcode	Product Name
2815	Anastrozole 1mg tablets
58870	Anastrozole 1mg tablets (APC Pharmaceuticals & Chemicals (Europe) Ltd)
62952	Anastrozole 1mg tablets (Alliance Healthcare (Distribution) Ltd)
47656	Anastrozole 1mg tablets (Teva UK Ltd)
4789	Arimidex 1mg tablets (AstraZeneca UK Ltd)
26227	Emblon 10mg tablets (Teva UK Ltd)
26273	Emblon 20mg Tablet (Berk Pharmaceuticals Ltd)
13630	Fareston 60mg tablets (Orion Pharma (UK) Ltd)
10121	Femara 2.5mg tablets (Novartis Pharmaceuticals UK Ltd)
26224	Fentamox 10mg Tablet (Opus Pharmaceuticals Ltd)
22013	Fentamox 20mg Tablet (Opus Pharmaceuticals Ltd)
42098	Fentamox 40mg Tablet (Opus Pharmaceuticals Ltd)
6779	Letrozole 2.5mg tablets
58587	Letrozole 2.5mg tablets (A A H Pharmaceuticals Ltd)
61583	Letrozole 2.5mg tablets (Actavis UK Ltd)
64465	Letrozole 2.5mg tablets (Sandoz Ltd)

46036	Nastrosa 1mg tablets (Discovery Pharmaceuticals)
24217	Noltam 10mg Tablet (Wyeth Pharmaceuticals)
24238	Noltam 20mg Tablet (Wyeth Pharmaceuticals)
9075	Nolvadex -forte 40mg Tablet (AstraZeneca UK Ltd)
7936	Nolvadex 10mg tablets (AstraZeneca UK Ltd)
7346	Nolvadex D 20mg tablets (AstraZeneca UK Ltd)
11377	Soltamox 10mg/5ml oral solution (Rosemont Pharmaceuticals Ltd)
15038	Tamofen -10 10mg Tablet (Pharmacia Ltd)
3648	Tamofen -20 Tablet (Pharmacia Ltd)
23972	Tamofen -40 Tablet (Pharmacia Ltd)
63980	Tamofen 20 tablets (Pfizer Ltd)
300	Tamoxifen 10mg tablets
41598	Tamoxifen 10mg tablets (Actavis UK Ltd)
55963	Tamoxifen 10mg tablets (Teva UK Ltd)
61675	Tamoxifen 10mg tablets (Waymade Healthcare Plc)
34010	Tamoxifen 10mg tablets (Wockhardt UK Ltd)
11389	Tamoxifen 10mg/5ml oral solution
50847	Tamoxifen 10mg/5ml oral solution sugar free
57312	Tamoxifen 10mg/5ml oral suspension
47841	Tamoxifen 20mg Tablet (Co-Pharma Ltd)
45330	Tamoxifen 20mg Tablet (Sandoz Ltd)

1416	Tamoxifen 20mg tablets
41590	Tamoxifen 20mg tablets (A A H Pharmaceuticals Ltd)
30919	Tamoxifen 20mg tablets (Actavis UK Ltd)
60586	Tamoxifen 20mg tablets (Alliance Healthcare (Distribution) Ltd)
33670	Tamoxifen 20mg tablets (IVAX Pharmaceuticals UK Ltd)
26956	Tamoxifen 20mg tablets (Kent Pharmaceuticals Ltd)
34513	Tamoxifen 20mg tablets (Mylan Ltd)
33470	Tamoxifen 20mg tablets (Teva UK Ltd)
29607	Tamoxifen 20mg tablets (Wockhardt UK Ltd)
2547	Toremifene 60mg tablets
5940	Exemestane 25mg tablets
17079	Aromasin 25mg tablets (Pfizer Ltd)
18885	Fulvestrant 250mg/5ml solution for injection pre-filled syringes
29632	Faslodex 250mg/5ml solution for injection pre-filled syringes (AstraZeneca UK Ltd)

Appendix 6: Interview guides

Survivor Focus Group Interview Schedule

Briefing

- The purpose of this focus group is to discuss the experiences of people living with and after breast cancer when being cared for in the community, and to understand what additional care or support might be needed
- The focus group will take approximately 2.5 hours
- Confirm that all participants have read and understood the participant information sheet and signed the consent form
- Confirm all participants have completed the survey

During the focus group

Examples of themes to be discussed:

- Medicines-related problems, e.g.: side effects, adherence, interactions, other
 - Current care provided by GPs, pharmacists and other community-based healthcare professionals
 - Roles of healthcare professionals - How did these change throughout cancer experience?
 - Accessibility of care – convenience and frequency of consultations, impact on life
 - Services provided – e.g.: Boots Macmillan Information Pharmacist services, Medicine Use Reviews, Cancer Care Reviews, other care or consultations
1. *Positive experiences of care, particularly provided by pharmacists*
 2. *Negative experiences: medicines problems that were not resolved efficiently, lack of care/information. Where in cancer experience did these problems occur?*
 3. *What could be done to improve care experiences? What additional care or support would have helped? Was there anything that could have been done differently? What additional services could pharmacists offer? – Opinions of each of these?*

Closing

- Summarise the discussion
- Would anyone like to add anything?
- Thank all participants for their contributions

Pharmacist Focus Group Interview Schedule

N.B. The content of the focus group will be based on the findings from the survivor focus groups. The final interview schedule will therefore be drawn up following analysis of this data.

Briefing

- The purpose of the focus group is to discuss potential opportunities of a community pharmacy intervention to support and improve the health outcomes of breast cancer survivors. It will aim to establish the views of this group as potential service providers, and consider any feasibility or operational issues
- The conversation will be based on survivor's ideas about how their experiences of breast cancer might have been improved by increased pharmacist involvement
- The focus group will take approximately 1.5 hours
- All comments and responses should be typed
- *Confirm that all participants have read and understood the participant information sheet and consent form*
- *Confirm all participants have signed and returned the consent form*

During the focus group

Content to be confirmed

Closing

- Does anyone have anything else to add?
- *Thank all participants for their contributions and close the discussion*

Stakeholder Meeting Schedule

N.B. The content of the meeting will be based on the findings from the survivor and pharmacist focus groups. The final interview schedule will therefore be drawn up following analysis of this data.

For stakeholders unable to attend, the presentation slides will be sent via email, and the discussion will take place in the form of a telephone interview.

Briefing

- The purpose of this meeting is to discuss perspectives of relevant stakeholders surrounding the opportunity for developing a community pharmacist-led intervention to provide support and improve health outcomes of breast cancer survivors
- The meeting will take approximately 1.5 hours, and will consist of a presentation followed by a discussion
- Confirm that all participants have read and understood the participant information sheet and consent form; signed the consent form and retained a copy of the information sheet

Presentation

Present a brief background to the research and findings of the study so far, summarising the issues faced by survivors and how pharmacists propose to address these

Discussion

- Establish views and requirements of stakeholders
- Discuss factors to consider when developing a service proposal, or considering commissioning prospects

Closing

- Summarise the discussion
- Does anyone have any other comments to add?
- Thank all participants for their contributions

Appendix 7: Patient and public involvement activity

Field Notes

- Family History, genetic links
- Menopause – am I postmenopausal? Which medicines are safe? Symptoms vs side effects of medicine
- Spreading or recurrence – lack of support, lack of checks/exams, no follow up care
- Side effects – (Sweating, hot flushes, weight gain, cramps, bleeding), severity, how long they last for, other peoples' attitudes, no information given, no medicine counselling
- Appearance – couldn't wear makeup because sweating was so bad, hair loss/ wig support
- Medication – danger of recurrence, effectiveness of AI vs tamoxifen, side effects, red flag symptoms, other medications to help with side effects – clonidine, SSRIs
- Proactivity – changing meds, looking for support from charities, family history
- Charities & support – Breast Cancer UK, Maggie's – patient support group (leaflets given at hospital), online support, chemotherapy clinic had community feeling, Macmillan (written support booklet)
- GP - GP didn't want to get involved. No CCR. No follow up or contact from primary care. Not wanting to bother GP, feeling embarrassed for worrying about recurrence
- Hospital support - Good support from hospital during first six months. – Surgeon, breast cancer nurse, radiotherapy. Yearly check-ups needed. Hospital care dropped off after six months. Very disappointing aftercare. No check-ups after six months one year in hospital – concerns about recurrence.
- What can pharmacists do - Could have done with regular chats and support from pharmacy, pharmacists need a better understanding of experiences and

problems faced throughout whole journey, written information/ booklets, vitamins and supplements guide, training of how to counsel patients, emotional support, when to refer- red flags, fast tract referral, no information given from hospital pharmacist, pharmacists need better knowledge, need to help manage side effects and warn about recurrence, signposting, more detailed knowledge of most common cancers, Could pharmacists be trained to check glands for lumps etc.? Knowing where glands are, etc.

- HCPs need to be more proactive
- Herceptin care and process
- Emotional support – dealing with fear of recurrence
- Lack of support surrounding mastectomy – what to expect – appearance, healing, lack of care afterwards – carrying heavy drains, showering, facing a mirror, lots of emotional trauma, would have liked to hear from other patients, or seen photos - have been prepared better

Focus Group Topic Guide

General feelings about the care from community-based healthcare providers

- Hospital vs community

Changes in care throughout journey during treatment vs follow up

- Hospital aftercare/follow up
- Were HCPs proactive/interested?

Positive and negative experiences

- Did they feel knowledgeable/empowered as a patient?
- What were best sources of support or care?
- Was enough care provided?
- Right levels of knowledge/interest from HCPs? Approachability
- Accessibility (frequency) Impact on day to day life, local services
- Right sort of care? What could have been done differently?
- Medicines related problems – switching, early discontinuation, side effects

Care and services offered/provided

- GPs – CCR
- Pharmacists – MURs, BMIP, PILs
- Others
- Sources of information
- Charities and support groups
- Other patients - peers

Additional support needed & from whom

- Medicines
- What to expect when going through various treatments – mastectomy, side effects of ET, Herceptin, CT, RT
- Managing side effects
- Recurrence/spreading
- Menopause
- Family history
- Getting back to 'normal' life
- Appearance
- Emotional support
- Sources of information
- Social life

What could pharmacists do to help? Opinions. Will the pharmacist fit the role?

Appendix 8: Survivor recruitment advert

Provided to pharmacies as posters (A3 and A4 sizes), and flyers (A5)

**IF YOU HAVE BEEN TREATED FOR BREAST CANCER
WE NEED YOUR HELP**

We are researching how care provided to people living with and after breast cancer could be improved by new community pharmacy services.

We need:

- female volunteers
- over 18 years of age
- started taking medicines for breast cancer at least 2 years ago
- have been looked after in the community (by GPs, nurses, pharmacists, etc.)

If this is you, we would like to invite you to take part in a discussion about your experiences and how care could be improved.

**FOR MORE INFORMATION,
PLEASE SPEAK TO A MEMBER
OF YOUR PHARMACY TEAM**

Alternatively, contact:

Lydia Tutt
Division of Pharmacy Practice and Policy,
School of Pharmacy,
University of Nottingham

Email: paxlt1@nottingham.ac.uk
Telephone: **0115 82 32285**

The University of Nottingham

UNITED KINGDOM • CHINA • MALAYSIA

The role of the community pharmacist in breast cancer services Final Version1.0:17/01/17

Appendix 9: Survivor participant information sheet



Division of Pharmacy Practice and Policy
School of Pharmacy
East Drive
Nottingham
NG9 2HY

Participant Information Sheet (Final Version 1.0: 17/01/17)

IRAS Project ID: 219843

Title of Study: The role of the community pharmacist in breast cancer services

Name of Researcher(s): Miss Lydia Tutt, Professor Claire Anderson, Dr Tracey Thornley, Dr Li-Chia Chen

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The purpose of this study is to identify how the care and support provided to people living with and after breast cancer (known as 'breast cancer survivors') could be improved by new community pharmacy services.

Why have I been invited?

You are being invited to take part because as a breast cancer survivor and user of a community pharmacy within your local area, we would like to find out about your experiences of being cared for in your community and we value your views about what additional care and support might be needed. We are inviting six to eight participants like you to take part in each focus group; and focus groups will be carried out within a minimum of three areas across England.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

Once you decide to take part, a member of the pharmacy team will collect your contact details to pass onto the researchers. A researcher will then contact you with details of when and where the focus group will take place (the focus group will be held somewhere local to you). You will also have an opportunity to ask any questions you may have.

When you arrive at the focus group you will be greeted by one of the researchers and asked to complete a short survey about your background and your treatment. You will also be required to sign a consent form.

The discussion will be led by a researcher, who will introduce each of the participants and give a brief introduction. Within the group, you will share your various experiences (both positive and negative) of any community-based care you received as part of your breast cancer journey. You will each discuss your views on current care experienced by yourself and the other group members. You will also discuss what additional care or support might improve future experiences of people living with or after breast cancer, including what support community pharmacists could provide.

You will only be asked to attend one focus group. The session will last approximately 2.5 hours in total.

Expenses and payments

Participants will not be paid to participate in the study. However, your travel expenses will be reimbursed (up to the value of £25) and refreshments will be provided.

What are the possible disadvantages and risks of taking part?

As part of the session you will be asked to share your experiences about your breast cancer and care with the researchers and other breast cancer survivors. We appreciate that negative experiences to do with your cancer can be a sensitive topic and we would like you to share only information you feel comfortable discussing. However, we would encourage you to share any negative experiences if you can, as this information will be useful in improving care in the future.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help others living with and after breast cancer in the future, by improving the care and support available in the community.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Chief Investigator, Professor Claire Anderson, using the contact details provided below.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

All participants will agree beforehand to treat anything said during the focus group as confidential and will be reminded not to relay any of the information discussed to anyone outside the room.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the focus group room will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, email address, telephone number) will be kept for six months after the end of the study so that we are able to contact you about the findings of the study (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say during the focus group is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

Involvement of the General Practitioner/Family doctor (GP)

Your GP does not need to be notified of your participation in this study. However, you may be advised to contact them (or another relevant healthcare practitioner) if a current concern with your treatment arises during the focus group discussion.

What will happen to the results of the research study?

The results of this research will form part of a PhD thesis. They may also be submitted for publication in any relevant scientific journals. If you are interested in receiving a copy of the published results, please notify the researcher when you attend the focus group. Your identity will be kept confidential in any reports or publications produced from this research.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded jointly by The Division of Pharmacy Policy and Practice, School of Pharmacy, University of Nottingham and Boots UK Ltd.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NHS Health Research Authority Research Ethics Committee.

Further information and contact details

Co-investigator/Facilitator: Miss Lydia Tutt
Postgraduate Research Student
Division of Pharmacy Practice & Policy
School of Pharmacy, University of Nottingham
Email: paxlt1@nottingham.ac.uk
Phone: 0115 82 32285

Chief Investigator: Professor Claire Anderson
Professor of Social Pharmacy,
Head of Division of Pharmacy Practice & Policy
School of Pharmacy,
University of Nottingham
Email: claire.anderson@nottingham.ac.uk
Phone: 0115 951 5389

Appendix 10: Letter detailing the survivor recruitment process in pharmacies

The University of Nottingham

UNITED KINGDOM - CHINA - MALAYSIA
Division of Pharmacy Practice and Policy
School of Pharmacy
University Park
East Drive
Nottingham
NG7 2RD

[date]

Dear [pharmacist name]

Re: The Role of the Community Pharmacist in Breast Cancer Services

Thank you for volunteering to help us to recruit survivor focus group participants for the first phase of our study.

You can start recruiting right away; the process is quick and easy. This pack should provide you with everything you need to begin, but please contact us at any time if you have any queries.

Included in this pack are the following documents:

- 3 x Posters
- 15 x Flyers
- 1 x Record of Participant Contact Details sheet
- 10 x Survivor Participant Information Sheets

Copies of these documents have also been emailed to you but if you require further paper copies, we are happy to post them to your store.

We are hoping to keep the recruitment period as short as possible. We expect it to last no longer than two months, but this may change depending on the number of participants we are able to recruit. We will keep you updated on any changes as the study progresses and we will notify you when it is time to stop recruiting.

The information below contains further details about how to begin recruiting.

Setting up for recruitment

1. Display posters or flyers where pharmacy customers can easily see or access them
2. Please ensure that all members of the pharmacy team are familiar with the information provided in this pack

Identifying potential participants

There are two possible methods of identifying potential participants:

- 1) Customers see a flyer or poster and express an interest in the study
- 2) Pharmacists may want to mention the study to any regular patients that they have spoken to about cancer as part of their role

Recruiting participants

The recruitment process is simple and each interaction should take less than a few minutes to complete. For each potential participant, please complete the following steps:

1. Confirm eligibility

All participants must meet the following criteria:

- Female
- Treated for breast cancer within primary care in England (i.e.: prescribed a medicine for breast cancer; such as tamoxifen, anastrozole, letrozole, fulvestrant, exemestane or toremifene.)
- Minimum of two years since first diagnosis of breast cancer was confirmed
- Over 18 years of age
- Able to give informed consent
- Able to understand or communicate in English
- Living within (or able to easily travel to) the South Warwickshire area

2. Provide Participant Information Sheet

Each potential participant should be given an information sheet, which will provide further details about the study.

3. Record details

Please use the Record of Participant Contact Details sheet to take down the name, address, email address, telephone number and preferred method of contact for each potential participant. (A member of the research team will then contact each participant directly to answer any further questions and make arrangements for their involvement in the study.)

At the end of each week, please email a copy of the record sheet to: paxt1@nottingham.ac.uk

The findings from this research will be used to inform the second phase of our study; a community pharmacist focus group to investigate views on the feasibility of introducing new services to meet breast cancer survivors' care needs. Please let us know if you would like to find out more about the findings of the survivor focus groups, or are interested in participating in the upcoming pharmacist focus group.

This study has been reviewed and given favourable opinion by NHS Health Research Authority Research Ethics Committee.

Thank you once again for your support with this study.

Kind regards,
Lydia Tutt

Lydia Tutt MPharm MRPharmS
Postgraduate Research Student
Telephone: 0115 82 32285
Email: paxt1@nottingham.ac.uk

Appendix 11: Record of survivor participant contact details

Record of participant contact details

Advice to pharmacy staff: Please use this form to record the contact details of any eligible people who express a potential interest in participating in the study (PLEASE COMPLETE IN BLOCK CAPITALS)

	Name of potential participant	Telephone Number	Address	Email address	Preferred method of contact (post/ telephone/ email)
1					
2					
3					
4					
5					
6					
7					
8					
9					

Appendix 12: Letter to pharmacies requesting support with survivor recruitment



UNITED KINGDOM • CHINA • MALAYSIA

Division of Pharmacy Practice and Policy
School of Pharmacy
University Park
East Drive
Nottingham
NG7 2RD

24th May 2017

Dear Pharmacist,

The Role of the Community Pharmacist in Breast Cancer Services

Breast cancer is the most common cancer in the UK. As breast cancer treatments improve and earlier diagnosis is possible, people are living longer with and after breast cancer. These survivors often require long term medication, and report a need for better care and support from community-based healthcare professionals. As experts in medicines management, community pharmacists are ideally placed to take on a larger role in providing support.

I am a postgraduate research student at the University of Nottingham and am writing to ask for your support with some important research that could help shape the future of community pharmacy and improve the lives of those living with and after breast cancer. This research is being carried out as part of my PhD, entitled '*The role of the community pharmacist in breast cancer services*'.

As part of this research, we will be arranging a local focus group within the South Warwickshire area for survivors (women living with and after breast cancer), exploring their experiences and views of the breast cancer care received in the community. We're also asking them to think about how community pharmacists might be able to address any unmet care needs and better support breast cancer survivors in the future.

We therefore need pharmacists and their teams within the area who are willing to help us recruit patients, to enable us to run these focus groups. This would simply involve:

- displaying posters or flyers
- identifying eligible patients
- recording their contact details
- providing them with an information sheet about the focus group

Each conversation with a potential participant should take less than a couple of minutes. We would then contact them directly to answer any questions they may have and arrange the focus groups.

The recruitment period is expected to run for one to two months from the end of May. If you are happy to support with recruitment or would like further information on the study, please email or telephone me as soon as possible (contact details provided at the end of this letter).

At a later stage in the research, we will also be arranging a web-based focus group for pharmacists, where we can discuss the findings of the survivor focus groups and explore perspectives on developing a service to

support breast cancer survivors. Participation in this event is optional, and will be open to community pharmacists regardless of whether they have assisted with survivor recruitment. We will provide more information closer to the time, but please contact me if you are interested in participating in this event.

Thank you in advance for your support.

Kind regards,
Lydia Tutt

Lydia Tutt MPharm MRPharmS
Postgraduate Research Student
Telephone: 0115 82 32285
Email: paxlt1@nottingham.ac.uk

Appendix 13: Community pharmacist participant information sheet

 The University of Nottingham UNITED KINGDOM • CHINA • MALAYSIA	Division of Pharmacy Practice and Policy School of Pharmacy East Drive Nottingham NG9 2HY
Participant Information Sheet (Final Version 1.0: 17/01/17)	
IRAS Project ID: 219843	
Title of Study: The role of the community pharmacist in breast cancer services	
Name of Researcher(s): Miss Lydia Tutt, Professor Claire Anderson, Dr Tracey Thornley, Dr Li-Chia Chen	
We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.	
What is the purpose of the study?	
The purpose of this study is to identify how the care and support provided to people living with and after breast cancer (known as 'breast cancer survivors') could be improved by new community pharmacy services.	
Why have I been invited?	
You are being invited to take part because as a community pharmacist, we would like to find out your views on some ideas for a new community pharmacy based service to support breast cancer survivors. We are therefore inviting 6-10 community pharmacists to take part in a web-based focus group.	
Do I have to take part?	
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.	
What will happen to me if I take part?	
Once you decide to take part, a member of the research team will contact you with details of when the focus group will take place. The focus group will be web-based, so the researcher will send you all the details you need to log in to it too. You will have an opportunity to ask any questions you may have, and you will also be emailed a consent form, which you will need to sign and return before the start of the focus group.	
Page 1 of 3	
The role of the community pharmacist in breast cancer services Participant Information Sheet Final V1.0 17/01/17	

When you log in to the focus group discussion, the researcher will greet you and introduce you to the other participants. Once all the participants have joined the conversation the researcher will give a brief introduction.

The researcher will then present some ideas from survivors who have been treated for breast cancer in primary care, about how their care could be improved and what pharmacists could do to improve their experiences. As a group you will discuss your views on these ideas; considering how such a service would work and whether it would be feasible.

The session will be a one-off and will last approximately 2.5 hours in total.

Expenses and payments

You will not be paid to participate in the study.

What are the possible disadvantages and risks of taking part?

There are no major risks of taking part in this study. The main disadvantage is the time you will be asked to contribute, which will be approximately 2.5 hours, plus a small amount of time beforehand to sign and return the consent form and access the online chat.

What are the possible benefits of taking part?

The findings of the study are expected to help community pharmacists by improving understanding of the requirements of breast cancer survivors being treated in primary care. On a wider scale, the information we get from this study may help bring about changes in service provision in the community and improve the care and support available to people living with and after breast cancer in the future.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you can do this by contacting the Chief Investigator, Professor Claire Anderson, using the contact details provided below.

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence.

All participants will agree beforehand to treat anything said during the focus group as confidential and will be reminded not to relay any of the information discussed to anyone outside the room.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the focus group room will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (address, email address, telephone number) will be kept for six months after the end of the study so that we are able to contact you about the findings of the study (unless you

advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

Although what you say in the focus group is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

The results of this research will form part of a PhD thesis. They may also be submitted for publication in any relevant scientific journals. If you are interested in receiving a copy of the published results, please notify the researcher when you attend the focus group. Your identity will be kept confidential in any reports or publications produced from this research.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by Pharmacy Research UK.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NHS Health Research Authority Research Ethics Committee.

Further information and contact details

Co-Investigator/Facilitator:	Miss Lydia Tutt Postgraduate Research Student Division of Pharmacy Practice & Policy School of Pharmacy, University of Nottingham Email: paxit1@nottingham.ac.uk Phone: 0115 82 3285
Chief Investigator:	Professor Claire Anderson Professor of Social Pharmacy, Head of Division of Pharmacy Practice & Policy School of Pharmacy, University of Nottingham Email: claire.anderson@nottingham.ac.uk Phone: 0115 951 5389

Appendix 14: Community pharmacist and stakeholder consent form



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Nottingham
UNITED KINGDOM • CHINA • MALAYSIA

PHARMACIST/STAKEHOLDER CONSENT FORM
(Final Version 1.0: Date 22.02.17)

Title of Study: The role of the community pharmacist in breast cancer services
IRAS Project ID: 219843

Name of Researcher: Lydia Tutt

Name of Participant: _____ Please initial box

1. I confirm that I have read and understand the information sheet version number 1.0 dated 17/01/17 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that any data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the focus group will be recorded and that anonymous direct quotes from the focus group may be used in the study reports. ☐
6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
7. I agree to take part in the above study. ☐

Name of Participant _____	Date _____	Signature _____
Name of Person taking consent _____	Date _____	Signature _____

2 copies: 1 for participant and 1 for the project notes

Appendix 15: Survivor consent form

SURVIVOR CONSENT FORM (Final Version 2.0: Date 22.02.17)

Title of Study: The role of the community pharmacist in breast cancer services

IRAS Project ID: 219843

Name of Researcher: Lydia Tutt

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 1.0 dated 17.01.17 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the focus group will be recorded and that anonymous direct quotes from the focus group may be used in the study reports. ☐
6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐
7. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

2 copies: 1 for participant and 1 for the project notes

Focus group:
Date completed:



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Nottingham**
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Breast Cancer Care Survey

The purpose of this survey is to gather some background information about you and your treatments for breast cancer, which may be helpful when describing the findings from the focus group.

In accordance with the Data Protection Act, the information you provide will be treated as strictly confidential and stored securely. Any information about you used for this research will have your name and any identifying details removed so that you cannot be recognised from it.

The survey should take approximately 5 minutes to complete.

Your Details

Initial(s) _____

Age: ☐ 18-25 ☐ 26-40 ☐ 41-55 ☐ 56-70 ☐ 71+

Your Medicines

- Are you currently taking any medicines for breast cancer? (Tick any that apply)

☐ Tamoxifen	☐ Fulvestrant
☐ Anastrozole	☐ Toremifene
☐ Letrozole	☐ Exemestane
☐ Other (please state) _____	
- Have you previously taken any other medicines for breast cancer? (Tick any that apply)

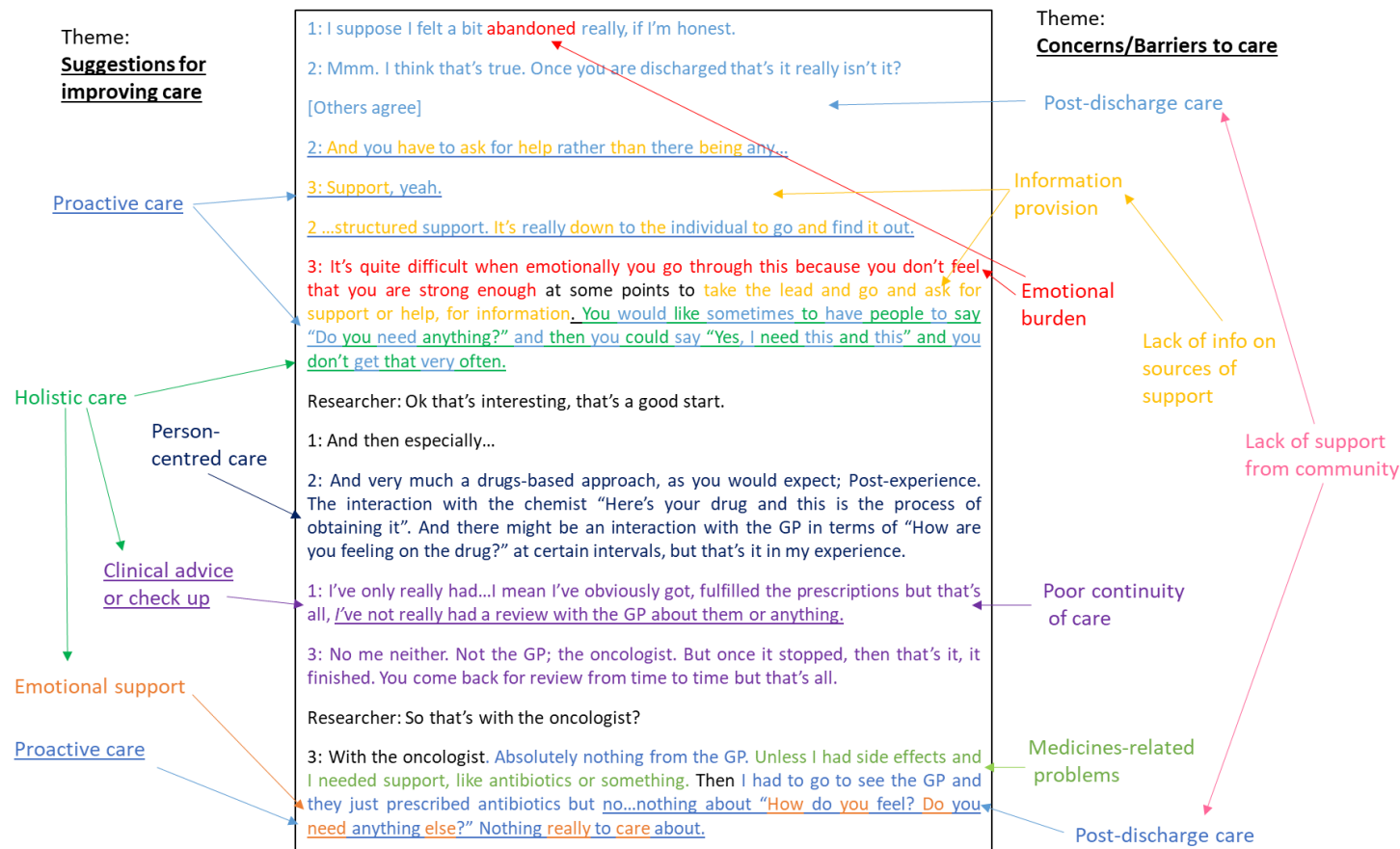
☐ Tamoxifen	☐ Fulvestrant
☐ Anastrozole	☐ Toremifene
☐ Letrozole	☐ Exemestane
☐ Other (please state) _____	
- When did you first start taking a medicine for your breast cancer? (Tick ONE only)

☐ Up to 1 year ago	☐ Up to 4 years ago
☐ Up to 2 years ago	☐ Up to 5 years ago
☐ Up to 3 years ago	☐ More than 5 years ago
- If you have ever changed to a different breast cancer medicine, what were your reason(s) for this?

The role of the community pharmacist in breast cancer services

Final version 1.0 17/01/17

Appendix 17: Excerpt of survivor transcript illustrating qualitative coding and analysis process



Appendix 18: Guide for participants of online focus group

Focus Group Guide

- The focus group will be held using Skype for Business. There is a free web app that you can use so no need to download the program if you don't already have it.
- You will need either a PC or Mac computer with an internet connection and audio capability (speakers/earphones). Please avoid using tablets or mobile phones as the app doesn't seem to work on these.
- The focus group discussion will be held using the instant message (IM) feature, so we will be typing our ideas and comments rather than talking. We won't be using the video or audio features, so you won't need a webcam, speakers or microphone.

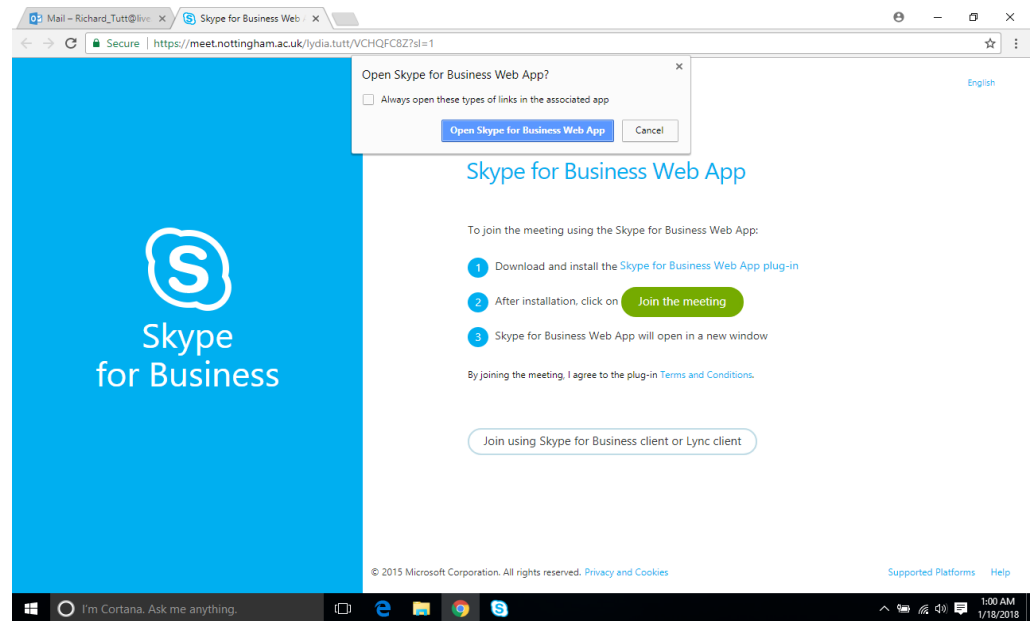
To join the meeting:

1. Click on link in email to go to the meeting. If you don't have Skype for Business you can use the web app. The link should appear as below:

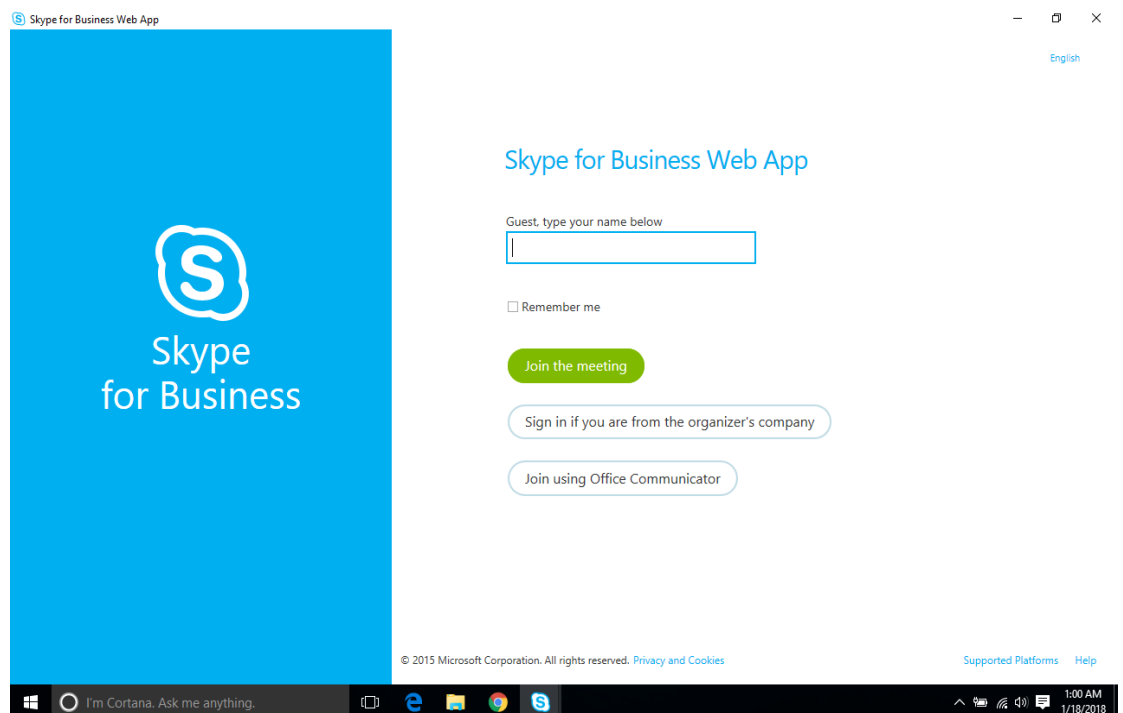
[→ Join Skype Meeting](#)

Trouble Joining? Try Skype Web App

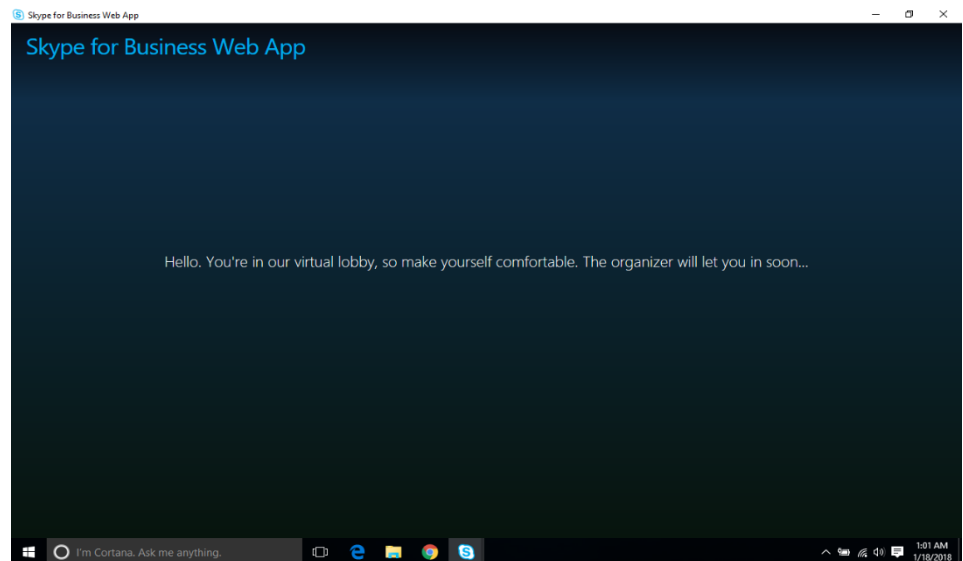
2. This should take you to the following window, and a pop up box will then appear. Click 'Open Skype for Business Web App'



3. Enter your first name in the space provided and click 'Join the meeting'

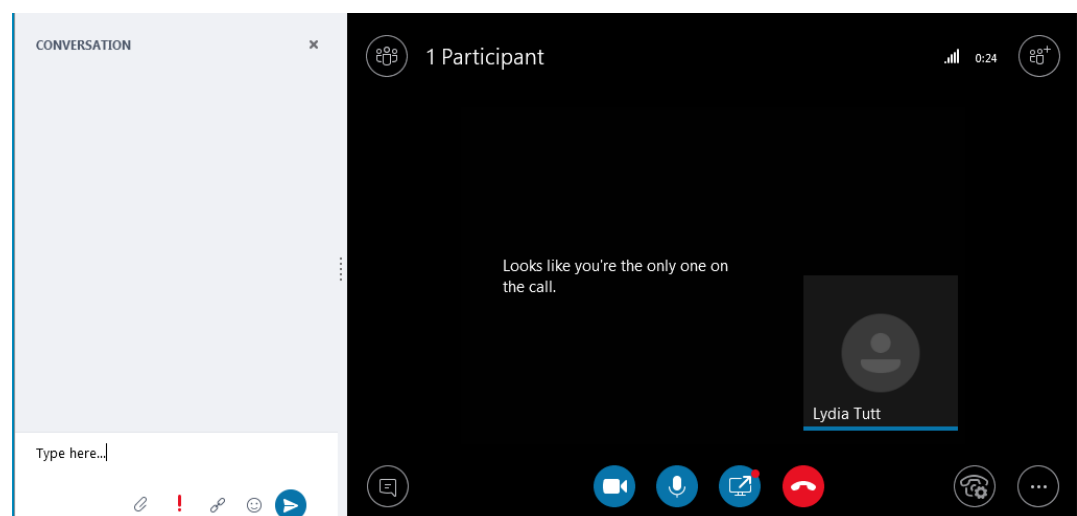
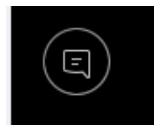


4. Once you have joined, you will be taken to a virtual 'lobby' where you can wait until everyone has arrived. Once everyone has managed to log in, I will let you in and we can start the focus group.



To take part in the focus group:

Once the focus group has started, you will see a screen showing the other participants. You now need to open the Instant messaging (IM) by clicking on the IM button in the bottom left corner. A conversation panel should now open on the left hand side of your screen. This is where the discussion will take place.



Technical Problems

- I'm hoping we won't have any, but if something goes wrong please let me know as soon as possible by sending me an email and I will do my best to solve it or work around it.
- If you get disconnected at any point you can go back to the link in the email and join again as above. You will return to the lobby and I will let you in as soon as possible.

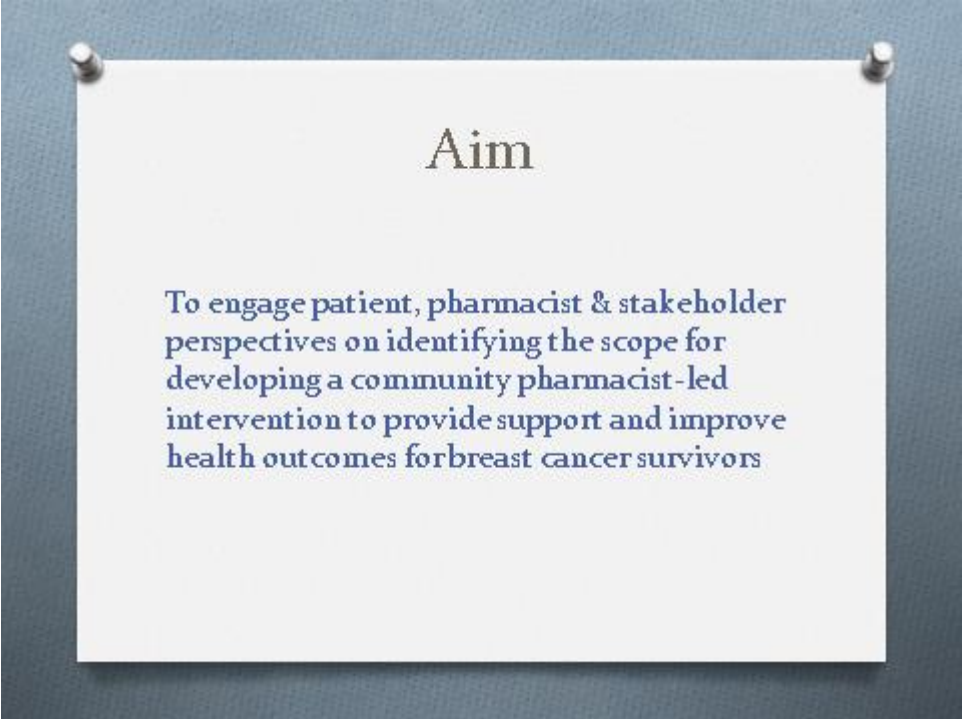
Focus Group Agenda

1. Briefing: Introduction and aims of focus group
2. Barriers to care: Key issues for survivors
3. How could pharmacists help?
4. Could a new pharmacy service feasibly improve survivor experience?
5. Closing: Summarising and agreeing findings

Appendix 19: Presentation for stakeholder participants



The role of the community pharmacist in breast cancer services



Aim

To engage patient, pharmacist & stakeholder perspectives on identifying the scope for developing a community pharmacist-led intervention to provide support and improve health outcomes for breast cancer survivors

Project Overview

- 1) Exploring treatment pathways
- 2) Survivor focus groups
- 3) Community pharmacist focus groups
- 4) Stakeholder interviews

Treatment pathways

- ◊ Retrospective cohort study using Clinical Practice Research Datalink (Nov 2005-Oct 2015)
- ◊ Investigated endocrine therapy treatment pathways in the primary care setting to help improve understanding of care needs and problems associated with long term medication use in breast cancer survivors

- ◊ 15039 female BC survivors included; 82% were prescribed ET
- ◊ 32% switched ET up to 4 times
- ◊ Of those with at least 5 years of follow up data following ET initiation, 53% did not complete recommended course
- ◊ Early discontinuation & frequent switching of ET indicate medicines related problems, increased risk of recurrence & mortality
- ◊ As experts in medicines, community pharmacists have opportunity to support survivors further

Findings from Breast Cancer Survivors

Barriers to care

- ◊ Lack of information provision
- ◊ Wrong level of support at wrong time
- ◊ Lack of healthcare professional expertise
- ◊ No continuity of care
- ◊ Lack of local services and support
- ◊ Pressures on NHS

Improving survivor experience

- ◊ Personalised care
- ◊ Holistic care
- ◊ Continuity of care
- ◊ Healthcare professional attitudes
- ◊ Right setting
- ◊ Healthcare professional roles & expertise

Findings from Community Pharmacists

How can pharmacists help?

- ◊ Appropriate signposting
- ◊ Advertising
- ◊ Emotional support, proactive
- ◊ Further training
- ◊ Working with local services
- ◊ Multi/interdisciplinary collaborations
- ◊ Right setting
- ◊ Providing right info at right time
- ◊ Support with pharmacy products

Possible interventions

- ◊ Cancer info drop in clinic
- ◊ HLP campaign
- ◊ Review
- ◊ Welcome pack

Any feasibility issues?

- ◊ Lack of knowledge and expertise
- ◊ Patient perceptions
- ◊ Training needed
- ◊ Time
- ◊ Funding
- ◊ Setting
- ◊ Is BC too specific?

Appendix 20: Ethical approval letter for qualitative work

		 Health Research Authority
		South East Coast - Surrey Research Ethics Committee
		Whitefriars Level 3, Block B Lewins Mead Bristol BS1 2NT
		Telephone: (020) 71048053
Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval		
07 March 2017		
Professor Claire Anderson School of Pharmacy East Drive Nottingham NG7 2RD		
Dear Professor Anderson		
Study title:	The role of the community pharmacist in breast cancer services	
REC reference:	17/LO/0298	
Protocol number:	16110	
IRAS project ID:	219843	
Thank you for responding on 03 March to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.		
The revised documentation has been reviewed and approved by the sub-committee.		
We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact please contact hra.studyregistration@nhs.net outlining the reasons for your request.		
Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.		
A Research Ethics Committee established by the Health Research Authority		

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

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permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Copies of advertisement materials for research participants [Survivor recruitment poster]	1.0	17 January 2017
Covering letter on headed paper [Covering letter]	1.0	17 January 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of insurance]		30 January 2017
Interview schedules or topic guides for participants [Interview schedules]	1.0	17 January 2017
IRAS Application Form [IRAS_Form_31012017]		31 January 2017
IRAS Application Form XML file [IRAS_Form_31012017]		31 January 2017
IRAS Checklist XML [Checklist_31012017]		31 January 2017
IRAS Checklist XML [Checklist_02032017]		02 March 2017
Letter from sponsor [Sponsor letter]	v1	30 January 2017
Non-validated questionnaire [Survivor survey]	1.0	17 January 2017
Other [Record of participant contact details]	v.1.0	17 January 2017
Participant consent form [Consent form]	2.0	22 February 2017
Participant consent form [Pharmacist and stakeholder consent form]	1.0	22 February 2017
Participant information sheet (PIS) [Survivor PIS]	1.0	17 January 2017
Participant information sheet (PIS) [Pharmacist PIS]	1.0	17 January 2017
Participant information sheet (PIS) [Stakeholder PIS]	1.0	17 January 2017
Research protocol or project proposal [The role of the community pharmacist in breast cancer services]	1.0	17 January 2017
Summary CV for Chief Investigator (CI) [Claire Anderson]		17 January 2017
Summary CV for student [Lydia Tutt]		17 January 2017
Summary CV for supervisor (student research)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

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- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance>

We are pleased to welcome researchers and R & D staff at our RES Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/LO/0298

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely



PP - Dr Mark Atkins
Chair

Email: nrescommittee.secoast-surrey@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: Ms Angela Shone

A Research Ethics Committee established by the Health Research Authority