Maintaining and regaining independence in activities of daily living for people with dementia during hospital admissions, the development of Occupational Therapy Personal Activity Programme (OcTPAP)

Lisa Patrick

BSc (Hons), MA (Research Methods)

Student ID number 4311547

School of Medicine

University of Nottingham

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Abstract

Background

People with dementia over the age of 65 occupy up to one quarter of hospital beds. They stay in hospital longer and are more likely to be readmitted. Hospital admissions are likely to be deskilling in terms of activities of daily living (ADL), leading to decreased quality of life impacting both people with dementia and their carers.

Currently, there is no evidence on what occupational therapy interventions are of benefit during acute hospital admission to help people with dementia maintain or regain their ADL independence.

Methods

An occupational therapy intervention aimed at improving ADL independence for hospitalised people with dementia was developed, using the Medical Research Council framework for developing and evaluating complex interventions. A sequential transformative mixed methods approach was used. The development of this Occupational Therapy Personal Activity Programme (OcTPAP) included four studies. Firstly, a systematic literature review was completed. It assessed the effectiveness and content of occupational therapy interventions for older adults to improve ADL independence during hospital admissions. The results of the systematic review produced a list of potential OcTPAP components and informed the next study. Secondly, semi structured qualitative interviews aimed to identify potential intervention components and their context were conducted. The interviews explored the views of key stakeholders selected using purposive sampling. Thirdly, the results from the first two studies were synthesised using the triangulation protocol and organised using the template for intervention description and replication (TIDieR). The synthesised data was subjected to a Delphi consensus. Using purposive sampling, occupational therapists were recruited to refine the OcTPAP description. Patient and Public involvement was integrated throughout the research process.

Results

The systematic literature review was completed in May 2018, updated in March 2019 and identified thirteen studies. Limited evidence of the effectiveness of interventions that included occupational therapy was found, with studies reporting clinically important improvements but not statistically significant improvements in ADL independence. Potential components identified for OcTPAP were: ADL retraining and practice, assessment, goal setting, individualised therapeutic planning, carer education and involvement, equipment provision, exercises, falls prevention focus, work with cognition, social interactions, polysensory stimulation, positioning, adaptations to the hospital environment, promotion of participation, group activities and planning for after discharge.

Semi-structured interviews with Occupational therapists, Physiotherapists, nurses, geriatricians, commissioners, people with dementia, carers, a physiotherapy assistant, a healthcare assistant, a dietitian and a speech and language therapist were completed between March and June 2019. Twenty participants were interviewed, and three themes emerged: matching the need, setting expectations and promoting participation. Each theme had five subthemes that provided information about the context of and the creation of potential OcTPAP components.

Data was synthesised from the first two studies using the triangulation protocol. Forty seven themes were produced and then formed into thirty eight statements to be refined through the Delphi consensus study.

Between August 2020 and October 2020 the Delphi consensus was completed, with twenty-eight participants in round one and twenty-seven in round two. All statements have reached consensus in two rounds.

Finally, the OcTPAP description following TIDeiR guidelines was produced from the gathered evidence.

Conclusion

The next step would be the completion of the proof of concept study to test the acceptability of delivery of OcTPAP in an acute hospital setting. Research into the active components of the intervention and their effect and interaction could support the normalisation of the intervention in clinical practice. Further research into which staff groups in acute hospital may struggle to accurately assess and match the level of support provided to patients with dementia to facilitate patient's participation in ADL is needed.

Dissemination

- Lecture “Research process – a real life example” for the **University of Derby** Research Methods module to Masters level students. Derby. March 2019.
- Invited speaker at the **“Dementia Research Uncovered” Patient and Public engagement with dementia research** event. Nottingham. April 2019.
- Presented my research in lay language at the **Nottingham elderly forum**. Nottingham. April 2019.
- Invited presenter at the research meeting at the **University of Bradford**. Bradford. April 2019.
- Invited presenter at the research meeting at the **Leiden University Medical Centre**. Leiden, Netherlands. August 2019.
- Invited speaker at the **2019 British Geriatric Society Autumn Meeting**. “Promoting activities of daily living in older inpatients with frailty and dementia”. Leicester. November 2019.
- Rapid presentation at **the Council for Allied Health Professions Research conference**. "Keep doing what you are doing – staying independent whilst in hospital for people with dementia". Online. September 2020.

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Dedication

To my grandmother, memories of you will be forever with me. Your charisma, sense of purpose, inner strength and light are my compass.

Statement from Funder

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Table of Abbreviations

ADL	Activities of Daily Living
BSc	Bachelor of Science
CAHPR	Council for Allied Health Professions Research
CMOP-E	Canadian Model of Occupational Performance and Engagement
CDR	Clinical Dementia Rating
CDM	Cognitive Disabilities Model
CREDES	Conducting and Reporting Delphi Studies
COVID-19	Coronavirus Disease
DSM-5	Diagnostic and Statistical Manual of Mental Disorders
EM	East Midlands
EMRAN	East Midlands Research into Ageing Network
FIM	Functional Independence Measure
GCP	Good Clinical Practice
IADL	Instrumental Activities of Daily Living
IPA	Interpretative Phenomenological Analysis
JBI	Joanna Briggs Institute
JBI-MAStARI	Meta-Analysis of Statistics Assessment and Review Instrument
JLA	James Lind Alliance
MMR	Mixed Methods Research
MOHO	Model of Human Occupation

MRC	Medical Research Council
MSc	Master of Science
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NICE-SCIE	National Institute for Health and Care Excellence - Social Care Institute for Excellence
NIHR	National Institute for Health Research
NMAHP	Nursing, Midwifery and Allied Health Professions
OcTPAP	Occupational Therapy Personal Activity Programme
PEOP	Person-Environment-Occupation-Performance
PhD	Doctorate of Philosophy
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	Prospective Register of Systematic Reviews
RCOT SS	Royal College of Occupational Therapy Special Section
RCT	Randomised Controlled Trials
SRQR	Standards for Reporting Qualitative Research
TIDieR	Template for Intervention Description and Replication
UK	United Kingdom
WHO	World Health Organisation
WHO-ICF	World Health Organisation - International Classification of Functioning

Preface

Position of the researcher

I have been an Occupational therapist for over nine years and my aspiration to improve patient care has led to undertaking a PhD in the field that I feel so passionate about. Completing Masters in Research Methods in 2017 opened my eyes to possibilities of changing clinical practice through research and inspired me to keep looking for answers myself if they were not already available.

Working on the wards for older people in an acute hospital made me realise what an impact hospital admissions have on people's lives. Seeing people with dementia being discharged from the hospital with their health stabilised, but what appeared to be reduced abilities to do basic things for themselves was concerning. This made me question what I could do as an occupational therapist and what does the evidence suggest.

This PhD is funded through a clinical training fellowship with the Alzheimer's Society and the National Institute for Health Research Applied Research Collaborations who provided me with learning opportunities and guidance throughout. Together with the guidance from the supervisory team, they helped my ongoing development as a researcher. In addition, having a PPI (Patient and Public Involvement) collaborator was key in ensuring that the research study incorporated the person-centred focus and the care giver perspective. The position of the PPI collaborator, Kate Sartain (KS), in relation to the research study is presented in her own words.

Position of the Patient and Public Involvement Collaborator

I returned to live within fifteen miles of my parents twenty six years ago following time spent in varying parts of the UK and overseas. I am married with three children and three grandchildren. I have two siblings. I assisted in the care of my mother and father for at least twelve years, both had dementia. During this time my sister, who lives reasonably close and assisted with the care of our parents, had treatment for cancer and my husband had open heart surgery. My brother lives 120 miles distant and visited his parents relatively regularly. He also hosted short breaks, mini holidays for Mum and Dad. He was unable to do the daily support. During this time I experienced good care in the community and within the hospital setting but sadly also there were times when the care was not so good. I attended a series of workshops over an 18 months period in 2009/10 organised by the then Strategic Health Authority to develop ideas on how best to implement the then National Dementia Strategy.

Following the deaths of my parents I have given time to support the professionals who were delivering the good care in a variety of ways. I have been a member of the PPI group for Frail older people with dementia based at the Queen's Medical Centre/ University of Nottingham for seven years. I wrote an article from the carers perspective "An outstanding example of hospital care for patients with dementia" which was published in the BMJ in April 2013. I was a member of the Steering committee for the OPTIMAL project, which looked at how NHS services are best used within care homes, a co-applicant on the VOICE study, which is using conversational analysis techniques to identify good communication skills between health professionals and patients with dementia in an acute hospital. I attended with other members of the VOICE team The European Alzheimer's conference in Berlin 2017. I was on the Steering committee for the Proactive Healthcare in Care Homes (PEACH) project. I speak to year four medical students on my role as a carer. I have made positive contributions to many other research projects which are presented to the group each month. I am a lay member on the trustees for Trent

Dementia. I have addressed conferences on the role of the carer and also medical students as part of their training.

My hopes are that this research will identify good practice which will be integrated into the education and training of healthcare professionals across the board.

Kate Sartain BSc

Chapter 1 – Introduction

This introductory chapter presents the background to topics in this PhD thesis. Dementia, dementia management in an acute hospital setting, activities of daily living, occupational therapy, rehabilitation are addressed. The rationale for the research and the study's aims and objectives are then discussed. Application of mixed methods research, philosophical position of the research and the researcher are described. Then, steps taken for the development of Occupational Therapy Personal Activity Programme (OcTPAP) and the thesis structure is presented. To conclude, the impact of the coronavirus disease 2019 pandemic is explained.

1.1 Dementia

1.1.1 Defining Dementia

"Dementia" is a general term used for several diseases that affect thinking, memory, problem-solving, language, behaviour and significantly impair the ability to complete everyday activities (World Health Organisation, 2017). Dementia is not an inevitable part of ageing and may be caused by one or more underlying pathological processes (Gibson et al., 2004). Presentation and symptoms can vary depending on the type and stage of dementia (World Health Organization, 2021).

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) specifies that for a diagnosis of dementia (major neurocognitive disorder) there must be evidence of significant change in previous levels of cognitive performance in one or more of the following domains: executive function, learning and memory, complex attention, language, social cognition and perceptual-motor cognition. The symptoms must not be caused by delirium or be better explained by another mental disorder such as schizophrenia. Furthermore, there must be an impact on independence in activities of daily living (American Psychiatric Association, 2013).

The most prevalent subtype of dementia is Alzheimer's disease, followed by vascular dementia, dementia with Lewy bodies, frontotemporal dementia and other causes which are rarer (Alzheimer's Society, 2014).

1.1.2 Prevalence of Dementia

In the United Kingdom (UK), the proportion of older people in the population is growing (Office for National Statistics, 2018). By mid-2045 the numbers of people aged over 66 is projected to increase by 28% to 15.2 million, comparing to 11.9 million in mid-2020 (Office for National Statistics, 2020). The numbers of people aged over 85 is projected to nearly double to 3.1 million, comparing to 1.7 million in mid-2020 (Office for National Statistics, 2020). With age, the likelihood of experiencing complex health issues increases, and so does the risk of developing dementia (Office for National Statistics, 2018, Wittenberg et al., 2019).

Dementia is a global challenge (World Health Organisation, 2020a) and a national health and care priority (World Health Organisation, 2020a, NHS England, 2021, Department of Health, 2011). Around 50 million people in the world have dementia (World Health Organisation, 2020a). In 2019 there was an estimated 885,000 older people with dementia in the UK, which is predicted to increase to 1.6 million in 2040 (Wittenberg et al., 2019). NHS Digital (2021) reports that over 60% of people aged 65 or over had a recorded diagnosis of dementia in 2021, with many still undiagnosed.

1.1.3 Cost of Dementia

The rising number of people with dementia is reflected in rising costs of care which impacts the health and social care system as well as individuals (Wittenberg et al., 2019). In 2019, total costs of dementia in the UK were estimated at £34.7 billion (Wittenberg et al., 2019). Social care costs account for 45% of these costs, unpaid care for 40% and health care for 14% (Wittenberg et al., 2019). The cost of dementia care is predicted to increase to £94.1 billion in 2040 (Wittenberg et al.,

2019). The family and carers of people with dementia may be affected by the physical, emotional and financial pressures (Chenoweth et al., 2016).

1.1.4 Symptoms of Dementia

A number of changes contribute to the loss of ability and independence for people with dementia, which could be thought of as cognitive and non-cognitive. The former could include memory impairment, difficulties with functioning in new environments, receptive and expressive dysphasia, apraxia, agnosia, and concentration (Gibson et al., 2004). Memory impairment is one of the symptoms of dementia (American Psychiatric Association, 2013). Dementia at the early stages often presents as difficulties with registering and retaining new information while being able to keep intact the habits and skills that were practised over decades (Gibson et al., 2004). The person with dementia's ability to make sense of the environment may also deteriorate, making it more challenging to function in new places or following unfamiliar routines, such as when going on holidays. Some people with dementia may have difficulties with language, such as being unable to understand words or struggle to find the words to express themselves (receptive and expressive dysphasia) (Adams et al., 2003). There may be issues with initiating activities (apraxia) or recognising objects, persons or sounds (agnosia) (Adams et al., 2003). The ability to concentrate may be affected, which could, for example, make it more difficult to complete lengthy tasks or practice newly learnt activities (Gibson et al., 2004).

Non-cognitive symptoms of dementia include difficulties with self-motivation, drive, insight, mood control (Gibson et al., 2004). Less commonly, people with dementia may experience illusions and hallucinations, disinhibition, change of sleeping rhythm and appetite (Downs and Bowers, 2014). Having less initiative and self-motivation has a profound impact on a person's daily functioning (Gibson et al., 2004). In addition, experiencing failure when attempting previously possible tasks could further diminish drive for people with dementia. This could result in further loss of confidence, loss of pleasure and self-deprecation (Gibson et al., 2004).

1.1.5 Dementia Severity

Dementia ranges in severity and the speed with which dementia progresses differs from person to person. The Clinical Dementia Rating Scale (CDR) takes into account judgement and problem-solving, memory, orientation, personal care, community affairs, home and hobbies. It suggests five stages: no impairment, questionable or very mild dementia, mild, moderate and severe dementia (de Waal et al., 2013).

The research presented in this thesis focuses on people with mild to moderate dementia, but all stages are described below.

The scale starts at “no impairment” which is described in CDR as the person having no memory issues or displaying inconsistent forgetfulness while being fully oriented. The person would be functioning independently both in community affairs and self-care also maintaining previous hobbies and interests. They would retain good judgement of past performance and solve everyday problems well (Morris, 1993).

In CDR, mild dementia is characterised by moderate difficulty in problem-solving, with social judgement usually still being intact. The person would experience moderate memory loss, which interferes with daily activities and is pertinent more so to the recent events. There is moderate difficulty with orientation to time, but the person is still able to orient to the place where they are. Prompts are needed with personal care, and the person has difficulties with functioning independently in community activities but appears normal to superficial inspection. Abandonment of more complicated hobbies and interests, as well as difficult home tasks, is apparent (Morris, 1993).

CDR characterises moderate dementia by the person having severely impaired problem solving, impairment of social judgement, and severe memory loss with the person only retaining highly learnt material and new material being rapidly lost. There is severe difficulty with orientation, need for assistance with personal care, and other activities of daily living. Only the ability to complete simple house tasks is retained. The person has limited hobbies, but the person still appears well enough to go to events outside of their own home (Morris, 1993)

Severe dementia is distinguished by severe memory loss, being unable to problem solve and make judgements, being too unwell to be taken to community activities and being oriented to only oneself and significant others. In terms of hobbies and house tasks, no significant function is observed with the person needing significant assistance with personal care (Morris, 1993).

1.2 Dementia Management in Acute Hospital Setting

1.2.1 National Dementia Strategy and Guidance

Improving the lives of people with dementia and their carers is at the forefront of political and policy developments (Department of Health, 2009b, Department of Health, 2015). Building the NHS of the Five Year Forward View lists improving quality of care and access to mental health and dementia services as one of the ten priorities (NHS England, 2015). The need to specifically improve hospital care for people with dementia is emphasised in the National Dementia Strategy and The Prime Minister's Challenge on Dementia 2020 (Department of Health, 2009b, Department of Health, 2015).

1.2.2 Acute Hospital Setting

National Health Service (NHS) provides comprehensive health service to the UK public and consists of primary care, secondary care, tertiary care and community health (NHS Digital, 2022). Primary care serves as "first point of contact" and comprises of general practice, optometry, dentistry and community pharmacy (NHS, 2022b). Tertiary care is composed of highly specialist services which require a referral, such as neurosurgery (NHS Providers, 2022). Community health includes services such as district nursing and child health services (NHS Digital, 2022). NHS secondary care services are often based in a hospital or a clinic, but some are based in community and provide planned or elective care. Urgent and emergency care, such as treatment after a fall or acute medical event, are also secondary care services (NHS Digital, 2022). The acute hospital setting is a branch of secondary care

where patients are treated for a brief but severe episode of illness caused by trauma or disease and during recovery from surgery (Northern Devon Healthcare NHS Trust, 2017, The Health Foundation, 2021).

Currently, people with dementia over the age of 65 occupy up to one-quarter of hospital beds (Dementia Statistics Hub, 2018, NHS England, 2015) and account for around 3.2 million bed days a year (Alzheimer's Society, 2016). While there is a drive to increase the services provided outside of hospitals, there is a consensus among experts that cutting the number of available hospital beds is not a realistic prospect in the near future (The King's Fund, 2015). Complex needs and cognitive impairment may result in lengthier assessment and recovery periods for people with dementia (Public Health England, 2015, Handley et al., 2017). In 2009 Sampson et al. in a longitudinal cohort study of 617 people found that people over 70 who have dementia account for 42% of the unplanned admissions to an acute hospital (Sampson et al., 2009). A more recent analysis of NHS data in 2017-2018 found a substantial increase of emergency admissions for people with dementia from 279 265 in 2012-2013 to 379,004 (Alzheimer's Society, 2020). Despite having increasingly integrated service models, people with dementia are still likely to need hospital services.

People with dementia tend to be older and have more complex health needs associated with underlying comorbidities (Handley et al., 2017). A survey conducted by the Alzheimer's Society (2014) found that 72% of people with dementia who responded had another medical disability or condition, however the number of the survey participants were not reported. It must be noted that having co-morbidities could make the care of people with dementia more complex.

1.2.3 Quality of Dementia Care in Hospitals

In 2009 the "Counting the Cost" report found considerable variation in the quality of dementia care in UK hospitals (Alzheimer's Society, 2009). In 2017, hospitals across England and Wales in the National Audit of Dementia demonstrated progress with continuing to implement many of the changes required to support

dementia care. Specifically, there have been improvements made at the organisational level, yet these do not always translate into enhancements in dementia care (Royal College of Psychiatrists, 2017). Out of the 199 hospitals, 61% reported having a dementia care pathway or bundle, comparing to 36% in 2012-2013 (Royal College of Psychiatrists, 2013). At ward level almost all of hospitals, 186 out of 199 had dementia champions. Care was rated highly by just under 70% of carers, but staff highlighted the need for additional support, more so out of hours. Less than a quarter of staff reported specialist dementia support was available always or most of the time (Royal College of Psychiatrists, 2017).

An updated report in 2019 found that some further care improvements have been made (Royal College of Psychiatrists, 2019a). For example, 10% of NHS staff in 2019 compared to 17% in 2017 said they had not received dementia training. The report also found that 66% of staff felt encouraged to accommodate the individual needs of people with dementia, compared to 61% in the previous report (Royal College of Psychiatrists, 2019a). However, this indicates that a large proportion of staff still feel they are unable to provide individualised care to people with dementia. One of the suggestions the report made was to improve gathering personal information about factors that may cause distress to the person with dementia and what usually helps in these situations (Royal College of Psychiatrists, 2019a).The report also recommended that people with dementia admitted as an emergency have a delirium assessment (Royal College of Psychiatrists, 2019a).

1.2.4 Impact of Hospital Admissions on Activities of Daily Living Independence

For all older adults, hospital admissions are likely to negatively impact their independence. Covinsky et al. (2003) found that 35% of older hospitalised patients were independent in fewer ADL at discharge than at their baseline. Furthermore, Boyd et al. (2008) found that less than a third of patients over 70 years who were discharged with new or additional ADL disability recovered to their baseline

function by 12 months after hospital discharge. Moreover, 41.3% of these died, and 28.6% did not return to the previous level of function (Boyd et al., 2008).

Similarly, a survey of carers of people with dementia found that 54% reported a decline in independence of people with dementia after leaving the hospital compared to their normal function (Alzheimer's Society, 2009). Just under a half of carers also reported that hospital stays had a negative impact on the general physical health of the person with dementia unrelated to the medical condition (Alzheimer's Society, 2009). The ability to recover ADL functioning in the acutely ill older people during hospitalisation is a predictor of 6-month survival (Soria et al., 2013). ADL are defined later in this chapter.

A combination of intrinsic and extrinsic factors are considered to be associated with the decline in independence with daily tasks. Intrinsic factors include but are not limited to the presence of co-morbidities, age, values and beliefs. Extrinsic factors could include care processes or environmental conditions. (Boltz et al., 2012).

Having cognitive impairment means that people with dementia have difficulties learning new skills or relearning the ones which are not used daily (Waite et al., 2008). Boyd et al. (2008) found that from the patients who were discharged at their normal ADL independence level, 67% maintained that level of function after 12 months from discharge. While this research was not specific to people with dementia, it highlights the potential long term impact of retaining ADL independence on discharge from hospital.

1.2.5 Reasons for Admission and Transfer Delays

Even though people are not usually admitted to acute hospitals for dementia, it is the coexistence of this condition that can significantly complicate patient care and increase the rates of adverse outcomes such as institutionalisation (Draper et al., 2011). The Alzheimer's Society (2009) reports that common reasons for hospital admission of people with dementia include urinary tract and respiratory infections, falls, hip fractures or stroke. People with dementia have longer hospital stays and

are more likely to be readmitted (Care Quality Commission, 2013, Alzheimer's Society, 2020).

Delays in being discharged from hospital care have also been identified as a recurring issue. An audit of UK and Australian acute hospitals found that 23% of inpatients did not meet the criteria for remaining in hospital, with 40% of these being related to rehabilitation needs (Reid et al., 2015). A delayed transfer of care summary report from 2010-2017 demonstrated that numbers of "awaiting further non-acute NHS care", which refers to rehabilitation, are consistently high (NHS England, 2017). For example, in March 2017, it accounted for 16% of delayed discharges. This highlights the need to focus on prevention of decline of function where possible, which may help reduce the need for further rehabilitation on discharge from an acute hospital. Rehabilitation is defined in section 1.5 of this chapter.

1.2.6 Outcomes of Hospital Admissions for People with Dementia

Hospital admissions for people with dementia can be an especially challenging experience. Having dementia was found to be significantly associated with having adverse events in an acute hospital, such as falls (Watkin et al., 2012, Mukadam and Sampson, 2011). Moreover, people with dementia are more likely to get readmitted to hospital than people without dementia, 25% in comparison to 17% (Dementia Statistics Hub, 2018). Over one-third of people with dementia who have an unplanned hospital admission are discharged to a different residence (Dementia Statistics Hub, 2018, Alzheimer's Society, 2016), which is very significant to a person who has dementia and their families.

Having dementia was found to be an independent risk factor for increased length of hospital stay (Holmes and House, 2000, King et al., 2006). A systematic literature review found that having dementia significantly increased the length of hospital admission by 6-30 days (Mukadam and Sampson, 2011). More recently, Möllers et al. (2019), in a literature review, found that people with dementia have longer hospital stays, with Alzheimer's Society (2016) reporting that, on average, the

length of hospital stays was twice as long as other older adults. Having longer hospital stays is likely to exacerbate the decline in independence, and may increase the need for rehabilitation (Alzheimer's Society, 2009, Boyd et al., 2008).

Public Health England (2015) reported that for an unplanned admission in 2012/2013, the median length of stay in hospital for people with dementia was six days. An analysis by the Alzheimer's Society (2020) reported mean length of stay for people with dementia in hospital has increased to 11.4 days in 2017/2018. Only 26% of the unplanned admissions were short hospital stays for a day or less (Dementia Statistics Hub, 2018). Alzheimer's Society (2020) estimate that more than half of people with dementia diagnosis were admitted to hospital in 2017/2018. There is a drive to reduce avoidable and unnecessary admission (NICE, 2022). However, improvements in care and attention to maintenance of independence would still be needed for the remaining numbers of people with dementia being admitted to hospitals.

1.2.7 Care Complexity for Hospitalised People with Dementia

For people with dementia, hospital admissions are challenging. In addition to existing co-morbidities and the injury or illness they were admitted with, the loss of a familiar routine and surroundings, and a busy hospital environment can aggravate dementia symptoms and increase the risk of delirium (Royal College of Psychiatrists, 2017). Issues with the physical environment, physical health, social environment and mental health all contribute to the complexity of both needed care for hospitalised people with dementia and care delivery.

Public Health England (2015) warns about the potential negative impact of the changes to daily routines and the disorientation due to changing of the living environment. Having dementia may exacerbate the perceptual and visuospatial problems that are associated with older age leading to distress, increased confusion and agitation (Waller and Masterson, 2015). Transfers between wards, lack of familiarity and clear signage, noise, bright lights, having a urinary catheter or intravenous lines could negatively impact the experience of people with dementia

during hospital admissions (Downs and Bowers, 2014). The physical environment significantly impacts physical and psychological wellbeing (Waller and Masterson, 2015). National Dementia Action Alliance (2020) recommends that hospitals create an environment that is supportive and comfortable, promotes safety, wellbeing and independence.

It can be challenging for hospitals to provide high-quality care for people with dementia as hospitals are risk-averse environments that are task-oriented and efficiency-focused (Graham, 2015). Patients' physical health also plays a role. The patients may be considerably more dependent on staff for the provision of care than typically because of the acute illness they got admitted to hospital with (Goldberg et al., 2012). In addition to any sensory deficits, the patients may be constipated, have urinary retention, have issues with skin integrity, have poor food and fluid intake and have difficulties expressing pain or communicating needs (Downs and Bowers, 2014). Having dementia is also a risk factor for falls, use of restraints and non-adherence with therapy (Lyons and Landefeld, 2010).

Issues with the social environment too contribute to making care for people with dementia more complex. Having infrequent interactions with staff, or being cared for by a different member of staff every day, or lack of family involvement, or lack of communication or discussion about goals for the admission can impact the person's wellbeing (Downs and Bowers, 2014).

Cognitive deterioration, the feeling of loneliness and staff's inability to address the patient's cognitive needs can contribute to the emotional distress for hospitalised people with dementia. People with dementia may require more nursing staff time than other patients due to behaviours that staff working in a busy environment may find challenging (Downs and Bowers, 2014). More than half of older people admitted to an acute hospital will have or will develop a mental health disorder, such as delirium, depression and dementia during their admission (The Royal College of Psychiatrists, 2005).

Distinguishing delirium and dementia symptoms may be challenging for inexperienced clinicians (Lippmann and Perugula, 2016). Delirium is a change in a

person's mental health with sudden onset and is characterised by severe confusion (Ravdin and Katzen, 2012). Delirium is usually caused by a temporary and reversible physical or mental illness (Ravdin and Katzen, 2012). Being easily distracted, difficulties with focusing, disorganised thinking or an altered level of consciousness are some of the potential presentations of delirium (Sandhaus et al., 2006). Older adults are especially vulnerable to developing delirium, with up to 60% of these in hospital experiencing it (Sandhaus et al., 2006). Having dementia and length of hospital stay are significantly associated with developing delirium, and so are illness severity, visual impairment, urinary catheterisation and low albumin level (Ahmed et al., 2014). Therefore, many of those with dementia in hospitals have complications from delirium, adding to their already complex care needs. Both delirium and dementia have an impact on the person's ability to continue with their daily activities (Weng et al., 2019).

1.3 Activities of Daily Living and Occupational Therapy

1.3.1 Definitions

As the research in this thesis focuses on how people with dementia manage their activities of daily living (ADL) and how occupational therapy may impact on ADL, definitions are given below.

Activities of daily living are routine activities that people tend to do every day. These include eating/swallowing, feeding, toileting and toilet hygiene, bathing, showering, dressing, functional mobility, sexual activity and personal hygiene and grooming (American Occupational Therapy Association, 2020, American Occupational Therapy Association, 2014). ADL are necessary for independently caring for oneself (Jacobs and Macrae, 2017).

Occupational therapy is a health and care profession that uses a "whole person approach" to both physical and mental health and utilises therapeutic use of everyday life occupations to help people overcome the effects of disability (American Occupational Therapy Association, 2020, The Royal College of Occupational Therapists, 2019). It "*provides practical support to empower people to*

facilitate recovery and overcome barriers preventing them from doing the activities (or occupations) that matter to them"(The Royal College of Occupational Therapists, 2019). Occupational therapists work in a variety of settings and with people of all ages. Occupational therapy philosophy of wholeness and individuality is in keeping with principles of person-centred care and dementia care principles (Gibson et al., 2004).

1.3.2 Occupational Therapists' Core Skills

Therapeutic use of occupation is central to the profession (American Occupational Therapy Association, 2020). Performance analysis, functional activity analysis, teaching and coaching skills, environmental analysis skills are among the core skills of occupational therapists (College of Occupational Therapists, 2016). Working with ADL is well established in occupational therapy. It is in line with its knowledge and expertise as well as its core values and beliefs (Curtin et al., 2009, WFOT, 2021). The use of graded activity in rehabilitation in specialities such as stroke and orthopaedics is well recognised and established. The potential of applying these skills as part of regular practice in dementia care is yet to be fully explored (Gibson et al., 2004).

1.3.3 Activities of Daily Living in Occupational Therapy

"Activities of daily living" is seen as one of the categories that occupations fall into, as detailed in the Occupational Therapy Practice Framework (American Occupational Therapy Association, 2020). The other categories of occupations are instrumental activities of daily living (IADL), work, education, play, leisure, health management, rest and sleep, and social participation (American Occupational Therapy Association, 2020). For example, preparing a meal would fall under IADL and eating a meal would be an ADL.

From the occupational therapy perspective, there is a difference between the concept of "activities" and "occupations". Occupation is defined as "*personalised*

and meaningful engagement in daily life events by a specific client" when "activity" is "*a form of action that is objective and not related to a specific client's engagement or context*" (American Occupational Therapy Association, 2020) p.7. Curtin et al. (2009) warn against narrowing the focus to activities of daily living or functional independence as the ultimate goals of occupational therapy rather than being occupation-focused. Occupation is a complex concept, and focusing on a narrower perspective may lead to overlooking the larger picture (Curtin et al., 2009). And therefore, even when focusing on the completion of a specific activity with an individual, the concept of enabling occupation must be central to the practices of occupational therapists.

1.3.4 Reasons for Selecting Activities of Daily Living

Dependence in ADL has a negative impact on the quality of life of people with dementia (Giebel et al., 2015). It also restricts their choices about the future and has an adverse effect on relationships (Heath et al., 2010). Moreover, the more severe the functional decline of their relative, the more the carers feel distressed and burdened (Giebel et al., 2015). Identifying the most effective components of care that keep people with dementia independent is the first of the top ten priorities identified by the James Lind Alliance for dementia (James Lind Alliance, 2021). Engaging in ADL tasks is a way of facilitating independence (Creek, 2010).

Postponing the decline of ADL independence in hospitalised people with dementia is of importance for individuals and society. The use of an evidence-based intervention that aims to maintain the ADL skills of people with dementia while in hospital may promote patient and carer-centred care and has the potential to improve patient outcomes. Helping people with dementia remain as independent as possible may limit the number of days spent in hospital, promote community discharges, reduce readmissions, therefore decreasing the pressure on the hospital resources and reducing or delaying the need for social care (Department of Health, 2009b, House of Commons, 2011). Currently, there is a lack of information about

the most clinically and cost-effective interventions to help people with dementia retain ADL independence in a hospital setting (Patrick, 2017).

1.4 Rehabilitation

1.4.1 Definition

In the World Health Organisation global action plan, rehabilitation is one of the core recommendations for care for people with dementia (World Health Organisation, 2017). Rehabilitation can be defined as "*a set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments*" (World Health Organisation, 2011) p.96. Rehabilitation comprises of problems and needs identification, linking the problems with the personal and environmental factors, setting rehabilitation goals, planning and implementing the solutions and assessing the effects (World Health Organisation, 2011). Rehabilitation aims to reduce the activity and participation limitations resulting from the impairment or disease and maximise function (WHO, 1981). According to an evidence-based description of effective rehabilitation by Wade (2020) rehabilitation may benefit anyone with a long term disabling condition at any stage and can be delivered in any setting.

It is important to acknowledge the differences between terms “rehabilitation” and “reablement”. Reablement has common features with rehabilitation, such as emphasis on improving independence by maximising the person’s intrinsic capacity and modifying the environment (Poulos et al., 2017). However, “reablement” usually refers to a specific service model of intermediate care (NICE, 2017). Other intermediate care service models are bed-based intermediate care, crisis response and home-based intermediate care (NICE, 2017). According to NICE guidelines reablement is usually provided in person’s own place of residence and lasts up to six weeks (NICE, 2017). Reablement may be used to prevent readmission to an acute hospital, enable them to continue living at home or support discharge from hospital (SCIE, 2020).

1.4.2 Rehabilitation as a Complex Intervention

Rehabilitation is a complex healthcare intervention as it has several interacting components (Wade, 2020). For example, rehabilitation can involve a number of healthcare professionals, has to be tailored to the individuals and differing admissions durations and is influenced by the behaviours of those delivering and receiving it (Medical Research Council, 2006).

Restorative or adaptive approaches to rehabilitation can be implemented. Restorative rehabilitation would often include interventions aimed at conditions that improve, for example, stroke (Gladman, 2008). Dementia is a progressive condition therefore adaptive rehabilitation may be more appropriate as it aims to optimise health in the face of residual or progressive impairment (Gladman, 2008, Alzheimer's Society, 2014).

1.4.3 Rehabilitation for Older People

The provision of adequate rehabilitation and re-ablement to "*prevent permanent disability, greater reliance on care and support, avoidable admissions to hospital, delayed discharge from hospital*" is cited as key in meeting the needs of older people and managing frailty (Oliver et al., 2014) p.38. While in the UK the emphasis is on the provision of rehabilitation outside of the hospital, it is acknowledged that the acute hospitals must play their part and ensure adequate inpatient rehabilitation (Oliver et al., 2014). Patients' functional ability post hospital discharge is closely related to the functional ability at discharge, which highlights the importance of rehabilitation during hospital admissions (Badriah et al., 2013).

There is evidence that inpatient rehabilitation specifically designed for older patients has the potential to improve function, decrease mortality and admissions to nursing homes (Bachmann et al., 2010). A systematic literature review of the evidence for the provision of rehabilitation for older adults during hospital admissions is presented in Chapter 2. Many studies of rehabilitation programmes for older people still exclude people with dementia, which makes addressing the needs of this population even more important (Taylor et al., 2012).

1.4.4 Rehabilitation for People with Dementia

There is evidence of benefit of rehabilitation for people with conditions with "natural recovery" in the acute phase of disorders of sudden onset (Wade, 2020) such as stroke (Langhorne et al., 2002), traumatic brain injury (Turner-Stokes et al., 2015), hip fracture (Nordström et al., 2018) and episodes of coronary artery disease (Anderson and Taylor, 2014). However, there is also evidence for benefits of rehabilitation for conditions such as spinal cord injury where there is no "natural recovery" expected (Donovan, 2007, Silver, 2005). In addition, rehabilitation has shown to be effective for progressive conditions such as osteoarthritis (Hurley et al., 2018) and Parkinson's disease (Ferrazzoli et al., 2018). There is also some evidence of the effectiveness of multidisciplinary rehabilitation programmes for neuropsychiatric symptoms, depression, and quality of life for people with dementia (Madureira et al., 2018).

The National Institute for Health and Care Excellence (NICE, 2018) guidelines for dementia advise that promotion and maintenance of independence and minimising the need for support is needed. Yet, rehabilitation is not routinely offered to people with dementia (Laver et al., 2020, Department of Health, 2003). A consensus study of 201 dementia experts also found that maintaining functional independence is one of the most important research priorities in the field (Shah et al., 2016).

A variety of rehabilitation approaches for people with dementia are described in the literature. A review of rehabilitative interventions for people with dementia found that most of the interventions were person-centred, in line with other rehabilitation for older people literature (Ravn et al., 2019). Principles of person centred care are described in detail in Chapter 4. Ravn et al. (2019) also found that nine out of 26 of the included studies described home-based interventions with a multidisciplinary approach being used in 14 studies. Multidisciplinary approach in this thesis is defined as a group of healthcare professionals from different disciplines working together and drawing on relevant skills to better understand complex situations and find solutions (NHS England, 2014).

NICE-SCIE guidelines for supporting people with dementia identified a number of interventions and strategies designed to enhance and increase functioning (National Collaborating Centre for Mental Health, 2007). The interventions were communication, ADL skill training, activity planning, assistive technology, adaptive aids, environmental modifications, telecare, exercise and promotion of mobility, rehabilitation, and a combination of interventions. However, there is no intervention specifically designed to help people with dementia maintain or improve ADL independence during hospital admissions.

Boltz et al. (2014) reported developing a family-centred intervention for hospitalised older people based around ideas of function-focused care. This study used comparative repeated measures design, with one hospital ward receiving the intervention and two wards serving as control groups. The study was not specific to people with dementia but reported that 52% of the sample presented with cognitive impairment on admission. Boltz et al. (2014) found improved ADL performance for intervention group participants, the number of patients who returned to their ADL baseline was significantly higher in the intervention group. No significant differences were found in average hospital length of stay or use of post-acute rehabilitation services or being transferred to a nursing home. Modest treatment effect on the number of 30-day hospital readmissions was stated. No occupational therapy input was reported. In 2018, the same research group has applied the same approach to hospital care of older people to hospitalised people with Alzheimer's disease and related dementias, according to the cluster-randomized controlled trial protocol (Boltz et al., 2018). This protocol was published in September 2018, after this PhD study had started (October 2017) and the results are not yet published. The intervention description does not specify occupational therapy input (Boltz et al., 2018). The research study reported in this thesis details an intervention specifically designed for people who have dementia and are admitted to an acute hospital from occupational therapy perspective.

While not specific to acute hospitals, there is evidence that non-pharmacological interventions such as cognitive rehabilitation, exercise and occupational therapy can help reduce functional and cognitive decline (Laver et al., 2016, Bahar-Fuchs et

al., 2018). Clinical guidelines suggest that rehabilitation programmes for people with dementia should use core principles of good rehabilitation programmes but be modified to account for cognitive, perceptual and mood peculiarities (National Collaborating Centre for Mental Health, 2007).

Gibson et al. (2004) suggest that teamwork, involving families and other support structures, adaptations and modifications, learning and motivation and removing excess causes of disability are key components of rehabilitation for people with dementia. When interviewed for a study, people with dementia and their carers agreed that rehabilitation for people with dementia should be individualised, emphasise the person's strengths and capabilities and promote quality of life throughout the progression of the condition (Laver et al., 2020). Better patient care could be achieved by acknowledging the multiple abilities as well as the needs of people with dementia and promotion of re-enablement and rehabilitation to achieve the patients' individual potential (Department of Health, 2010).

1.4.5 Place of Occupational Therapy in Dementia Care and Rehabilitation

NICE guidelines recommend the provision of occupational therapy to people with mild to moderate dementia to support functional ability (NICE, 2018).

A systematic review found that occupational therapy provided at home was effective in improving ADL and a number of behavioural and psychological symptoms as well as the quality of life for people with dementia (Bennett et al., 2019). There is also evidence for occupational therapy home interventions having a positive impact on how competent the caregivers feel (Graff et al., 2006) and reducing caregiver burden (Gitlin et al., 2005).

Cuevas-Lara et al. (2019) systematic review reported that occupational therapy intervention groups had higher ADL function scores but advised that there was limited evidence to conclude whether occupational therapy programmes for older hospitalised people were effective for improving ADL independence. However, they found that one of the occupational therapy interventions significantly reduced delirium and improved cognitive function (Cuevas-Lara et al., 2019). It must be

noted that this review was not specific to people with dementia. Another systematic review of occupational therapy interventions specifically reviewed evidence for adults with Alzheimer's disease (AD) and related neurocognitive disorders (Smallfield and Heckenlaible, 2017). They reported that there was strong evidence for occupation-based interventions, physical exercise, and error-reduction learning for enhancing occupational performance (Smallfield and Heckenlaible, 2017). Smallfield and Heckenlaible (2017) reviewed interventions from different settings, and it must noted that occupational therapists face certain challenges when working within an acute setting irrespectively of the speciality or patient group (Britton et al., 2015). For example, a scoping review reported misunderstanding of the nature of the occupational therapists' role and the value of occupational therapy in the acute setting (Britton et al., 2015).

1.5 Aims and Objectives of This Research Study

This introduction chapter highlights that people who have dementia who are admitted to an acute UK hospital due to a medical condition may not receive the care needed for them to maintain their independence in activities of daily living.

The primary aim of this research study was to develop an occupational therapy rehabilitation intervention for people with dementia that would be delivered in an acute hospital setting, Occupational Therapy Personal Activity Programme (OcTPAP).

The objectives of this research study were:

1. To review the effectiveness of occupational therapy rehabilitation interventions on independence in activities of daily living for older patients during hospital admissions.
2. To identify and describe the content of the occupational therapy component of the interventions aimed at independence in activities of daily living for older patients during hospital admissions.

3. To explore the opinions of key stakeholders on the essential components of the OcTPAP, aimed at independence in activities of daily living for older patients with dementia during hospital admissions and the context for this intervention.
4. To articulate OcTPAP's mechanism of action
5. To synthesise the gathered data on the content of the interventions and the essential components of the OcTPAP.
6. To refine the list of potential OcTPAP components.
7. To produce a rehabilitation intervention description.

1.6 Mixed Methods Research

Mixed methods research (MMR) combines quantitative and qualitative data collection and analysis in a single study (Creswell et al., 2004). Mixed methods research has philosophical assumptions and not just methods of inquiry. The underlying principle of mixed method research is that integrating qualitative and quantitative approaches results in a more full understanding of the research problem comparing to using only one of either of these approaches (Creswell and Plano-Clark, 2017). To address the research question in this thesis, a sequential transformative mixed methods approach was used (Creswell and Poth, 2016, Creswell, 2003). Sequential transformative MMR design is characterised by the collection and analysis of one data type first (quantitative or qualitative) first, then followed by the other data collection. The findings are integrated in the interpretation phase (Creswell, 2003).

There is still some debate on whether qualitative and quantitative methods are compatible due to their ontological and epistemological differences, but MMR is mostly accepted and commonly used in health sciences (Regnault et al., 2018). Health services research often involves analysis of multidimensional, complex processes and systems (Creswell et al., 2004). Qualitative methodologies are traditionally used for the research questions concerned with why and how a phenomenon occurs and to describe individuals' experience (Fetters and

Freshwater, 2015). To answer research questions that investigate causality, magnitude of effects and generalisability it is the quantitative methodologies are used in health services (Fetters and Freshwater, 2015). MMR is able to draw upon the strengths of both approaches and register various aspects of the same phenomena and lead to new insights (O'Cathain et al., 2007). This allows a broader and deeper understanding makes it appealing to healthcare researchers (Doyle et al., 2016). A pragmatic approach where the research question guides the choice of methodology and not the other way around is well suited to mixed methods research (O'Cathain et al., 2007).

1.7 The Philosophical Position of the Research and the Researcher

Even if not acknowledged by the researcher, all research is underpinned by a philosophical approach. There is a close link between the choice method, methodology and philosophical approach used to address a research question (Grix, 2018). The research was completed from a pragmatism stance as it aligned with the research aims and MRC framework for the development of complex interventions (Medical Research Council, 2006).

Pragmatism advocates selecting methodological approach that best suits the research question. Pragmatic epistemology was adopted for this study as it emphasises the validity and forms of justification as the real epistemological concerns of empirical inquiry (Avis, 2003). Pragmatism considers knowledge as only meaningful when coupled with action. Focus on applied research and valuing different forms of knowledge makes pragmatism suitable when developing an implementable healthcare intervention (Talisse and Aikin, 2008).

1.8 Steps Taken to Develop the Intervention

Rigorous and transparent intervention development is vital prior to proceeding to a definitive clinical trial to avoid potentially effective intervention being rejected as

inefficacious (Richards and Hallberg, 2015). The Medical Research Council (MRC) framework for developing and evaluating complex interventions was used (Medical Research Council, 2006). This research was started under the MRC guidance from 2006 (Craig et al., 2008), the new guidance came out in 2021 (Skivington et al., 2021) and was not applied to the study but is addressed in Chapter 6.

MRC framework recommends identifying evidence base, identifying or developing appropriate theory and modelling the process and outcomes as the three stages of developing a complex intervention (Medical Research Council, 2006). Therefore, to build the OcTPAP, an evidence-based complex intervention, the following steps were taken:

(1) Review and assessment of best practice evidence and identification of potential OcTPAP components through a systematic literature review (Chapter 2).

(2) Identification of potential intervention components, their context and context for the OcTPAP through qualitative interviews with stakeholders (Chapter 3).

(3) Theory and proposed mechanism of action development (Chapter 4)

(4) Synthesis of the systematic review and interviews findings, intervention modelling, for the OcTPAP (Chapter 4).

(5) Getting consensus on essential OcTPAP components through a Delphi study (Chapter 5)

(6) Producing OcTPAP description (Chapter 6)

1.9 Thesis Structure

This thesis comprises of four studies, the completion of which resulted in the production of the OcTPAP as per the research aim. The studies included a systematic literature review, qualitative interviews, intervention modelling and Delphi consensus. An overview of the methods used in each component of the research study is presented in Figure 1. The rationale for the choice of these methods is detailed in the subsequent chapters.

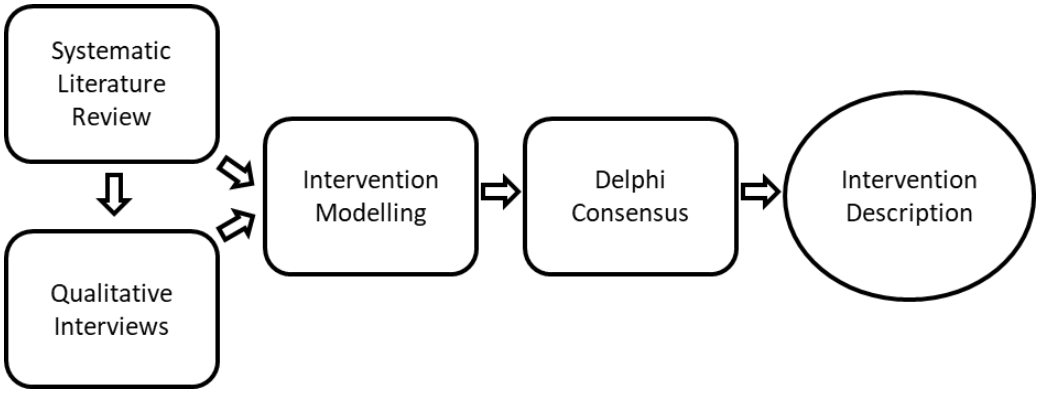

Figure 1 - Research Study Components

1.10 Coronavirus Disease Pandemic and its Overall Impact

In January 2020, the first two patients tested positive for Coronavirus disease (COVID-19) in the UK (The British Foreign Policy Group, 2021). Coronavirus disease is a highly infectious disease symptoms of which may include high temperature, cough, tiredness and loss of taste or smell. Older people and people with underlying medical conditions are more likely to experience more severe symptoms, for example difficulty breathing and become seriously ill (World Health Organisation, 2021). It has been characterised as a pandemic, and in only a few months of first reports in China the disease has spread to nearly all countries in the world (World Health Organisation, 2020b). In January 2020, WHO declared a global health emergency (The British Foreign Policy Group, 2021). To date, the pandemic in the UK had a tremendous impact on people's lives, health and wellbeing, with many lives lost. The healthcare system and the socio-economic situation in the country as also impacted.

Since the start of the pandemic, the UK government has introduced a number of rules and restrictions related to COVID-19, with some eased, and some reintroduced later. For example, in March 2020 government introduced a lockdown banning all non-essential travel and contact with other people, requiring people to stay at home and work from home if appropriate. This lockdown was then eased with various conditions in place, and then another lockdown came into force in November 2020 (Institute for Government analysis, 2021). Most COVID-19

consequences are still unknown, with governments still planning their approach to stabilise the situation despite the invention and roll out of vaccines.

Healthcare also had to rapidly adapt in response to increased demand for critical care. Non-urgent care was suspended, quality improvement projects and audits were paused, and staff were redeployed (Royal College of Psychiatrists, 2021). The National Audit of Dementia examined the effect of the pandemic on hospital care for people with dementia by contacting hospital dementia leads and carers (Royal College of Psychiatrists, 2021). It found that almost half of dementia strategy plans and projects were suspended. Just over a quarter of dementia strategies were updated or created due to the pandemic. The pandemic also has impacted the carers, with 90% reporting that they were not allowed to visit the person with dementia they cared for in hospital. There were some reports of more efficient discharge procedures reducing length of stay and reports of using technology and liaison teams to communicate with carers.

The last component of this research study, the Delphi consensus, was completed August-October 2020. As planned, it was completed remotely, but it was aimed at occupational therapists working in the healthcare system, which was still dealing with the crisis imposed by the COVID-19. The potential impact of this on recruitment or study results will be discussed in Chapter 5. Research conclusions in light of the COVID-19 pandemic will be discussed in more detail in Chapter 6.

Chapter 2 - A Systematic Review of the Effectiveness and Content of Occupational Therapy Rehabilitation Programmes for Older Hospitalised Patients

This chapter begins with exploring the rationale for the choice of method to review literature. Then a systematic literature review of the effectiveness and content of occupational therapy programmes to improve activities of daily living independence for older hospitalised patients, and its results are described (Figure 2).The findings in relation to existing literature are discussed.

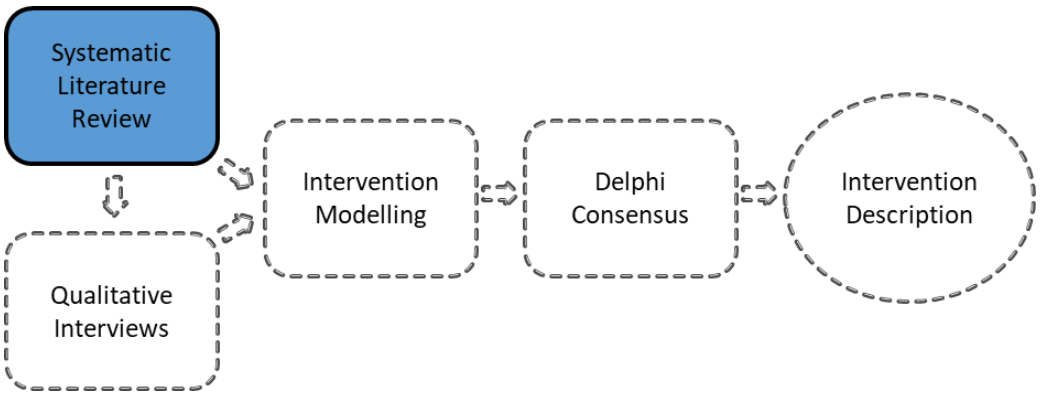

Figure 2 - Research Study Components - Systematic Literature Review

2.1 Rationale

2.1.1 Review type

Methods such as narrative literature review, scoping literature review, realist review and systematic literature review were considered to support OcTPAP development. Narrative literature reviews, also referred to as literature reviews, examine recent or current literature but do not follow a specified protocol (Grant and Booth, 2009). They summarise the previously published research and can address more than one question (Ferrari, 2015). Narrative literature reviews are especially prone to selection bias for article inclusion, meaning two researchers

completing a narrative literature review on the same topic could get distinctly different outcomes (Grant and Booth, 2009). Transparency and reproducibility were of importance for the development of OcTPAP as per MRC guidelines for the development of complex interventions (Craig et al., 2008), therefore narrative literature review was not a suitable method to use for this research study.

Scoping literature reviews were also considered. They aim to identify the extent and type of research available on the selected topic (Grant and Booth, 2009). Scoping literature reviews incorporate a range of study designs and can help identify gaps in research (Levac et al., 2010). They are similar in rigour to systematic reviews, but they do not aim to assess the quality of the retrieved research or synthesise evidence from these studies (Majid et al., 2018, Pham et al., 2014). Synthesising the evidence facilitates better understanding of the findings and involves merging information from studies investigating the same thing and (Cochrane, 2022). In addition, assessing the quality of the included studies was of value to the OcTPAP development as it could highlight the trends affecting the evaluation of similar interventions.

Realist reviews as a method of synthesising evidence about complex interventions are increasing in popularity (Rycroft-Malone et al., 2012). These reviews are rooted in realist philosophy and explore the relationship of the overall context, mechanisms and the outcomes of the intervention (Wong et al., 2013). Realist reviews are not reproducible (Pawson et al., 2005) and there are challenges with developing a synthesis framework which reflects the complexity and variation in evidence without overwhelming details (Rycroft-Malone et al., 2012).

Systematic literature reviews are considered the “gold standard” (Smith and Noble, 2016) and aim to provide a comprehensive synthesis of relevant research evidence to answer a very specific research question (JBI, 2021). One of the strengths of systematic reviews is the use of rigorous and transparent methods. Systematic reviews include the assessment of quality of the research studies (JBI, 2021). This helps to highlight methodological concerns with research on the set topic and can inform the design of future studies. For OcTPAP, issues with how to best test the effectiveness of complex interventions were of interest, to support future research

of this intervention. MRC guidelines recommend that a systematic review of evidence should be completed if not already available (Craig et al., 2008).

2.1.2 Focus of the systematic review

Currently, there are no published occupational therapy interventions specifically aimed at maintaining activities of daily living (ADL) independence for hospitalised older people with dementia (Patrick, 2017). Therefore, to gather relevant information for the development of such an intervention, a review of the evidence was required. The researcher (LP) decided that the population of older people in the same context will be reviewed, rather than the subset of patients with dementia or cognitive impairment from a different rehabilitation setting.

Rehabilitation settings outside of acute hospitals often include programmes which are delivered over a longer period of time in comparison to a hospital admission duration. Examples of community rehabilitation programmes for older people with dementia range from seven weeks to six months in duration (Cera et al., 2014, Capotosto et al., 2017, Fajersztajn et al., 2008, Pedroso et al., 2018, Santana-Sosa et al., 2008, Satoh et al., 2017, Toots et al., 2016). These programmes differ in the frequency of therapy input per week, for example Cera et al. (2014) reports individualised interdisciplinary program being delivered for 90 minutes two times a week and Fajersztajn et al. (2008) describes an exercise programme of one hour once a week. It must be noted that all of these rehabilitation studies were specific to people with dementia, but were conducted outside of the UK. The NHS Benchmarking Network reported that in 2017 in England the length of stay in bed based intermediate care services was 26 days (NHS Benchmarking Network, 2017). One of the aims of intermediate care services is to "*support timely discharge from hospital and maximise independent living*" (Department of Health, 2009a). Halfway Home initiative recommends that the intermediate care services are limited to six weeks (Department of Health, 2009a). Anecdotally, intermediate care services which are often based in care home settings offer four to eight weeks of rehabilitation. This is relevant as there is evidence that for example for older adults

who experienced a medical event such as hip fracture or stroke, more time spent engaging in therapeutic activity was associated with better functional outcomes (Host et al., 2014, Tijsen et al., 2019). Such a difference in the period of rehabilitation and therapeutic input compared to an acute hospital setting raises questions about transferability of these interventions for people with dementia from rehabilitation services outside of acute hospitals to acute hospital setting.

It is reasonable to assume that the research findings from rehabilitation studies conducted in older populations in acute hospital setting can be extrapolated to older adults with dementia even though not all findings are likely to be relevant. Therefore, interventions that are being delivered in an acute hospital setting for all older people were reviewed.

2.2 Objectives of the Review

The two objectives of this review were:

- To identify the effectiveness of occupational therapy rehabilitation interventions on activities of daily living independence for older hospitalised patients.
- To identify and describe the occupational therapy component of the retrieved interventions.

2.3 Methods

This systematic review followed the recommendations of the Joanna Briggs Institute (JBI) Manual for Evidence Synthesis (Tufanaru et al., 2020), the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Page et al., 2021), and was registered with the International Prospective Register of Systematic Reviews (PROSPERO reference CRD42019125829).

The initial searches for the review were conducted in May 2018. To ensure the inclusion of all relevant studies prior to using the gathered information in the next phase, which was intervention modelling, the systematic review was updated in March 2019. The purpose of the systematic review was to provide information at a

specific stage of the study (Intervention modelling described in Chapter 4) when the results were integrated and formed foundation for the next step of the research (Delphi consensus described in Chapter 5). Therefore, the systematic review was not updated on the completion of the thesis.

2.3.1 Eligibility Criteria

Types of Participants

This review included studies that had participants aged 55 years or older who were admitted to an acute care setting. An acute hospital care setting was defined as a location where patients stay overnight and are treated for a brief but severe episode of illness caused by trauma or disease and during recovery from surgery (AHS, 2009, The Health Foundation, 2021). This review excluded studies with patients who had a planned admission to hospital, as this patient group may have different difficulties compared to patients admitted as an emergency.

Studies where more than half of the sample had a reported stroke were excluded. NICE (2019) recommends admitting everyone with suspected stroke to a specialist acute stroke unit in a hospital. These units must have a specialist stroke multidisciplinary team, and patients who have a stroke follow a designated pathway (NICE, 2019). In addition, there was a recent systematic review that evaluated the effectiveness of ADL focused occupational therapy for stroke patients (Legg et al., 2017).

Types of Interventions/Phenomena of Interest

This review included studies that evaluated a rehabilitation intervention aimed at maintaining or improving ADL independence and where involvement in the delivery of the intervention from an occupational therapist was recorded. Rehabilitation was defined as "*a set of actions that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments*" (WHO, 2011) p.96. Only interventions with occupational

therapy input were of interest as occupational therapy was key to OcTPAP development and delivery.

Types of Outcomes

Studies that measured the ADL pre intervention and post intervention within 72 hours of being discharged from a hospital were included. This was done in an attempt to reduce the effect of contextual factors that may impact ADL following the discharge (for example if only measured a month post discharge) and assess the impact of the intervention during the admission.

Types of Studies

The review included experimental study designs: randomized controlled trials and non-randomized controlled trials, quasi-experimental and before and after studies.

A summary of the inclusion and exclusion criteria is presented in Table 1.

Table 1 - Systematic Review - Inclusion and Exclusion Criteria

Inclusion criteria	**Yes/No**
• All participants are over 55 years of age.	
• Participants were admitted to an acute hospital.	
• Intervention has input from an occupational therapist.	
• Occupational therapy component of the intervention is aimed at activities of daily living.	
• Activities of daily living are measured pre-intervention and within 72 hours of discharge.	
• The study is a randomized controlled trial or a non-randomized controlled trial or a quasi-experimental study or a before and after study.	
Exclusion criteria	**Yes/No**
• The admission was planned/elective.	
• More than 50% of study participants reported to have had a stroke.	

2.3.2 Information Sources

An electronic database search was conducted on titles and abstracts from inception to May 2018 and then from May 2018 to March 2019 for the systematic review update. The following databases were included as they were most relevant to the field of study: AMED, CINAHL, MEDLINE, EMBASE, PsycINFO, PubMed, Cochrane Library, PEDro, OTseeker. AMED is an online database for Allied and Complimentary Medicine Research. CINAHL is Nursing and Allied Health Professionals Research online database. MEDLINE is an online database for Life Sciences, Biomedical and Health Services Research. EMBASE is medical literature database. PsycINFO is an online database for Behavioral Science and Mental Health. PubMed is a digital archive of life sciences and biomedical research, including which also covers search of MEDLINE. Cochrane Library is a collection of databases which includes evidence to inform healthcare decision-making. PEDro is an online database of physiotherapy interventions and OTseeker is a database containing resources relevant to occupational therapy interventions. Studies published in any language were considered for inclusion in the review.

2.3.3 Search

The keyword search strategy used is presented in Table 2. One reviewer (L.P) undertook the searches.

Table 2 - Systematic Review - Keyword Search Strategy

	Search Terms
1	Old* OR elder* OR aged OR geriatric
2	Rehabilitat* OR restorat* OR maintenance OR reablement OR recover* OR function OR functional OR “occupational therapy” OR OT OR independen*
3	“activities of daily living” OR “daily activit*” OR “ADL” OR ADLs
4	Inpatient* OR hospitali?ed OR hospital* OR acute
5	1 AND 2 AND 3 AND 4

2.3.4 Selection Process

After the removal of the duplicates, the titles and abstracts of papers were screened by one reviewer (LP). If it was unclear if they have met the criteria, the full-text article was screened by LP. If it was still unclear, a second reviewer assessed these studies and a decision was made through discussion, involving a third reviewer if no agreement was reached. Authors of the articles that could not be found in full text were contacted asking if they could provide the article for review. Then, these full-text articles were screened for inclusion if the request was successful.

Potentially eligible full text papers were checked again against the inclusion criteria by L.P. and a second reviewer independently before data extraction.

2.3.5 Data Collection Process

Data from the included papers was extracted by two independent reviewers. The adapted extraction tool from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) was used (JBI, 2022). Data extraction for two articles was completed independently by all the reviewers and then discussed to pilot the extraction tool and improve consistency. LP completed the data extraction for all the studies. The role of the second reviewer for data extraction was divided between PL, RH, SG and JH.

The data extracted included specific details about the interventions, populations, study methods, and outcomes relevant to the systematic review question. The extraction form is presented in Appendix A.

Data Items

The primary outcome was the level of ADL independence, to assess the effectiveness of the interventions. Data about time points of these measures were collected, with admission and discharge time points being of main interest for the ADL independence outcome measures.

Secondary outcomes were rates of institutionalisation following discharge, rehospitalisation and length of hospital stay. For all outcomes of interest, data were sought if available irrespectively of whether the study used standardised or non-standardised outcome measures.

Data on the intervention content description was extracted from the articles as direct quotes and then summarised in line with Template for Intervention Description and Replication (TIDieR) headings.

2.3.6 Risk of Bias in Individual Studies

The included papers were independently assessed for methodological quality by LP and another reviewer (PL, RH, SG or JH). Standardized critical appraisal instruments from the JBI-MAStARI were used (JBI, 2022) (Appendix B and C). Any disagreements that arose between the reviewers were resolved through discussion or with a third reviewer. All studies were included irrespectively of their methodological quality.

2.3.7 Synthesis Methods

It was planned that once the selected papers had been screened and the sample finalised, consideration would be given towards the applicability of a meta-analysis. The reviewers and a health economist (JL) planned to discuss and evaluate the appropriateness of a meta-analysis, through study comparisons, based upon study participants, types of interventions, types of outcomes and study types criteria specified in this study protocol. Three potential courses of action were to be considered:

1. Perfect criteria matches available: fixed-effects meta-analysis would be undertaken, averaging a common treatment effect across near-identical studies. If treatment effect were likely to be heterogeneous, then proceed with meta-analysis. If appropriate for the analysis of subgroups or subsets, the studies would be considered in relation to whether the occupational therapy intervention was stand-alone, was a part of a program or was combined with another approach.

2. Partially matched criteria, yet common outcome measure: random-effects meta-analysis was to be conducted, averaging a varying treatment effect across heterogeneous studies using inverse variance weighted estimators. If appropriate for the analysis of subgroups or subsets, the studies would be considered in relation to whether the occupational therapy intervention was stand-alone, was a part of a program or was combined with another approach.

3. Very poorly matched criteria: meta-analysis would not be appropriate, attempts to do so would produce highly misleading and biased results. In this case, narrative synthesis approach was to be used and be structured around by whom the intervention was done, what was done and what the effects on outcomes were, keeping the synthesis as transparent as possible. Commentaries summarizing key aspects of the studies in relation to the sub-group within which they were included in would be produced. In a final step, the scope, differences and similarities among studies will be used to draw conclusions across the studies.

For the analysis of intervention descriptions quantitative content analysis and thematic content analysis were considered. Data on the intervention descriptions was analysed using thematic content analysis (Bengtsson, 2016). This method was chosen as the aim of reviewing the intervention descriptions was to produce a list of potential intervention components. In quantitative content analysis, rather than looking to interpret the results, the researcher is interested in summarising them and focusing on the frequency of theme occurrence (Neuendorf, 2017).

2.4 Results

2.4.1 Study Selection

A search of the named databases completed in May 2018 identified 11,171 publications, with 2196 publications added in the March 2019 search update. Search results were uploaded onto citation software Endnote X8 and duplicates were removed. Any remaining duplicates were removed manually, resulting in 8158

being screened overall by title and abstract by one reviewer (LP) against the inclusion criteria.

One hundred and six potentially relevant publications were identified and, where possible, reviewed full text. PRISMA flow diagram is presented in Figure 3. Authors of the articles that could not be found in full text were contacted, and consequently the articles were reviewed if the request was successful. Full-text studies or abstracts that did not meet the inclusion criteria were excluded.

Insufficient information was available about five studies, and one protocol for a potentially eligible study was categorised as “awaiting assessment”. Two conference abstracts duplicating full articles of studies already selected for inclusion were excluded. Thirteen articles describing thirteen studies met the predefined inclusion criteria and were included in the systematic review.

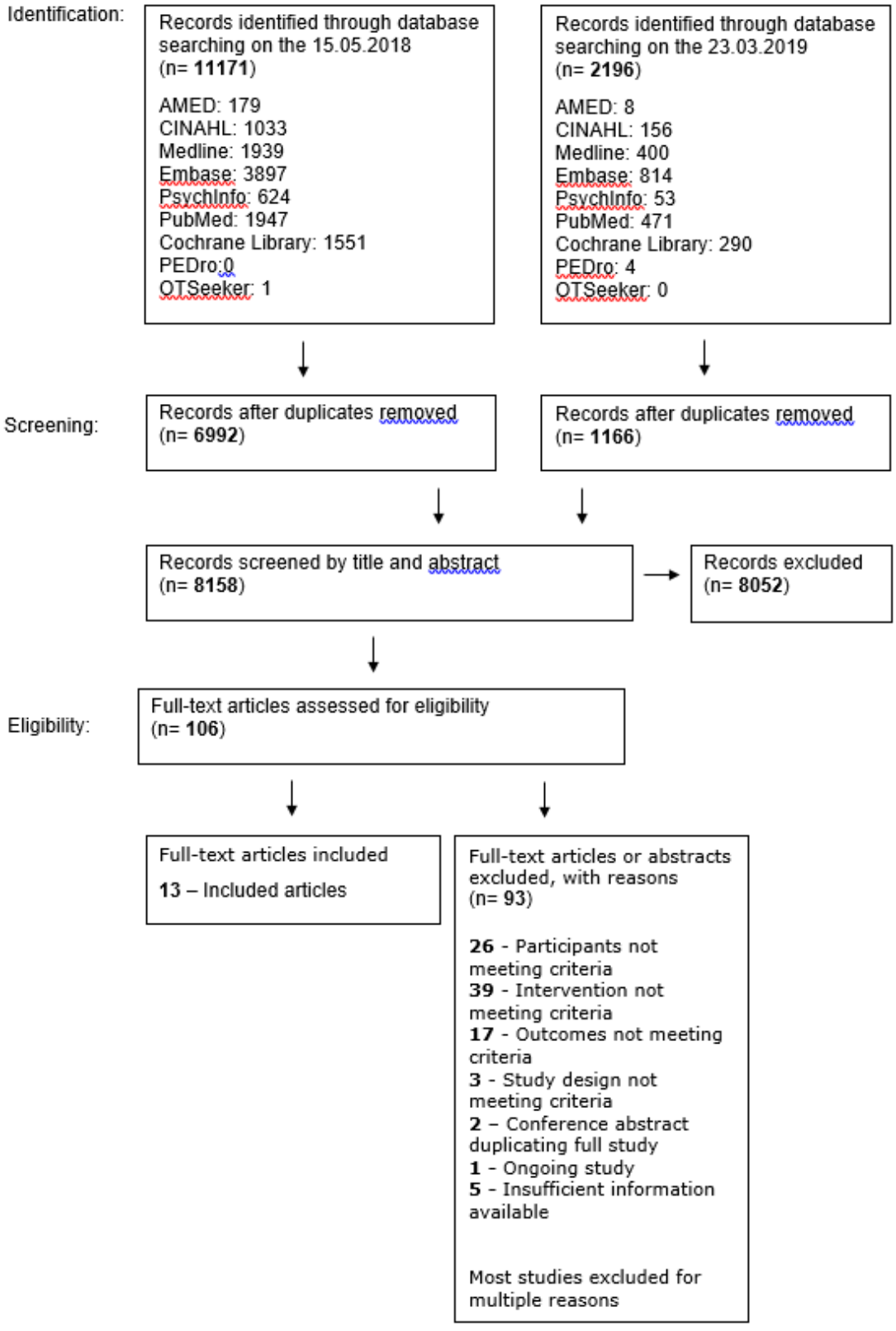

Figure 3 - Systematic Review PRISMA Flow Diagram

2.4.2 Study Characteristics

A summary of the main characteristics of the included studies such as study type, study location, settings and study aims can be found in Table 3. The thirteen studies included in the review were published between 1988 and 2019.

Two studies were completed in Sweden (Asplin et al., 2017, Stenvall et al., 2007), two in the United States (Covinsky et al., 1998, Landefeld et al., 1995), two in Australia (Eyres and Unsworth, 2005, Shearer and Guthrie, 2013). One study was completed in Spain (Abizanda et al., 2011), one in Chile (Álvarez et al., 2017), one in United Kingdom (Kennie et al., 1988), one in Italy (Landi et al., 1997), one in Canada (Manville et al., 2014), one in Switzerland (Trombetti et al., 2013)and one in Peru (Zelada et al., 2009). Seven studies were randomised controlled trials (RCTs) (Abizanda et al., 2011, Álvarez et al., 2017, Covinsky et al., 1998, Eyres and Unsworth, 2005, Kennie et al., 1988, Landefeld et al., 1995, Stenvall et al., 2007). The other six studies were of quasi-experimental design (Asplin et al., 2017, Landi et al., 1997, Manville et al., 2014, Shearer and Guthrie, 2013, Trombetti et al., 2013, Zelada et al., 2009).

The outcome measures used to measure ADL independence in the studies were Katz ADL index index (Kennie et al., 1988, Stenvall et al., 2007, Zelada et al., 2009), Barthel Index (Abizanda et al., 2011, Shearer and Guthrie, 2013), Functional Independence measure (Álvarez et al., 2017, Eyres and Unsworth, 2005, Trombetti et al., 2013), Traffic Light System-Basic ADL instrument (Asplin et al., 2017), the Resident Assessment Protocol (Landi et al., 1997) and three non-standardised outcome measures (Covinsky et al., 1998, Landefeld et al., 1995, Manville et al., 2014).

Table 3 – Systematic Review - Studies' Main Characteristics

Study	Study type	Location	Setting	Study aims
Abizanda et al. (2011)	RCT	Spain	Hospital, acute geriatric unit	To analyse whether occupational therapy intervention in an acute geriatric unit is beneficial for functional improvement following hospital discharge. The secondary objective was the reduction in acute confusional episodes during hospitalisation in the intervention group.
Álvarez et al. (2017)	Pilot RCT	Chile	Hospital, intensive care unit	Determine the impact of occupational therapy intervention in duration, incidence and severity of delirium in older patients in the intensive care unit. The secondary outcome was to assess functionality at hospital discharge.
Asplin et al. (2017)	Prospective controlled intervention study	Sweden	Hospital, comprehensive geriatric care unit	To evaluate a modified programme of coordinated inpatient rehabilitation during the acute phase after hip fracture surgery with focus on patients' perceived participation. Secondary aims were to investigate the effect on activities of daily living, functional balance and confidence and physical performance.
Covinsky et al. (1998)	RCT	United States	Hospital, Acute Care for Elders unit	To measure the effectiveness of the Acute Care for Elders unit on change in ability to independently perform activities of daily living between admission and discharge. The secondary aim was determining costs.
Eyres and Unsworth (2005)	Pilot RCT	Australia	Hospital	To compare outcomes for clients in the experimental and control groups in terms of: - Self-care performance - Confidence levels in terms of ability to manage occupations on discharge

				- Client perceptions of quality of life
Kennie et al. (1988)	RCT	United Kingdom	Hospital, orthopaedic unit	To compare postoperative collaborative care between orthopaedic surgeons and Physicians in geriatric medicine with routine orthopaedic care in older women with proximal femoral fracture. To determine whether postoperative management by a physician in geriatric medicine could shorten hospital stay, improve personal independence at discharge, reduce the level of care needed after discharge, and do these without increasing morbidity and mortality.
Landefeld et al. (1995)	RCT	United States	Hospital, general medical care	To evaluate a clinical system of care designed to improve overall outcomes in a heterogeneous group of older adults who were hospitalised for acute illnesses.
Landi et al. (1997)	Case series with historical controls	Italy	Hospital, geriatric medical ward	To describe the feasibility and effectiveness of an integrated rehabilitation program in a series of older patients admitted in an acute geriatric ward.
Manville et al. (2014)	Before-and-after structured retrospective chart audit.	Canada	Hospital, transitional care unit	To determine whether providing older people alternate level of care patients with interdisciplinary care on a transitional care unit achieves better clinical outcomes and lowers costs compared with providing them with standard hospital care.
Shearer and Guthrie (2013)	Pilot non-randomised controlled study	Australia	Hospital, acute geriatric unit	To investigate whether individualised activities of daily living retraining programmes improve functional outcomes, influence the choice of discharge destinations and reduce length of stay for older people in acute care.

Stenvall et al. (2007)	RCT	Sweden	Hospital, geriatric orthopaedic unit and conventional ward	To investigate the short- and long-term effects of a multidisciplinary postoperative rehabilitation programme in patients with femoral neck fracture.
Trombetti et al. (2013)	Non-randomised controlled study	Switzerland	Hospital, geriatric rehabilitation care ward	The primary objective of the study was to assess the effects of the program in improving gait and balance performances and the level of independence in activities of daily living as compared to standard “usual care.” The secondary objectives were to assess the impact on length of hospital stay, in-hospital fall outcomes, as well as rehospitalisation and mortality rates.
Zelada et al. (2009)	Prospective controlled study	Peru	Hospital, geriatric care unit compared with conventional care	To compare the incidence of functional deterioration after hospitalisation in a geriatric care unit with that occurring after admission in a conventional care unit.

Studies included varying degrees of detail when describing the occupational therapy component of the intervention, with studies such as Abizanda et al. (2011) providing detailed summary and studies such as Covinsky et al. (1998) just stating that occupational therapist was a part of the multidisciplinary intervention.

The description of the occupational therapy component in studies is presented in Table 4.

Table 4 - Systematic Review - Occupational Therapy Component Description in Studies

Study and Intervention type	Description of occupational therapy component
Abizanda et al. (2011) Delivered/ led by OT	**What:** Day 1: Physical, functional, cognitive, social, and emotional assessment. Need analysis for iatrogenic prevention (risk of pressure sores, immobilization syndrome, falls, confusional syndrome, and urinary incontinence), need for retraining in basic and instrumental activities of daily living, need for technical aids, and need for instruction of the primary caregiver in patient mobilization techniques. Preparation of the individual therapeutic plan. Day 2 until discharge: The therapeutic plan always depended on the patient's psychophysical abilities and was based on: •Cognitive stimulation and confusional syndrome prevention: ◦Reality orientation. •Instructions to the family or caregivers on how to prevent complications such as immobility syndrome, confusional syndrome, falls, urinary incontinence, or pressure sores, and patient stimulation. • Retraining in activities of daily living: ◦Mobility in bed ◦Sitting and standing ◦Transfers: chair to bed, wheelchair to bed, wheelchair to toilet. ◦Dressing, bathing and personal hygiene, and toilet use. Day of discharge: In addition to the regular daily intervention, a second 30-min session included: •Instruction for relatives or caregivers on managing the patient's residual deficits.

	•Assessment of possible technical aids for use at home. •Recommendations for patient maintenance or increased independence at home, in activities of daily living, and social and occupational activities. •Resolution of possible questions. **Who delivered:** Occupational therapists trained by a specialised geriatric therapist and by unit geriatricians who supervised the entire process. **How:** One to one sessions. **Where:** Acute Geriatric Unit. The unit had 22 beds, and most admissions (95%) were referred from the emergency room. **When and How much:** Day 1 – approximately one hour. Day 2 until discharge - 8-3 pm, Monday-Friday. 45-min sessions with the patient and relative or regular caregiver including (when relevant) 10 minutes of reality orientation, 5 minutes of education of family and carers, and 30 minutes of retraining in activities of daily living. Day of discharge - in addition to the regular 30 minutes daily intervention, a second 30-min session. Average of 5 sessions during hospitalisation.
Álvarez et al. (2017)	**What:** Occupational therapy interventions included the following (described in more detail in the article): polysensory stimulation, positioning, cognitive stimulation, basic activities of daily living, exercises to keep the patient's upper extremities active and functional, family participation. **Who delivered:** Occupational therapist

Delivered/led by OT	**How:** unclear if the intervention was delivered “one to one” and with carer present or some components were in a group. **Where:** intensive care unit in an acute hospital **When and How much:** started in the first 24h of the patient's admission into the ICU. Delivered twice a day (morning and evening) for 5 consecutive days, 40minutes sessions.
Asplin et al. (2017) Programme which combined OT and physiotherapy	**What:** Promoting patient participation through closer collaboration between the OT, the physio therapist (PT) and the patient. Patients encouraged to take a more active part in and personal responsibility for their training and setting of rehabilitation goals. Education for the patient about the therapists’ roles in the inpatient rehabilitation process as facilitators in the patient’s recovery process, making it clear that it is important that the patient felt involved and part of the team. Goal setting using TLS-Basic ADL. Patient asked “Which activities are important for you to achieve during your inpatient care?” The individual goals were followed up and adapted throughout the hospital stay using the TLSBasicADL protocol. Strengthening patient’s self-efficacy by challenging their fear of falling and encouraging patients’ to progress their exercise (under supervision) to help patients gain confidence to take increased responsibility. Physical component included a training kit consisting of a sliding sheet and leg band to facilitate transfers in/out of the bed, a reaching aid, and stocking aid for training of ADL. Written and photographic instructions were included. Patient encouraged to keep an exercise diary.

	Patients received self-training exercises to perform daily to suit their level of dependence, adapted and intensified as they progressed. OT instructed patients in the use of ADL aids, and assessed the need for aids in the home environment prior to discharge. More intensive training of transfers, walking, balance and personal activities of daily living. Written and verbal information regarding prevention of falls given prior to discharge. OT and PT filled in a training protocol showing when and how often patients received treatment**.** Collaboration meetings (to plan daily training and treatment plans for patients) in addition to the routine twice weekly interdisciplinary meetings. Patients were continually given feedback concerning their progress using the TLS-BasicADL protocol. Patients were asked daily about adverse reactions to treatment such as increased pain or fatigue. Adverse events (such as increased pain or fatigue) were documented in the patient records and treatment was adapted as required. **Who delivered:** occupational therapist and physio therapist staffing levels approximately 0.12 OT and PT per patient. **How:** not clear if this intervention was only delivered as “one to one” sessions or also included groups. **Where:** Comprehensive geriatric care unit **When and How much:** First discussion within 24 hours postoperatively. Intensive training with OT or PT was offered at least 3 times/day by OT and PT (Monday-Friday) from day 2 after surgery.

Covinsky et al. (1998) OT was a part of wider geriatric rehabilitation program	Occupational therapy input provided as part of the multidisciplinary team, but specifics of this input were not detailed in the article.
Eyres and Unsworth (2005) Delivered/led by OT	**What:** Self-care program, instrumental activity of daily living tasks (e.g.cooking, laundry, café visits), functional and community mobility (walking outdoors, accessing the garden or park). **Who delivered:** Occupational therapist and an allied health assistant. **How:** not clear if this intervention was only delivered as "one to one" sessions or also included groups. **Where:** acute wards at a large acute, metropolitan teaching hospital **When and How much:** Daily.
Kennie et al. (1988) OT was a part of wider geriatric rehabilitation program	Experimental group received OT, however duration, frequency of treatment was not reported. No description of occupational therapy. Multidisciplinary case conference once a week (with OT input).

Landefeld et al. (1995) OT was a part of wider geriatric rehabilitation program	Additional occupational therapy input provided as part of the multidisciplinary team, but specifics of this input were not detailed in the article.
Landi et al. (1997) Programme which combined OT and physiotherapy	**What:** ADL and instrumental ADL training. Purposeful activity to achieve his or her maximal functional independence. Functional and self-care retraining, adaptive equipment training, and cognitive exercise. OT and PT closely together design and implement an individualized therapeutic exercise program. Step 1: Multidimensional assessment. Program: Evaluation of sociodemographic, neuropsychological, functional and medical areas. Goals: Identifying the problematic areas, the risk of having a problem, the rehabilitation potential. Step 2: For patients in bed. Program: Bed positioning, active and passive exercises, bed adaptive equipment, dressing the upper body, eating independently. Goals: Restoring or preserving normal function, preventing or correcting contractures, increasing range of motion, maintaining integrity of the skin, increasing circulation, providing proprioceptive and kinaesthetic stimulation.

	Step 3: For patients on the ward. Program: Transferring from bed, chair or wheelchair positioning, elementary group activities, ADLs training. Goals: Increasing body alignment, improving postural control, enhancing upper extremity, preventing contractures, increasing autonomy, alleviating burden care. Step 4: Therapy gymnasium. Program: ADL and IADL training (eating, dressing, walking, grooming, using toilet, washing, cooking, using a telephone), providing adaptive equipment. Goals: Maintaining and increasing ability in performing activities of daily living and other functional activities, increasing perceptual/cognitive skills, promoting positive self-image through purposeful activities. **Who delivered:** OT and PT **How:** One to one and in groups **Where:** Acute medical geriatric ward, university hospital. In addition, the rehabilitation gymnasium was equipment to permit an integrated and comprehensive rehabilitation approach. **When and How much**: Starting with assessment within 24 hours of admission.
Manville et al. (2014) OT was used as part of wider geriatric rehabilitation program	**What:** Provision of rehabilitation service. Activity aides lead group programs for activation and socialisation. **Who delivered:** rehabilitation service provided by a 0.5 FTE (full time equivalent) occupational therapist, 0.5 FTE physiotherapist, and a 0.5 FTE rehabilitation aide, but were a part of a wider multidisciplinary intervention. **How:** "one to one" and groups. **Where:** Hospital, transitional care unit. **When and How much:** Daily.

Shearer and Guthrie (2013) Delivered/led by OT	**What:** Assessments involved patient/carer interview, case not review, observation of occupational performance and discussion with family/carers and the MDT. ADL retraining (Kitchen tasks, personal ADL's, Functional ambulation) individually focussed and goal specific. Programme included personal ADL (e.g., showering, dressing, grooming and toileting), simple domestic tasks (e.g., hot or cold drink preparation, toast preparation) and functional ambulation (i.e., ambulation in the context of an ADL for example, walking while preparing a hot drink). Ongoing review of programme completed by clinical OT throughout patient's admission. **Who delivered:** provided by an appropriately trained occupational therapy assistant, under the direction of the clinical occupational therapist. **How:** "one to one", unclear if also delivered in groups. **Where:** Acute geriatric unit in a large teaching hospital. **When and How much:** Three times a week for up to a maximum of one hour per session. Type and intensity of intervention clinically determined by clinical OT.
Stenvall et al. (2007) OT was a part of wider geriatric rehabilitation program	**What**: The training included both specific exercise and other rehabilitation procedures delivered by a PT, OT as well as basic daily ADL performance training, by caring staff. The patients always do as much as they can by themselves before they are helped. The rehabilitation was based on functional retraining with a special focus on fall risk factors. Home visit by an OT and/or a PT. Patients offered further outpatient rehabilitation after discharge.

	The PT/OT co-operated with colleagues working in community service for further consultation after the patient was discharged from hospital. The PT or OT followed up all patients with a telephone call 2 weeks after discharge and a home visit 4 months postoperatively. **Who delivered**: OT as part of the team. All staff received a 4-day course on caring, rehabilitation, teamwork and medical knowledge, including sessions about how to prevent, detect and treat various postoperative complications, such as postoperative delirium and falls. **How**: "one to one". **Where:** Acute hospital geriatric unit specialising in geriatric orthopaedic patients. **When and How much**: Assessment within the first 24 hours. Daily training by OT.
Trombetti et al. (2013) OT was a part of wider geriatric rehabilitation program	**What:** Multidisciplinary comprehensive assessment. Individually tailored management plan. Work with fear of falling, environmental hazards including home safety assessment. Workshops on fear of falling covered various fixed topics such as beliefs about fall risk, fall risk behaviours, and coping strategies, including work on the ability to find a way to get up if a fall occurs. **Who delivered**: OT, but part of multidisciplinary team intervention. **How**: "one to one" **Where:** Geriatric ward in a teaching hospital. **When and How much**: OT led weekly workshops on fear of falling.

Zelada et al. (2009) OT was a part of wider geriatric rehabilitation program	Occupational therapy input provided as part of the multidisciplinary team, but specifics of this input were not detailed in the article. Article advises to read Landefeld et al. (1995) for intervention protocol, but no details on OT input is provided there either.

Study heterogeneity was assessed with help from a health economist (JL) as per protocol through visual examination of the data extraction table on details related to the characteristics of participants, types of interventions, outcomes and study types. As a result of the heterogeneity of the studies, meta-analysis was not appropriate therefore thematic content analysis was conducted.

2.4.3 Quality Assessment of the Included Studies

The results of the methodological quality appraisal for studies that are randomised controlled trials is presented in Table 5 and quasi-experimental studies in Table 6.

Table 5 - Systematic Review - Completed JBI Critical Appraisal Checklist for Randomised Controlled Trials

Study / **Checklist question**	Abizanda et al. (2011)	Álvarez et al. (2017)	Covinsky et al. (1998)	Eyres and Unsworth (2005)	Kennie et al. (1988)	Landefeld et al. (1995)	Stenvall et al. (2007)
Was true randomization used for assignment of participants to treatment groups?	✓	✓	U	U	✓	✓	✓
Was allocation to treatment groups concealed?	✓	✓	×	U	×	✓	✓
Were treatment groups similar at the baseline?	✓	✓	U	×	✓	✓	✓
Were participants blind to treatment assignment?	×	×	×	×	×	×	U
Were those delivering treatment blind to treatment assignment?	×	×	×	×	×	×	×
Were outcomes assessors blind to treatment assignment?	✓	U	U	✓	×	×	×
Were treatment groups treated identically other than the intervention of interest?	U	✓	U	✓	U	✓	×
Was follow up complete and if not, were differences between groups in terms of their follow up adequately	✓	✓	✓	✓	✓	✓	✓
Were participants analysed in the groups to which they were randomized?	✓	✓	✓	✓	✓	✓	✓
Were outcomes measured in the same way for treatment groups?	✓	✓	✓	✓	✓	✓	✓
Were outcomes measured in a reliable way?	✓	✓	U	✓	✓	×	✓
Was appropriate statistical analysis used?	✓	✓	U	✓	✓	✓	✓
Was the trial design appropriate, and any deviations from the standard RCT design accounted for in the conduct and analysis of the trial?	✓	✓	✓	✓	✓	✓	✓

✓ - yes; × - no; U – unclear

Table 6 - Systematic Review - Completed JBI Critical Appraisal Checklist for Quasi-Experimental Studies

Study / **Checklist question**	Asplin et al. (2017)	Landi et al. (1997)	Manville et al. (2014)	Shearer & Guthrie (2013)	Trombetti et al. (2013)	Zelada et al. (2009)
Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	✓	✓	✓	✓	✓	✓
Were the participants included in any comparisons similar?	✓	✓	✓	✓	✓	✓
Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	✓	✓	U	U	✓	✓
Was there a control group?	✓	✓	✓	✓	✓	✓
Were there multiple measurements of the outcome both pre and post the intervention/exposure?	✓	✓	×	×	U	✓
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	✓	U	✓	✓	✓	✓
Were the outcomes of participants included in any comparisons measured in the same way?	✓	✓	✓	✓	✓	✓
Were outcomes measured in a reliable way?	U	U	U	U	✓	✓
Was appropriate statistical analysis used?	✓	×	U	✓	✓	✓

✓ - yes; × - no; U – unclear; N/A – not applicable

Six out of seven articles reporting on Randomised Controlled Trials (RCTs) fulfilled at least 8 out of 13 quality assessment criteria, indicating moderate to high level of quality (Abizanda et al., 2011, Álvarez et al., 2017, Eyres and Unsworth, 2005, Kennie et al., 1988, Landefeld et al., 1995, Stenvall et al., 2007). The remaining article only fulfilled four, mostly due to the reporting style, which created difficulty establishing its methodological quality (Covinsky et al., 1998). The main methodological concern in the seven RCTs was participants and those delivering the treatment not being blind to treatment assignment. If participants were aware of their allocation, there is a risk that they may have responded differently compared to the situations when they were not aware of treatment allocation impacting recovery, resulting in an information bias. Blinding of those delivering the treatment would not have been possible due to the nature of the intervention.

The remaining six articles reported on non-randomized experimental studies (Asplin et al., 2017, Landi et al., 1997, Manville et al., 2014, Shearer and Guthrie, 2013, Trombetti et al., 2013, Zelada et al., 2009). Three articles fulfilled at least eight out of nine quality assessment criteria, indicating high quality (Asplin et al., 2017, Trombetti et al., 2013, Zelada et al., 2009). The remaining three articles were of low to moderate quality (Landi et al., 1997, Manville et al., 2014, Shearer and Guthrie, 2013). Four out of six studies were unclear on whether the outcomes were measured in a reliable way (Asplin et al., 2017, Landi et al., 1997, Manville et al., 2014, Shearer and Guthrie, 2013).

2.4.4 Results of Syntheses

Effectiveness

The effectiveness of occupational therapy rehabilitation interventions aimed at improving independence in ADL for hospitalised older patients is summarised below. Meta-analysis was not appropriate due to the heterogeneity of the studies.

Studies were grouped in relation to whether the occupational therapy intervention was stand-alone, a part of a program or combined with another approach.

Seven studies investigated interventions where occupational therapy was used as part of wider rehabilitation programs for older people (Covinsky et al., 1998, Kennie et al., 1988, Stenvall et al., 2007, Manville et al., 2014, Zelada et al., 2009, Trombetti et al., 2013, Landefeld et al., 1995). Four studies investigated interventions delivered or led by occupational therapists (Abizanda et al., 2011, Álvarez et al., 2017, Eyres and Unsworth, 2005, Shearer and Guthrie, 2013). The remaining two studies investigated programmes that combined occupational therapy and physiotherapy (Asplin et al., 2017, Landi et al., 1997). The effectiveness is described in these subgroups.

Three out of seven interventions where occupational therapy was used as part of wider rehabilitation programs for older people used the Katz ADL index (Kennie et al., 1988, Stenvall et al., 2007, Zelada et al., 2009), three used non-standardised outcome measures for ADL independence (Covinsky et al., 1998, Landefeld et al., 1995, Manville et al., 2014) and one used Functional Independence measure (FIM) (Trombetti et al., 2013). All seven studies reported an improvement in ADL independence in the intervention group or less deterioration. Only a few studies stated that their findings were statistically significant, with it being unclear in some of the other studies due to poor reporting.

Two out of four interventions that were delivered or led by occupational therapists used the Barthel Index (Abizanda et al., 2011, Shearer and Guthrie, 2013) and the other two used FIM as outcome measures for ADL independence, and therefore, intervention effectiveness (Álvarez et al., 2017, Eyres and Unsworth, 2005). Two studies found statistically significant improvements in functional independence in their intervention groups. The other two studies commented on higher functional recovery in intervention groups despite not showing statistical significance, which could be explained by a lack of statistical power.

One of the two studies where the intervention used combined occupational therapy and physiotherapy Traffic Light System-Basic ADL instrument (Asplin et al., 2017) and the other used information from the Resident Assessment Protocol as outcome measures (Landi et al., 1997). Asplin et al. (2017) found statistically

significant differences between groups in lower body hygiene independence and dressing and Landi et al. (1997) in personal hygiene, eating and locomotion.

Secondary Outcomes of Interest

Four out of thirteen studies did not report on institutionalisation rates (Álvarez et al., 2017, Asplin et al., 2017, Manville et al., 2014, Zelada et al., 2009). Nine reported higher rates of returning to previous living arrangements for the intervention group, and two reported no difference between groups. Fewer than half of the studies reported statistically significant results.

Only three studies reported re-hospitalisation rates with mixed results and no statistical significance (Eyres and Unsworth, 2005, Stenvall et al., 2007, Trombetti et al., 2013). One study reported no difference between groups, one higher rehospitalisation in the intervention group and the other lower in the intervention group.

Length of stay was measured in twelve studies. Five found shorter stays in the intervention group, and another five found longer stays in the intervention group. Less than half of the studies reached statistical significance for this outcome. One study reported no difference between groups.

Three studies out of the thirteen stated cognitive impairment was an exclusion criterion.

The studies in all three subgroups found improvements in ADL independence in the intervention group despite not showing statistical significance. The studies included in this review used a variety of outcome measures, study designs and considerably differed in terms of intervention content, making a comparison of results between studies difficult.

Evidence relating to patients returning to their previous living arrangements was higher for the intervention groups, with half of the studies reporting not reaching statistical significance. Notably, some studies did not include information on how many participants were discharged to rehabilitation facilities.

Three studies that reported on re-hospitalisation rates provided mixed evidence. The reported comparison of length of hospital stay between intervention and control groups also was inconsistent across the studies. Some of this could be explained by the heterogeneity in the content of the interventions provided. Cuevas-Lara et al. (2019) also found limited evidence of the occupational therapy interventions reducing the number of readmissions or reducing the length of stay.

Description of the Content of the Interventions

Thematic content analysis of the intervention descriptions was completed. Fifteen key themes (potential intervention components) were identified and are listed in Table 7 against the articles. Three studies (Kennie et al., 1988, Landefeld et al., 1995, Zelada et al., 2009) had no description of the occupational therapy component of the intervention, in all of these studies occupational therapy was used as part of wider rehabilitation programs for older people. The frequency, start time and duration of all the interventions were summarised.

Table 7 - Systematic review - Themes from Intervention Descriptions

Study / Theme	Abizanda et al. 2011	Alvarez et al. 2017	Asplin et al. 2017	Covinsky et al. 1998	Eyres Unsworth 2005	Kennie et al. 1988	Landefeld et al. 1995	Landi et al. 1997	Manville et al. 2014	Shearer Guthrie 2013	Stenvall et al. 2007	Trombetti et al. 2013	Zelada et al. 2019
ADL retraining, practice	✓	✓	✓		✓			✓		✓	✓		
Goal setting, individualised therapeutic plan	✓		✓					✓		✓	✓		
Planning for after discharge	✓				✓			✓			✓		
Equipment	✓		✓					✓					
Exercises (not purposeful activity)		✓	✓					✓			✓		
Falls prevention focus	✓		✓								✓	✓	
Adaptations to hospital environment				✓				✓			✓	✓	
Carer education & involvement	✓	✓								✓			
Assessment	✓							✓		✓		✓	
Cognition work	✓	✓						✓					
Social interaction	✓							✓	✓				
Polysensory stimulation		✓						✓					
Positioning		✓						✓					
Promoting participation			✓								✓		
Group activities								✓	✓				

Seven studies focused on retraining ADL as a strategy to increase independence (Abizanda et al., 2011, Álvarez et al., 2017, Asplin et al., 2017, Eyres and Unsworth, 2005, Landi et al., 1997, Shearer and Guthrie, 2013, Stenvall et al., 2007). This ranged from practising basic ADL such as eating, hygiene and bed transfers to instrumental ADL tasks like cooking and laundry.

Goal setting and preparation of an individualised therapeutic plan was reported in five out of thirteen studies (Abizanda et al., 2011, Asplin et al., 2017, Landi et al., 1997, Shearer and Guthrie, 2013, Stenvall et al., 2007). Some of the studies pointed out that the goals were continuously reviewed and adapted by professionals. One of the studies specified that the goals were to be achieved during inpatient care. Two studies highlighted the importance of encouraging the patient to take an active part in and personal responsibility for goal setting and achieving these.

An assessment was described as a part of the interventions in four of the studies (Abizanda et al., 2011, Landi et al., 1997, Shearer and Guthrie, 2013, Trombetti et al., 2013). Physical, functional, cognitive, social, neuropsychological and emotional assessment, as well as assessment of need for retraining in basic and instrumental ADL, were listed.

Planning for discharge was a part of the intervention in four studies (Abizanda et al., 2011, Eyres and Unsworth, 2005, Landi et al., 1997, Stenvall et al., 2007). This included assessments for aids to use at home, recommendations for increased independence at home, assessments of the home environment, onwards referrals and community reintegration.

Assessment for and provision of technical aids was specified as a separate theme in three studies (Abizanda et al., 2011, Asplin et al., 2017, Landi et al., 1997), both during and after the admission.

Four studies detailed prescribing exercises (Álvarez et al., 2017, Asplin et al., 2017, Landi et al., 1997, Stenvall et al., 2007), with one of the studies stating that the exercises were aimed to help with improving independence with transfers. Other studies described exercises aimed at increasing range of motion, preventing or correcting contractures and use of targeted exercises such as upper limb exercises.

Bed, chair and wheelchair positioning, use of devices and adaptations to prevent oedema and pressure sores, and positioning to improve postural control and prevent contractures was reported in two of the studies.

Falls prevention was addressed in four of the interventions (Abizanda et al., 2011, Asplin et al., 2017, Landi et al., 1997, Stenvall et al., 2007). This comprised of needs analysis and focus on the fear of falling.

Three studies reported using cognitive stimulation or cognitive exercises as part of their intervention (Abizanda et al., 2011, Álvarez et al., 2017, Landi et al., 1997). Polysensory stimulation was cited in two studies (Álvarez et al., 2017, Landi et al., 1997).

Adaptations to the hospital environment were reported in five studies (Covinsky et al., 1998, Landi et al., 1997, Manville et al., 2014, Stenvall et al., 2007, Trombetti et al., 2013). Ward design with the aim of preventing disability and maximising independence was discussed.

Three studies specified social and emotional components were included in the assessment and rehabilitation interventions (Abizanda et al., 2011, Landi et al., 1997, Manville et al., 2014).

Gathering information from carers, discussing the rehabilitation with them and recommendations on how caregivers can help prevent complications were reported in three studies (Abizanda et al., 2011, Álvarez et al., 2017, Shearer and Guthrie, 2013).

Two studies reported the use of group work as well as one to one activities in their rehabilitation programme (Landi et al., 1997, Manville et al., 2014).

Frequency, start time and the duration of the described interventions varied. The frequency of the intervention delivery ranged from once a week to three times a week, some beginning in the first 24 hours of admission, with others starting after the active period of disease has been managed. The reported intervention duration per session was between 40 minutes and an hour.

This review provided a summary of common themes among occupational therapy interventions aimed at ADL independence being delivered in acute hospital settings to older adults.

2.5 Discussion

2.5.1 Findings in Relation to Existing Literature

All studies reported improvements in overall ADL independence or individual ADLs. The results of most of the studies in the review were not statistically significant concerning ADL independence. Notably, having a sufficiently large sample size to answer the research question of interest was an issue in some of the studies. In addition, heterogeneity of the outcome measures used and varied levels of methodological quality in studies reduced the certainty of conclusions. However, a similar systematic review also concluded that occupational therapy interventions for hospitalised older people are effective in improving ADL function (Cuevas-Lara et al., 2019). Another systematic review that was not specific to occupational therapy concluded the presence of beneficial short term effect after discharge and a less marked long term effect of inpatient rehabilitation compared to usual hospital care (Bachmann et al., 2010). Therefore, the findings of this systematic review are in concordance with other evidence.

The most common out of fifteen intervention components was ADL retraining and practice. Cuevas-Lara et al. (2019) systematic review listed training and re-education in ADLs; training, issue and evaluation of the use of equipment; and recommendations and referrals on discharge as the most common strategies implemented by all their studies. All of these were also identified in this review as well as additional ones as, unlike Cuevas-Lara et al. (2019) review, this review also included quasi-experimental and before and after studies.

A systematic literature review was completed by Cuevas-Lara et al. (2019) and looked at the effectiveness of occupational therapy programmes in older hospitalised people. They did not look at the effectiveness of interventions during the admission (by specifying the time points for activities of daily living measures).

This was essential for this research study as it is mainly the impact on independence during the hospital admissions that was of immediate interest. Focusing on improvements or maintenance of independence during the admission reduces the additional factors that may impact changes to activities of daily living following the discharge. Furthermore, this systematic review excluded studies where hospital admissions were pre-planned (i.e. elective), and it considered occupational therapy interventions which were stand-alone, were a part of a program or were combined with another approach.

2.5.2 Strengths and Limitations

The main limitation of this review was extending it beyond population with dementia, however this was required as there were no published occupational therapy intervention to review aimed at ADL independence for hospitalised people with dementia (Patrick, 2017). Another limitation of this review is the inability to perform a meta-analysis, therefore only enabling to make preliminary conclusions about the effectiveness of occupational therapy programmes for the selected population.

One of the strengths of this review is demonstrating a synthesised overview of breadths of published occupational therapy interventions which resulted from the inclusion of different study designs in the review. While a comprehensive search to identify all suitable studies was completed, duplication of this search by a second reviewer would have been beneficial but was not possible due to resource and time constraints. Searches beyond bibliographic databases would have also strengthened the conclusions.

Future research would benefit from investigating intervention start times, frequency and duration which may help find how to get the most benefit from these programmes, as this still remains unclear. Investigations into how patient subgroups, such as people with cognitive impairment, respond to these interventions would also help tailor the rehabilitation programmes. Future studies may also need to use sufficient samples sizes to detect the effect with more

confidence. This may also aid in identifying specific ADL that are more likely to improve or deteriorate following rehabilitation programmes.

2.6 Conclusions

There is some but limited and uncertain evidence that the provision of occupational therapy during hospital admissions for older people could improve the functional ability of older patients. This may be explained by differences in the content of the interventions, heterogeneous outcome measures used, and the study's sample sizes. No conclusions can be made on the effectiveness, effective dose or start time of the occupational therapy intervention from the available evidence.

Chapter 3 - Exploring the Views of Key Stakeholders on the Essential Components of the Rehabilitation Intervention aimed at Maintaining and Regaining Independence in Activities of Daily Living for People with Dementia during Hospital Admissions - A Qualitative Interview Study

This chapter presents a qualitative study completed using semi-structured interviews to explore the opinions of stakeholders on what Occupational Therapy Personal Activity Programme (OcTPAP) for people with dementia in an acute hospital setting should include (Figure 4). This study sought to provide further evidence on potential intervention components and their context. Standards for Reporting Qualitative Research (SRQR) guided the content of this chapter (O'Brien et al., 2014).

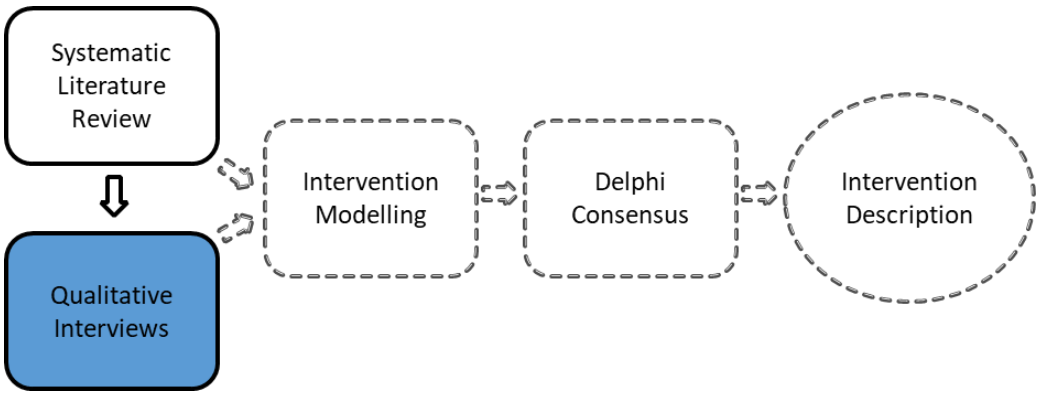

Figure 4 - Research Study Components - Qualitative Interviews

3.1 Background and Philosophical Underpinnings

3.1.1 Background

A comprehensive understanding of both available literature and opinions of people with dementia, their carers and professionals involved is essential to inform the

development of a rehabilitation programme (Bhattacharya, 2017). Currently, there are no published dementia-specific rehabilitation programmes for older people for acute hospitals as presented in Chapter 2. Therefore, a qualitative study was completed following the systematic literature review (Chapter 2) to seek views of the key stakeholders on the essential components of the rehabilitation programme.

Qualitative research has been increasingly recognised for contributing to evidence-based practice in clinical settings (Holloway and Galvin, 2016). It can help explore why things are happening and generate ideas to help solve clinically focussed problems (Bhattacharya, 2017). It is recognised that a qualitative approach is essential for capturing the complexity and differing experiences of care delivery when developing complex interventions for a dynamic clinical setting (Rycroft-Malone and Burton, 2015).

Qualitative research aims to provide interpreted in-depth understanding of the perspectives and experiences of the research participants (Bryman, 2016, Ritchie et al., 2014). Human behaviour, experiences, beliefs and complex interactions were of specific interest for this study as they are a part of routine healthcare provision and therefore contribute to how interventions are perceived and delivered (Holloway and Galvin, 2016).

This qualitative study was needed to explore key stakeholders' opinions to understand what core components the rehabilitation programme should consist of and their context. The research question that was addressed was:

"What components should a rehabilitation programme for hospitalised people with dementia consist of?"

3.1.2 Qualitative Paradigm

The choice of method, methodology and philosophical approach used to address a research question are closely linked. All research is underpinned by a philosophical approach even if this is not acknowledged by the researcher (Grix, 2018).

The methodologies can provide the necessary guidance for the researchers (Carter and Little, 2007). Carter and Little (2007) state that it is not possible to undertake knowledge creation without knowingly or implicitly adopting a theory of knowledge and knowledge construction. Contrary to their position, Avis (2003) argues that the validity of the claims produced by research cannot be limited to the demonstration of following the rules and procedures from a comprehensive methodological theory to generate the evidence. Instead, the internal consistency of the arguments supporting the knowledge claim and how they relate to the existing knowledge and social theory create the epistemological justification of the research.

While understanding different epistemologies, paradigms and traditions is advisable, many authors caution against "epistemological determinism" and advise that it is not essential to make an ideological commitment to a particular tradition (Ritchie et al., 2014). Within the broader framework of qualitative research exist a number of different approaches, such as phenomenology, ethnography and grounded theory (Ritchie et al., 2014). These and other approaches were examined before deciding on an approach to address the research question.

Phenomenology as a philosophical approach is concerned with producing an in-depth understanding of a small number of individuals (Creswell and Poth, 2016). It aims to condense the several participants' experiences of a phenomenon to describe the universal essence (Creswell and Poth, 2016).

Ethnography stems from anthropological studies and examines behavioural patterns of a social group (Ritchie et al., 2014). Studying the behavioural patterns of healthcare professionals providing care to hospitalised people with dementia would provide useful information. It would not allow the generation of potential intervention components for this research study, but would provide information on the barriers and facilitators.

Grounded theory aims to go beyond description to formulate a theory (Gubrium et al., 2012). The theory development is "grounded" in the data gathered from the participants and explains how the process is experienced by the participants. However, it assumes that the participants would have all experienced the process

(Creswell and Poth, 2016), in case of this research study, the delivery of an intervention aimed at maintaining ADL independence. The participants would have experience of what could be done to help people with dementia maintain independence, but not necessarily the experience of an intervention, as currently, there are no reported dementia-specific interventions of that kind. The aim of this study is not to explain how the process works but to create one, making grounded theory not suitable for this study (Gubrium et al., 2012).

The choice of the research methods should be guided by the research objectives and the nature of the information that the research needs to provide (Ritchie et al., 2014). As discussed in Chapter 1 of this thesis, the research for the development of OcTPAP has been completed adopting pragmatism as philosophical position. Pragmatism recognises that reality has potential to change and is concerned with how action can generate possibilities (Deering et al., 2021). Pragmatism can help consider knowledge in relation to what works for whom and understanding the context (Deering et al., 2021).

3.2 Component Aims

This component of the research study aimed to explore the opinions of key stakeholders on the essential components of the rehabilitation programme, OcTPAP. The objectives of this study were to identify essential components for OcTPAP and to explore the context for the intervention.

3.3 Method

3.3.1 Data Collection and Management

The Rationale for Selecting Interviews as a Method

Several different qualitative methods were considered to answer the research question, including interviews, observations, and focus groups.

Observations provide an opportunity to collect data by observing naturalistic behaviours. While observations could provide information about current clinical

practice, they do not provide the rationale for decisions behind people's actions. Moreover, observations would not be able to gather ideas from the participants on what components a new intervention should include (Musante and DeWalt, 2010, Renjith et al., 2021).

Focus groups were also considered. A focus group is a meeting with a facilitator where a small group of participants discuss a specified topic to generate data (Wong, 2008). One of the benefits of using focus groups is that they allow for the construction of shared group meaning through discussion, which is advantageous when applied to a multidisciplinary context of health care (Wong, 2008). However, focus groups were regarded as unsuitable for the following three reasons.

Firstly, the short duration of a focus group, compared to interviewing the same participants individually, may not offer sufficiently detailed information to develop an intervention (Acocella, 2012). This study was interested in a range of opinions but needed to capture the in-depth knowledge as this topic has not been previously explored. Secondly, it is essential to develop an intervention that is acceptable to the people who will be delivering and receiving it before the evaluation. Therefore, opinions of patients, carers, commissioners and a range of clinicians were of interest (Craig et al., 2008). Even if separate focus groups were held for each of these categories, the presence of other people could influence the way opinions are expressed. Participants would be more likely to state what is viewed as more socially desirable. This is referred to as social power (Pereira et al., 2016) and undermines the ability of this method to explore a phenomenon in-depth and generate innovative ideas, which is crucial for the development of the intervention (Wong, 2008). Thirdly, there is a possibility of certain group members dominating the discussion. This may be a concern for people with dementia with their cognitive impairment making it more challenging to take part in a focus group, potentially impacting the quality of collected data (Bowling, 2014).

The anticipated benefits of using observations or focus groups to answer the research question were outweighed by their limitations. Therefore, the one-to-one interview approach was adopted.

Interviewing is a method commonly used in qualitative research and can be described as “conversation with a purpose”(Webb and Webb, 1932). In-depth qualitative interviews can provide knowledge based on the meanings that life experiences hold for the interviewees. An unstructured interview approach would allow the participants to retain more control over the process and topics being discussed. However, it could result in not answering the research question due to deviating from the initial topic of interest (Jamshed, 2014). Semi-structured interviews were chosen, as they are designed around a set of predetermined prompts yet allow the participants to express their views in their own terms when answering open-ended questions (DiCicco-Bloom and Crabtree, 2006). Furthermore, semi-structured interviews offer the flexibility to probe a bit more or a bit less in response to varying replies, promoting a deeper understanding (Bryman, 2016, Smith and Flowers, 2021).

Interview Guide Development

Having an interview guide helps explore participants' opinions more systematically and comprehensively and keeps the interview focused on the topic of interest (Jamshed, 2014). The in-depth qualitative interviews guide was developed based on the TIDieR checklist (Hoffmann et al., 2014). The TIDieR guide aims to improve the completeness of reporting intervention descriptions and provides a checklist with 12 items and their explanation. For example, the “What (materials)” section of the checklist was explored by asking the participants “What resources would be needed to do that [the intervention]?” The findings from the systematic literature review (Chapter 2) provided potential ideas to explore intervention components.

The interview guide was discussed with the PPI collaborator and reviewed by the supervisory team, which included clinicians and academics who have specialist knowledge in this area of research and clinical practice. The interview guide was then piloted with a clinician to ensure the questions enabled the conversation flow and tested whether the content of the questions helped answer the main research question. Amendments were made in consultation with the supervisory team.

Strategies on using open questions and avoiding leading questions were also explored with the experienced qualitative researcher (JH). This researcher also assisted in adapting the guide for different participant groups, such as carers, patients and commissioners. An interview guide for the patients and the clinicians are included as examples (Appendix D). After the first interviews, the interview guide was amended as the researcher (LP) learned more about the topic from the participants' perspectives.

Data Collection

It is known that the interview settings can impact on the type of data generated (Galletta, 2013). The participants were given a choice on whether the interview took place at a meeting room in the University of Nottingham (Nottingham) or their own home or workplace if it was within the East Midlands area. The researcher arranged a convenient date and time to suit the participants.

The interviews were digitally audio recorded with the participants' consent, anonymised and then transcribed verbatim. All data were anonymised, and participants were given a participant number. Electronic recordings and documents were stored on a secure dedicated web server with access restricted by user identifiers and passwords in keeping with established protocols for information governance and data protection guidelines (MRC, 2012, Great Britain, 2018). NVivo 11 software was used for data management (QSR International, 2019).

To increase the credibility of the study, an experienced qualitative researcher (JH) read two interview transcripts and provided advice on the interview technique for the subsequent interviews.

3.3.2 Eligibility Criteria

Participants had to belong to at least one of these categories: a person with diagnosed dementia, a carer for a person with dementia, a clinician involved in the

care of hospitalised patients with dementia, or a commissioner of NHS or social care services. The eligibility criteria were as follows:

For people with dementia:

- Experience of an acute hospital admission to a Health Care of Older People ward or its equivalent within the last twelve months.
- Not permanently residing in residential or nursing home facilities.
- Not already receiving full assistance with all activities of daily living tasks prior to the last hospital admission.
- Able to give informed consent.
- Sixty-five years of age or over.

For carers:

- Experience of supporting a person with dementia during an acute hospital admission to a Health Care of Older People ward or its equivalent within the last three weeks to twelve months.
- Carer of a person with dementia who was not already receiving full assistance with all activities of daily living tasks prior to the last hospital admission.
- Able to give informed consent.
- Eighteen years of age or over.

For clinicians:

- Experience of two or more years of working with older people with dementia and experience of working in an acute hospital setting.
- Able to give informed consent.
- Eighteen years of age or over.

For commissioners:

- Previous or current involvement in the decision making around commissioning NHS or social care services.
- Able to give informed consent.
- Eighteen years of age or over.

3.3.3 Sample Size

Following recommendations by Kuzel (1992), twenty participants were selected for this study. Twelve to twenty interviews are advised when trying to achieve maximum variation or when trying to capture disconfirming evidence (Kuzel, 1992). Furthermore, Guest et al. (2006) suggest that an almost full range of thematic discovery (88%) occurs within the first twelve interviews, with new themes emerging infrequently after that.

3.3.4 Sampling Strategy

Purposive sampling was used to allow the selection of participants more likely to generate appropriate data to answer the research question (Patton, 2014). This method relies on the researcher's ability to choose the information-rich participants based on particular criteria for the in-depth study (O'Leary, 2010, Patton, 2014). A strategy was developed based on the researcher's clinical knowledge of the research area, the literature from the systematic review (Chapter 2) and discussion with the supervisory team. The strategy detailed what professional expertise or personal experience participants need to have to support the development of the intervention to be delivered by occupational therapists. A table used to monitor participant experience representation is presented in the results section of this chapter. This strategy supported the presence of all stakeholders that were deemed relevant to consider the topic from different perspectives and ensure "information richness" (Busetto et al., 2020).

The researcher (LP) and the supervisory team (PL, RH, SG, JH) agreed that at least two of the recruited participants would need to have experience of dementia, and at least two, a carer for a person with dementia. It was also agreed that occupational therapy workers, physio therapy workers and nursing staff should be represented with at least three participants per category, as these professionals are key to the rehabilitation process. The researcher and the supervisory team were also aware that some participants may self-identify as belonging to more than one category. The researcher and the supervisory team reviewed the table regularly to ensure one area of expertise was not overrepresented.

3.3.5 Recruitment

Participants were recruited through existing clinical, academic and professional bodies and networks within the East Midlands, including EMRAN (East Midlands Research into Ageing Network), the British Geriatrics Society, AGILE (specialist interest group for Chartered Physiotherapists working with older people), Royal College of Nursing, RCOT SS Older People (Royal College of Occupational Therapy Special Interest Group), East Midlands Council for Allied Health Professions Research. Patient and carer participants were identified through local support groups including East Midlands PPI Senate, Carers Federation, the Alzheimer's Society network, Nottingham Elders Forum, Derbyshire Carers Association, the Carers in Hucknall group, the Beeston Memory Café group, the Rushcliffe Dementia Café group, the Dementia, Frail Older People and Palliative Care PPI advisory Group at the University of Nottingham, and through the Join Dementia Research register. Study details and recruitment posters were emailed to these networks asking to advertise the study. Potential participants were invited to contact the researcher if they wished to participate in the study. Potential participants from the Join Dementia Research register who fitted the inclusion criteria were contacted directly to offer participation by phone or email, depending on the details they provided on the register.

Potential participants who expressed interest in participating were informed of all aspects pertaining to participation in the study via email or phone conversation, if still interested, the participants were considered against the eligibility criteria and the sampling framework. The list of people who volunteered to participate in the study was considered in the order they contacted the researcher. If a potential participant was from an already overrepresented category, the next participant on the list was considered for suitability. If suitable, the participants received the Participant Information Sheet (Appendix E), and a suitable time and place for the interview were arranged. Written informed consent was sought prior to the interview.

Patient and carer participants were offered a one-off payment of £20 to participate in the interview. A one-off payment of £20 was also offered for clinicians and commissioners if they took part in the interview outside of their normal working hours. If participants decided to travel to be interviewed at a University of Nottingham meeting room, reasonable expenses of up to £50 were offered to cover costs, such as travel or hiring a carer. Costs above £50 were considered depending on the circumstances. This was outlined in the participant information sheet, which advised how to claim the expenses or payments.

3.3.6 Consent

All participants provided written informed consent (Appendix F) before participating. The participant information sheet was available in two formats. A brief and simplified participant information sheet was available to facilitate understanding if needed (Appendix G). The process for obtaining participant informed consent was in accordance with the Mental Capacity Act (2005a). The researcher has experience in assessing mental capacity and taking consent from those with cognitive impairment. The researcher also completed a good clinical practice refresher training online. One copy of the consent form was kept by the participant and one was kept by the researcher.

3.3.7 Ethical Approval and an Amendment

Ethical approval was obtained from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics committee on the 6th of March 2019, reference number 235-1902 (Appendix H). An amendment to the selection criteria for persons with dementia was submitted and subsequently approved (Appendix I). The amendment aimed to support the recruitment as there were difficulties with finding participants with experience of more recent hospital admissions. Therefore, the requirements were updated to allow selection of participants who had a hospital admission on a Health Care of Older People ward or its equivalent in "the last 12 months" rather than "the last 3 weeks - 3 months". The original requirement of the admission lasting at least five days was also removed. On study completion the participants recruited to this category of participants fit the original selection criteria.

3.3.8 Data Analysis

Data Analysis Methods

Thematic analysis was chosen as the method of data analysis for this study after careful consideration of a range of methods. This approach allows data to be systematically identified, organised and for patterns of meaning across a dataset to be found. It offers an insight into collective or shared meanings and experiences (Braun and Clarke, 2012). Narrative analysis and interpretative phenomenological analysis (IPA) were also considered, however were less suitable for answering the set research question.

Narrative analysis focuses predominantly on how the participants tell their stories (Hansen, 2006). Narrative analysis could provide rich insights into individuals' beliefs in context of their lives and focuses on the participant interpretation of the world (Riley and Hawe, 2005). IPA is another qualitative approach that is interested in personal lived experience (Smith and Shinebourne, 2012). It closely aligns with the philosophical approach of phenomenology and aims to explore how participants make sense of their experiences. (Smith and Osborn, 2015).

In contrast, the thematic analysis looks at broader issues and brings together multiple opinions into themes. This aligns with the aims of this research and the pragmatic stance that the researcher has adopted.

Data Organisation Method

Framework Analysis was used as a method of data organisation when thematically analysing the data. One of the strengths of this method is that it aligns itself to any one theoretical underpinning (Gale et al., 2013). It is mainly used to thematically analyse semi-structured interview transcripts. It provides a systematic way of categorising and managing data while being robust and transparent, which enhances the credibility and dependability of findings (Ward et al., 2013, Gale et al., 2013).

Framework Analysis is particularly suitable for multidisciplinary health research with Patient and Public involvement (PPI) input (Gale et al., 2013) and for the development and evaluation of complex interventions, which aligns with the aims of the overall study (Atkins et al., 2015). One of the strengths of the Framework Analysis approach is that it allows the incorporation of emergent and *a priori* findings (Iliffe et al., 2015). The former is known as the inductive approach, where patterns are derived from the collected data. The latter is known as the deductive approach, where collected data is used to test an already developed hypothesis.

Using a combination of inductive and deductive approaches would allow deriving a broad range of themes to identify potential components for the rehabilitation programme being developed (Ritchie et al., 2014). A combined approach was appropriate as it allowed for the specific issues to be explored while permitting the discovery of other unexpected aspects of the participants' experience or their understanding of the topic (Gale et al., 2013). Furthermore, incorporating existing evidence and stakeholder views has been highlighted as an essential part of successful intervention development by individuals involved in healthcare intervention development and wider stakeholders (Turner et al., 2019).

Steps of Data Analysis

The following seven stages detail the process of Framework Analysis, which was completed following the analysis procedure described by Gale et al. (2013). It must be noted that even though presented as linear, the process is iterative and stages are interdependent (Gale et al., 2013).

1. Transcription.

Firstly, a word by word transcript of the audio recorded interview was made. Transcriptions may be completed by either the researcher to immerse in the data further or by a professional transcriber (Gale et al., 2013). This research study used the services of a professional University of Nottingham transcriber experienced in working with studies in the healthcare field. To help immerse herself in the data, the researcher (LP) used strategies such as re-listening to the audio recordings of the interviews. Subsequently, the researcher felt comfortable to pass the next interview data onto the transcriber.

The researcher (LP) has checked all the completed transcripts for accuracy. The transcripts were printed out and had large margins and enough space between the lines to allow for making notes and coding.

2. Familiarisation.

At this stage, the researcher immersed herself in the data and gained an overview of the data content and its relevance to the research question (Ritchie et al., 2014). The researcher reviewed field notes, repeatedly listened to audio recordings. Initial thoughts, ideas and impressions were recorded.

3. Coding.

The next step was reading the transcript line by line and applying a label to describe what was interpreted as valuable. These labels are known as codes and are the basic elements that allow the classification of data. Coding is a part of the analysis (Braun, 2006).

Firstly, the researcher and the PPI collaborator trained in coding independently coded a transcript manually, applying the inductive approach. The inductive

approach assumes coding the data without trying to fit into an existing framework of codes and is driven by the data (Braun, 2006). Then, the researcher and the PPI collaborator met to discuss reflections on the process, whether the PPI collaborator thought the themes represented a PPI perspective, go through any arising questions and compare the initial coding. Next, two more transcripts were independently coded.

4. Developing the coding framework.

An initial analytical framework was created from the three transcripts that were analysed using open codes by the researcher and the PPI collaborator.

Independent of the inductive coding, a deductive framework was constructed. The deductive approach is a "top down" approach that is driven by looking for the themes that are based on existing theory or previous research (Braun, 2006). The deductive framework included information that would be required to design a complex intervention (Sermeus, 2015) and took into account the findings of the systematic review (Chapter 2). For example, themes such as the creation of an individualised therapeutic plan, falls prevention, provision of technical aids were included in the framework from the Systematic review. The initial framework was reviewed by the supervisory team and applied later in the process.

The inductive and deductive frameworks were then combined. This set of codes was then applied to all subsequent transcripts manually. Any new codes were integrated within the analytical framework, meaning that there were several iterations of the analytical framework before no additional codes emerged.

5. Applying the coding framework.

At this stage, the final coding framework was applied to all transcripts using NVivo11.

6. Data charting.

The data from each transcript was summarised by codes generating a matrix. Each participant's quotations were recorded and then summarised in rows, and the codes were listed in columns. Using NVivo 11 to code the data ensured traceability

to the original transcripts and added transparency, enabling linking individual experiences and meanings to the emerging themes. A few iterations of themes configurations were completed, with themes being re-grouped and renamed prior to deciding on the final themes. An example of an earlier iteration of the themes and codes is presented in Appendix J.

7. Interpreting the data.

Themes and subthemes were checked against the audio recordings, original transcripts, and field notes to ensure appropriate context. No further merging of themes was required. Additionally, a table of silences and contradictions was created to highlight subthemes that participants did not talk about or disagreed on, which was used to help interpretation alongside field notes (Appendix K).

At this stage, the PPI collaborator reviewed the theme and subtheme titles for clarity and wording which were then amended following her advice. The outcomes were presented to and discussed with the supervisory team to improve rigour. An experienced qualitative researcher (JH) who was part of the supervisory team has also reviewed some themes to trace if they represent the content of the gathered data accurately.

3.3.9 Patient and Public Involvement

To ensure the developed interventions embrace everyone's needs, service user involvement at all stages of the research process is recommended (Department of Health, 2005b, Cowley et al., 2019). The participant information sheets (Appendix E and G), consent form (Appendix F) and recruitment posters (Appendix L) were reviewed by the Dementia, Frail Older People and Palliative Care PPI Advisory Group at the University of Nottingham and the Alzheimer's Society Research Network monitors to ensure that the language is suitable for members of the public. The PPI collaborator (KS) for the study jointly developed the interview guide to make sure the questions were clear, appropriate and relevant (Appendix D).

Emerging evidence supports involving PPI members in qualitative data analysis (Byrne et al., 2009, Bourke, 2009, Nind, 2011). Despite being frequent consumers of

health and social care, the involvement of older people as partners in research has been limited (Cowley et al., 2019). PPI members can draw on personal experience to make sense of the data (Ward et al., 2013) which improves the quality, robustness and validity of the analysis (Best et al., 2017, Staley, 2009). The PPI collaborator for the study contributed to the interview data analysis (co-coding). The PPI collaborator had previously attended a specially developed PPI training programme on qualitative data analysis described in Cowley et al. (2019). The training focused on the use of Braun and Clarke's thematic analysis approach and included a practical component to apply the method.

Co-coding is when the coding of the data is completed by at least two researchers and is a tool for improving the credibility of the findings (Busetto et al., 2020). A subset of three transcripts was coded independently by the researcher (LP) and the PPI Collaborator (KS) and then compared, with codes discussed and consolidated during a face to face meeting. Patient and Public involvement both in guiding the research and in the analysis of the findings is increasingly seen as a quality indicator (Busetto et al., 2020).

3.3.10 Reflexivity

There is a general acceptance in qualitative research that the researcher's self is unavoidably a fundamental part of the data analysis (Denscombe, 2017). Reflexivity is viewed as continuous critical self-evaluation and active recognition and acknowledgement of the researcher's own position and how it may affect the research process and its results (Guillemin and Gillam, 2004). It is demonstrated through a detailed description of the relationship of the researcher and participant's characteristics, such as cultural background or age. Finally, it provides context to allow a deeper understanding of the work and increases the credibility of the findings (Berger, 2013).

To incorporate reflexivity within the study, a self-check was continuously completed. Being reflexive helps the researcher to become aware of, for example, the questions or topics she tends to avoid exploring further, facilitating a more in-

depth engagement with the data and its analysis (Berger, 2013). The researcher (LP) kept field notes and a reflective diary. If the researcher felt the need to further explore an issue or situation, reflective diary records were used to facilitate discussion with an experienced qualitative researcher (JH). A reflective diary is a tool that helps the researchers critically explore how their own background and views may impact their research, which helps with research transparency (Ortlipp, 2008).

The researcher (LP) made notes in her reflective diary prior to and immediately after the interviews. These detailed the thoughts and feelings that arose during preparation and the interview itself and any observations about the environment or participants' behaviour. In addition, the diary was helpful at the interpretive stage of the interview analysis. Reflective writing is acknowledged as fundamental to developing critical thinking (Mortari, 2015).

Prior to conducting interviews, both the researcher and the PPI collaborator wrote a statement detailing their background and the potential influence it may have on data analysis. Both statements are available in the Preface of this thesis. These statements were then referred to during the interpretive stage. For example, the researcher noted that being a therapist practising in an acute environment herself may have added an "insider" status when conducting the research in the healthcare setting (Asselin, 2003). This was evidenced by the use of "we" when formulating questions to some of the participants about what is normal practice in acute hospitals. "What you mentioned earlier, it's knowing the person. Do you think we take that into account in hospitals?" (from the interview with Participant 9). Therefore, the researcher had to remain alert to how there may be shared experience of care in a healthcare setting between the researcher and the participant, yet be perceptive to a different perception of this experience (Berger, 2013). For example, if one of the participants shared views which opposed these of the researcher and the rest of the participants.

It must be noted for the purposes of transparency that some of the participants were colleagues of the researcher. Therefore, the researcher-interviewer effect should be taken into consideration, as the participant's responses could have been

affected by the researcher and the participant relationship (Singleton and Straits, 2012). It is proposed that the participant may have tailored their answers in response to the researcher's social characteristics and behaviour when administering the interview (David and Sutton, 2004). Furthermore, the participants were made aware that the findings from the study will be used to make recommendations to improve clinical practice. Therefore the responses could have been intentionally or unintentionally altered given the participant's own vision of the ward, trust or healthcare priorities and future practice. To balance this, the researcher (LP) reflected in this in her reflective diary, to further increase her awareness of this relationship and its impact on the research process.

3.4 Results

Data collection occurred between March and June 2019. Participants were recruited from the East Midlands region. Nineteen interviews with twenty participants were completed as two participants (a carer and a person living with dementia) chose to be interviewed together. Interviews lasted between 25 and 69 minutes. The average length of an interview was 43 minutes. A heterogeneous group of participants, including clinicians, commissioners, people with dementia, and carers, was recruited. Participants' characteristics are described in Table 8.

Table 8 - Qualitative Interviews - Participants' Characteristics

Roles / Participant	Occupational therapist	Healthcare assistant	Physiotherapist	Physiotherapy assistant	Geriatrician	Dietitian	Nurse	Speech and language therapist	Commissioner	Person with dementia	Carer
Participant 1			X								
Participant 2			X								
Participant 3				X							
Participant 4	X								X		X
Participant 5					X						
Participant 6						X					
Participant 7	X										
Participant 8	X										
Participant 9							X				
Participant 10					X						
Participant 11	X										
Participant 12							X				
Participant 13		X									
Participant 14								X			
Participant 15											X
Participant 16							X		X		
Participant 17										X	
Participant 18											X
Participant 19											X
Participant 20										X	

Listed below are the themes that emerged from the interview data divided into subcategories, followed by more detailed explanations. Detailed summaries of the themes and subthemes can be found in Appendix M.

Matching the need

- Just right.
- Enough time and staff numbers.
- Knowing the person and what is the usual.
- Adapting approach.
- Sharing information.

Setting expectations

- Training and awareness.
- Knowing the rules.
- Patient voice.
- Carer involvement and support.
- Acceptability of risk.

Promoting participation

- Responsibility of encouraging independence.
- Keeping home routine.
- Environmental cues.
- Purposeful and meaningful activity.
- Setting goals.

3.4.1 Matching the Need

This theme covers the importance of providing the exact amount of assistance to facilitate independence in activities of daily living. It also explains the need for having enough staff and for the staff to have sufficient time to deliver better care and the staff adapting their approach to working with people with dementia. Understanding of the individual patients and their circumstances and how this can be communicated is discussed.

Getting it Just Right

All participants spoke about staff providing either too much or not enough help.

> *"I think, generally, probably staff feel just a little bit binary, so either people can do it, or they can't do it, and there's not perhaps, the middle ground is a bit unsure."*
>
> Participant 14

Participants specified that staff need to be able to assess accurately what the patient can and cannot do and progress or adapt the strategies as the situation changes.

> *"Provide facilities and staff who are capable of the flexibility and the insight required to be able to adapt and adopt processes, attitudes, conversation, and physical needs, to the different circumstances."* Participant 15

Enough Time and Staff Numbers

The majority of the participants stated that staff do not have time to encourage patients to do things for themselves, and therefore may choose a less time-consuming option.

> *"There is always quite a lot going on. And I think, in order to, it, that makes it very difficult for the staff that are currently on the wards to get people up and about and doing things for themselves, because there's not always enough staff to watch everybody. If it is something that they can do but they might need assistance with, it's often quicker for somebody else to do it for them, and I think that's one of the main barriers."* Participant 6

Only one participant (healthcare assistant) felt that staff already get to spend a lot of time working with patients. Most of the other participants have suggested that having more staff and staff time to deliver better care may help.

> *"I think, at the moment, the therapists struggle to get round, to just do the assessments. [laughs] If you had more therapists, you probably could do more with people then"* Participant 10

Knowing the Person and what is the Usual

Knowing the previous level of ability, what the normal routines are and trying to recreate these during the hospital admission was suggested as important by the participants in this study.

> *"She wouldn't go to the toilet. And they'd take her and she'd just find it really frustrating and, and it turned out that she worked in a paper shop and that she couldn't go to the toilet all day and she had to wait until the end, and the toilet was actually outside, so it's that recognition …"* Participant 9

Participants highlighted the importance of how the information is gained, recorded and communicated.

> *"Well, if, if they're feeding me, right, straightaway, they should know, right, that I can feed myself, because they're doing it daily. Right? So they should know…"* Participant 17

Not knowing the patient's previous level of ability was thought to delay appropriate care. Participants emphasised the need to get the information from a variety of sources (family, carers, records) to get the bigger picture and knowing about the patient's preferences, what is important to them and their past social history, routines and preferences.

> *''There's no point in forcing singing in a group on somebody who's never engaged with people and doesn't want that. But it's how you get that biography and then it's how you understand who they are.''* Participant 5

Adapting Approach

The presence of stereotypes about dementia was seen as unhelpful.

> *"…the first thing is, just because somebody got that label of dementia, or the diagnosis, doesn't necessarily mean they can't do anything, and it's just not having a blanket dismissal of their ability."* Participant 2

Participants spoke about the need to understand the impact dementia can have on the patient and adapt their approach accordingly.

> *"We're not unpicking which part they have difficulties with but actually, which part they have strengths with, and you can work to that strength. It's a very kind of deficit based approach to care and rehab, rather than a re-ablement."* Participant 1

Participants also voiced their views about patients not always being aware of their own abilities.

> *"And sometimes, the patients think, "Oh, I'm ill, I can't get out of bed", but actually, they could."* Participant 6

Sharing Information

Having access to previous information from the community to better understand the patient and their situation was discussed.

> *" There are computer programmes like System One that, again, we don't always have that access to"* Participant 5

Participants highlighted issues with how the information about enabling patients was handed over during the admission in the way that works best for staff and keeps carers up to date.

> *"We need to be able to communicate it to the staff in a way that suits them and works for them, and then they need to understand what we've said in order for them to be able to carry it on"* Participant 14

3.4.2 Setting Expectations

This theme includes participant's views on the staff training and awareness, making sure the "patient voice" is listened to and the carers feel supported. The importance of setting expectation for the hospital admission in terms of independence and the associated risk is also covered.

Training and Awareness

One of the participants spoke about evidence-based practice and the importance of leadership and "reabling" culture on the ward.

> *" I think, is the fact that frontline clinicians aren't aware of that evidence, so we're not getting that message across from, kind of research into clinical practice*." Participant 1

A recurring theme from the data was a sense that more understanding and staff training around dementia care is needed. This would not be just a one-off opportunity for staff training, but a continuous effort.

> *" In an ideal world, you'd have to have people that had been trained to look after people with dementia, and understand, you know, just understand what, what they're going through."* Participant 20

Learning from colleagues from different professions was also suggested. Participants reported differences in training levels depending on the type of the ward (e.g. geriatric vs orthopaedics).

> *"On the more specialist units or where they're more specifically trained, the acceptance of risk is a lot different. Whereas on the more general wards, even though people are aware of dementia, I think people are just so scared of the patient falling, or doing themselves an injury, and then the subsequent complaint, so, I think that's the over- that seems to be the overriding factor in how a lot of staff can behave with a dementia patient"* Participant 2

Knowing the Rules

Participants stated that explaining what is expected from the patient and staff "*like a patient contract but it's not an enforceable thing*" during the hospital stay would be beneficial. Patients and carers need to be given information on how they can "*keep their daily activities going*" to avoid misconceptions.

Perceptions around what the patient's role is in "*pyjama induced paralysis*" from both patients and family were brought up by many participants. They also stated that often there is a specific routine to the ward. Participants reported the need for the carers to know which facilities they can use and where things are and feeling welcome to contribute to care if they can.

> *"So the son, funnily enough, said to me … that's why he hadn't really done anything, because he didn't think he was able to do that. And then, he was saying, the physio had gave him that impression."* Participant 7

One of the participants indicated that some clinicians would try to develop services using the funding not as initially intended by commissioners.

> *"So you can get "service creep" by people developing services. Other times, you'll get clinicians who keep people on their caseload too long. Because they don't want to discharge them. … You can't stop that happening, but you just have to be mindful that it doesn't get too big, and start costing us too [much] from our tax money''* Participant 16

Patient Voice

Valuing and respecting the patient's choices and autonomy even if they are not what the staff would choose was discussed. Participants described shared decision making and patients being in control and "*having that ethos of a partnership*".

> "*I think we probably are quite prescriptive with that and I think, definitely, with goals, we're quite prescriptive. Because in our head, we know how our system works, so we probably do that in our own way, and it's more that we probably ask people, when we want to give an intervention, are they happy with the intervention that we're going to give them. But we probably don't do, yeah, we probably don't talk to them as much about, oh, "I think you might be having problems with this, how do you feel about that?" We probably don't have that conversation as much."* Participant 11

One of the participants spoke of patients being too unwell to make decisions. Several participants showed awareness of the patients' mental capacity issues.

> *"it's also hard, I think, with people who come in acutely medically unwell to put them at the heart of their own care because they might not be in a position where they can tell you what they want or, or they know what they want, or even what to think about what they want, they just want to feel better, because they feel so unwell."* Participant 8

One of the participants emphasised that patients should also take responsibility for completing their rehabilitation if able. Another participant also reflected on the need to involve the patients in decisions about their care and the wider changes to the provision of the services.

> *"Things like physiotherapy are really good for helping people to get up and about but it's important that patients that can continue that when they're not with a physiotherapist, and that, if they're able to like, do their exercise and get up out of bed, that they carry on doing that rather than sort of sitting and waiting for somebody else to come and say, "Right, we're going to do this now"."* Participant 6

Carer Involvement and Support

Most of the participants spoke about involving family members in decision-making, valuing their knowledge about the patient, and keeping them updated.

> *"Well, the carer or whoever is with that person needs to be involved with the process"* Participant 18

While carers coming in to help with care if they feel able to was discussed, participants also specified that carers may need a break from care giving.

> *"You're worried, you're trying to do everything else, you're trying to do hospital visiting, which is stressful in itself, and tiring, and so there's a lot of pressure on you as the carer, still coping with life"* Participant19

Gaining information from both paid and unpaid carers was suggested. A quarter of the participants stated that carers may need educating on what to expect or advising on some care aspects.

> *"I think, how you include the family in terms of care, whilst it's delivered on the ward, education to the family to know what they can be doing in an acute phase, to support the rehab."* Participant 4

Acceptability of Risk

Participants described staff's risk-averse behaviours due to concerns about consequences such as patient harm and complaints.

> *"There's a very much a blame culture, that if someone falls over, there's lots of forms to fill in, never mind the poor patient, [laughs] it's not the forms, and you'll be blamed for not, for not, for letting the patient wander"* Participant 12

Participants stated that it would be preferable to help keep independence without increasing the risks. Perceptions about risk levels in different environments were also discussed.

> *" With an auxiliary [nurse] who was helping with personal hygiene, they said one of the reasons they did that is because they don't want someone to fall, and they just felt it was safer if they did that rather than someone try and do their own toileting"* Participant 11.

3.4.3 Promoting Participation

This theme explores whose responsibility it is to help the patients retain independence in activities of daily living, the importance of recreating normal routines, and the role of environmental cues. Settings goals to promote participation and the application of purposeful and meaningful activities is discussed.

Responsibility of Encouraging Independence

Participants who were healthcare professionals reported that hospital staff often chose the easier option for them instead of encouraging the patient to be independent. It was suggested that every activity should be seen as an opportunity for rehabilitation involving the patient as much as possible.

> *"I think it's making sure that, like I say, each member of staff is trying to help that patient maintain their independence and trying to encourage it and that we aren't falling into that routine of, "I'm just going to feed you because it's quicker", I think we need to be making sure that we are encouraging independence."* Participant 13

Participants' opinions were divided on whether there should be a designated person for rehabilitation or if it should be the whole team's responsibility. Some participants stated that encouraging independence is everyone's responsibility, including domestic staff and family carers or the wider community.

> *"So I think, with assistance, don't just think that it's our role. Because it's a wider community role as well so it's family members or care staff, and care staff want to come in"* Participant 9

However, a number of participants spoke about patients making decisions about how to stay independent and taking responsibility for getting more active. Starting rehabilitation early on, ensuring continuity and seven-day working for more specialities were also suggested.

> *"It should be seven day working, because we find, just as we're progressing a patient, you hit the weekend"* Participant 3

Keeping Home Routine

A more flexible approach to the daily schedule to mimic the patient's home timetable was suggested. However, participants also acknowledged that having set hospital routines has some benefits. Participants highlighted the need for the patients to be able to practise daily routines in the most familiar way.

"Always getting as much as you can from the patient themselves and having understanding of what's normal for them, and obviously trying to make … what was going on at home as similar to here as possible." Participant 7

Patients having their own belongings and familiar items in the hospital and staff helping the patients to use them was suggested as a way of maintaining and promoting independence during a hospital admission. Although, two of the participants voiced concerns about patients' items getting soiled or going missing.

"…patient may still be incontinent, due to their illness, and a pair of jamas or a gown is far easier to quickly whip off and on than normal clothes. It it's the patient's normal clothes, then, you're sort of gingerly handing it back to the relatives to wash and we have run out of clothes in the end anyway" Participant 12

Environmental Cues

Participants spoke about the need for environmental cues that invite participation (by creating context) and allow participation (through better facilities) for patients to do things for themselves, including a better environment layout. Participants stated that staff could encourage independence by offering an option for the patient to do something more independently.

"If you're sat under a shower, there's a context, I'm in the shower, I need to wash myself, and hopefully, things will just click" Participant 2

The benefits of a more homely and dementia-friendly environment were also discussed by the participants.

"Because there's so many of you, you sort of all, like, for breakfast, you're all fed. Whereas, if it had been a small place, then you could have had a little kitchen, you could have gone in and done it yourself" Participant 20

Purposeful and Meaningful Activity

Participants reported a lack of availability of stimulating activities for patients on the wards. This extended to a lack of social interactions on topics not related to clinical needs.

> *"I think that's just taking everything away from you. You know, meeting people, not chatting to anybody. And it's, I think it's a loneliness, that is. They ought to make it where you can mix."* Participant 20

Participants suggested that more "homelike" and generation-appropriate activities should be available. Staff should be creative in creating meaningful activities for patients to get involved with that they "might be doing when they get home".

> *"Rather than putting them to bed at seven, eight o'clock at night, they might think "Oh, let me catch up on Emmerdale or Coronation Street". Just try and bring a little bit of home to here."* Participant 3

Setting Goals

Many participants highlighted the need to set realistic and specific goals that are important to the patient and family. Some participants clarified that this should be "within the restriction of the setting".

> *"To have shared decision making, to include a holistic approach with family members around desired goals, it's around the enabling approach, to get the patient to do as much for themselves as they can do, within their own time that they would need to be able to do that."* Participant 4

Setting a plan for every day was suggested, with a whole team involved in the effort to achieve it. One of the participants warned that this should not be just a "paperwork exercise".

> *"People are set goals, but how meaningful they are, other than for covering your back in a paperwork exercise, is, I don't know, debateable, I think"* Participant 8

3.5 Discussion

This study sought to explore the perspectives of the key stakeholders on the core components of the OcTPAP aimed at activities of daily living independence for older patients with dementia during hospital admissions and the context for this intervention.

There was a strong consensus among the participants that staff had limited time to encourage the patients to be more independent. Increased levels of activity in patients and increased therapy time have been found to be important predictors of better rehabilitation outcomes (Tijsen et al., 2019). Nevertheless, it is acknowledged that acute hospital wards are fast-paced environments that put growing demands on staff (Archibald, 2002), and good dementia care is time-consuming (Teodorczuk et al., 2014).

The ability of staff to provide "just right" amount of support with activities was essential according to this study's participants. Acute hospital staff expressing concerns about being able to accurately adapt the activities and the environment to fluctuating abilities of hospitalised people with dementia to facilitate patient's participation at the optimal level has not been previously highlighted in published dementia research. The participants felt that adapting their approach to help people with dementia required understanding the impact of having dementia on the patients. The need for more training to increase awareness of good principles of dementia care for staff was highlighted as necessary. This is consistent with NICE Dementia guidelines which advise that all staff should be given training in person-centred and outcome-focused care for people living with dementia (NICE, 2018). The latest national audit of dementia in hospitals found that 89% of staff reported receiving some form of dementia training (Royal College of Psychiatrists, 2019a). However, it was difficult to establish its quality as 47% of hospitals could not report how many staff received at least Tier 1/informed dementia awareness training. The breakdown of the trained staff by staff groups was not available.

Consistent with Kitwood's theory of person-centred care (Innes et al., 2012), this study's participants felt that there was a need to understand patient's preferences, their past lives and what is important to them. The participants suggested knowing patients' usual level of ability and replicating patients' normal routines while in the hospital as much as possible. In contrast, a qualitative study that evaluated a specialist community-based dementia service provided an example of an alternative focus to rehabilitation (Gladman et al., 2007). The project leader, an occupational therapist, advocated a thorough assessment of patients' daily routines, similarly to the findings presented in this chapter. However, it was proposed that this assessment process took up to 12 weeks (Gladman et al., 2007), which would not be feasible in an acute hospital setting due to the short length of admissions. In Gladman et al. (2007) study, while care was delivered with rehabilitative focus, it was aimed at maintaining personhood rather than maintaining independence in task performance. Both of these approaches to rehabilitation are underpinned by principles of person-centred care as advised by NICE (2018).

The participants in this study raised the issue of communicating information both within and outside of the hospital services. NICE guidelines for dementia care (2018) recommend sharing and recording appropriate information in the person's care and support plan. It is widely acknowledged that the quality of interactions and communications among clinicians largely contributes to patient outcomes (Iedema, 2007). Due to the complexity of delivering care to the contemporary patient population a range of professionals, speciality departments, services, organisations or care providers may need to be involved. Currently, there is a strong emphasis on the provision of integrated care, which creates a more seamless interaction between all of these mentioned above for the patient benefit (Curry, 2010), which is congruent with this qualitative study findings.

This study found shared decision making and the patient being in control were important components for supporting independence in ADL during a hospital admission. Study's participants suggested the patient should be taking responsibility for completing their rehabilitation, but it must be noted that

rehabilitation of people with dementia could be impacted by the effect dementia has on both a person's motivation and ability (Williams, 2005) and by their acute illness.

The participants of this qualitative study have pointed out the inclusion of paid and unpaid carers as valuable sources of information. It is widely emphasised that it is essential to meet the needs of both the carer and the person with dementia (NICE, 2018). Lindhardt et al. (2008) state that partnership with close relatives of the patients is essential. It helps nurses fully understand the patients' needs, resulting in suitable and sufficient treatment and care. Nevertheless, Curran and Wattis (2011) warn that due to the honest desire to reduce risk the carers may deliberately decrease the variety of activities the person undertakes, thus further reducing their ability to maintain skills through practice. The findings from the study presented in this chapter highlight the need to support the carers through additional education in relation to dementia care or rehabilitation.

Seven-day working for more specialities was suggested by this qualitative study's participants and is recommended by NHS Improvement. It aims to achieve high-quality consistent care whatever day patients enter a hospital (NHS Improvement, 2017). A study investigating occupational therapy service on an acute unit for older patients not specific to people with dementia, found seven-day working beneficial to patients (Davies, 2017). However, it was noted that this has an impact on clinicians' work-life balance.

The participants suggested mimicking patients' home timetable and practising daily routines in the most familiar way. Chan et al. (2020) in their qualitative review of older patients' engagement in functional self-care, found that the hospital regulations and daily ward routines resulted in patients feeling restricted when they tried to perform their ADL. Similarly, Clarke et al. (2017) also found that patients feel there is a lack of choice due to routine dictated by staff and treatment regimens with which they have to comply with. In contrast to Chan et al. (2020) findings, two of this study's participants who were both clinicians recognised the potential benefits of having set hospital routines.

Creating an enriched environment by increasing opportunities for practice and promoting active engagement was suggested by Tijsen et al. (2019), which echoed the views of this study's participants. While Tijsen et al. (2019) literature review looked at rehabilitation environment for older people, it was not specific to people with dementia. Another more recent review investigated the needs of people with dementia in hospitals and found the environment important for enabling independence (Rosvik and Rokstad, 2020). In line with this study's findings, the need for the environment to be easy to navigate was highlighted, recommending a dementia-friendly design with a homelike set-up (Rosvik and Rokstad, 2020). They also found that there was little emphasis on meaningful interaction and basic nursing care in an acute hospital setting with staff excessively monitoring patients' safety. This further explains why this study's participants may have suggested encouraging patient independence by offering an option for the patient to do something more independently. Lack of autonomy has been found to be a barrier to activity on hospital wards (Boltz et al., 2010).

The participants in this study spoke about the lack of availability and engagement in meaningful activities or social interactions not linked to their health. Even though not specific to patients with dementia, another study that explored how older people spend their time in hospitals discovered similar issues (Clarke et al., 2017). They found that patients often felt bored and passive, unlike at home, and voiced willingness to engage in ward-based activities if these were available.

Furthermore, Clarke et al. (2017) highlighted several external and personal barriers that participants felt stopped them from engaging in more meaningful activities. These included a set hospital routine, lack of facilities and stimulation, and patients feeling too unwell, tired or traumatised to participate in activities at the beginning of admission, which is consistent with this qualitative study's findings. Importantly, there is a perceived contrast between meaningful occupations pre-hospitalisation and unfamiliar occupations in hospital (Cheah and Presnell, 2011). The nature of the hospital environment may result in previously meaningful occupations losing their sense of meaning, which would be important to note when adapting patients' daily activities during their hospital stay.

This study's participants acknowledged that patients may adopt a "sick role". Hospital admission often acts as a reasoning for the adoption of a sick role as the person is automatically exempt from their normal responsibilities and routines (Faulkner and Aveyard, 2002). The presence of healthcare staff also strengths this belief, which encourages the perception that the patients are not expected to look after themselves (Faulkner and Aveyard, 2002). Participation in their own care may be perceived as being in direct conflict with the perceived obligations of a sick role which is to comply with the opinions of health professionals and the set regiment (Faulkner and Aveyard, 2002). Nevertheless, a feeling of helplessness at not being able to care for themselves was also reported, stemming from the nurses taking charge of performing ADL for them (Chan et al., 2020). Consistent with the Learned Helplessness Theory (Parrish, 2009), this qualitative study's participants reflected on patients' choices and autonomy and how these are impacted. Chan et al. (2020) reported another explanation for some patients choosing not to participate in self-care. They found that patients did not want to add to the nurses' workload (Chan et al., 2020). A patients' acute illness may result in them requiring more help from staff (Goldberg et al., 2012).

Another reason for adopting "sick role" behaviour is a lack of understanding of the consequences of allowing hospital staff to complete their ADL for them. Faulkner and Aveyard (2002) suggest that staff should provide the patients simple and clear explanations of the benefits of participation. Similarly, these qualitative findings suggest that discussing the expectations for the duration of the admission in terms of ADL independence with both patients and their carers would be beneficial.

The risk-averse behaviours described in the this study has also been reported in Stevenson et al. (2016) literature review exploring the risk in dementia care. They found that respecting rights and needs while avoiding harm was challenging for both carers and professionals. The professionals were found more likely to be risk-averse, which may be due to legal duties and fear of litigation, which echoes the concerns this study's participants expressed over patient harm and complaints. According to a report by Tadd et al. (2011), the clinical governance's preoccupation with avoiding risk and the focus on quantitative measures for the quality of care has

unintended adverse effects on care delivery and patient's experience. The data from this qualitative study suggests the need for the staff to balance the risk avoidance and independence promotion.

It is recognised that goal setting is an essential part of the rehabilitation process (Bachmann et al., 2010, van Seben et al., 2018). Consistent with the reports from some of this qualitative participants about the restrictions of the settings, van Seben et al. (2018) found that professionals thought patients' goals had to be related to discharge criteria, such as basic self-care activities performance. Also, their findings suggest that older people are often not able to formulate goals or that they set unrealistic ones (van Seben et al., 2018). This may be even more pertinent for people with dementia due to cognitive impairment. Data from this qualitative study specified that goals have to have importance for the patient and be discussed with their carers. A recent study specific to patients with dementia in rehabilitation for older people found goal-setting in patients with mild to moderate dementia was feasible (Dutzi et al., 2019).

The participants in this study emphasised the importance of involving the whole ward team in achieving the set out rehabilitation goals. Tijsen et al. (2019) echo this by stating that the quality of rehabilitation can be improved by the multidisciplinary team having shared goals and good communication within the team. Nevertheless, the study participants did not agree on whether rehabilitation itself should be the responsibility of the whole team or a designated team member. A literature review by Stockwell-Smith et al. (2018) presented distributed responsibility as a barrier to discharge planning for older adults living with dementia resulting from the lack of clarity regarding individuals' roles or accountabilities. This may also apply to the context of rehabilitation. In contrast, an overview of reviews specific to rehabilitation concluded that multidisciplinary rehabilitation team care effectively improves rehabilitation intervention (Momsen et al., 2012). Similarly, this qualitative study's participants acknowledged the need for multidisciplinary involvement in the rehabilitation process but also added that a wider circle of people could be involved, such as the hospital's domestic staff or paid carers from the community teams.

The research in this PhD thesis aimed to develop an occupational therapy rehabilitation intervention for people with dementia that would be delivered in an acute hospital setting. While it was assumed by the researcher (LP) that OcTPAP would be delivered in a multidisciplinary environment, it was specifically the description of the occupational therapy input that was of interest. The findings from the qualitative study described above, highlighted the interconnectedness of delivering such an intervention and the importance of united approach from all clinicians, patients and their carers in facilitating independence in ADL. It became apparent that OcTPAP description, even if underpinned by occupational therapy concepts and theory, should include the rest of the multidisciplinary team on the ward.

3.6 Strengths and Limitations

Dependability, credibility, confirmability and transferability are the principles by which the trustworthiness of qualitative data is appraised (Bradshaw et al., 2017).

Dependability

The dependability of this research study is demonstrated by the detailed description of the study's processes and procedures, which were also reviewed and approved by the Ethics committee, reference number 235-1902 (Appendix H). There is also a record of the changes that were made to the original study design and are detailed under the Ethics amendment. Furthermore, the trustworthiness of the findings was supported by an experienced researcher (JH) reviewing selected interview transcripts, coding and the framework analysis matrix.

Credibility

In relation to the credibility of the study, the researcher's background as a healthcare professional could have assisted in developing a trusting relationship with some of the interviewed participants (Bradshaw et al., 2017). However, it must

be noted that the researcher having an "insider" status could have impacted the data collection. Sharing an identity, language, and common professional experiential base with the participants who were clinicians may have helped build the researcher–participant relationship (McEvoy, 2001). At the same time, working in the same field may have resulted in the researcher having a set of assumptions about the setting and as a result reducing the researcher's ability to probe for deeper meaning (Asselin, 2003). The researcher's "insider" status was acknowledged before the data collection began, and the researcher prepared strategies to minimise this to ensure a better understanding of the phenomenon under study, such as keeping reflective diary. A concise and accurate account of how the data was collected and analysed was maintained to create an audit trail so that other researchers could follow the process and concur with the findings.

One of the strengths of this study was the presence of PPI collaboration in the development of the recruitment and study information material, piloting the interview guide and analysing the interview data (Cowley et al., 2019). Both the researcher and the PPI collaborator wrote a statement to acknowledge their previous experiences and understanding. These aimed to help make sense of data and demonstrate reflexivity and transparency of the research methods used.

The data was strengthened by interviewing healthcare professionals providing daily care for people with dementia, as opposed to including a broader range of healthcare professionals with more limited experience of dementia care. This helped to improve the completeness of information gathered and the credibility of interpretations generated. Commissioners, carers and people with dementia were also included. Understanding critical issues of independence from the patients' perspectives was crucial to ensure that healthcare interventions were informed by the individuals who were most affected and who would benefit from them.

Confirmability

The confirmability of the research findings could be demonstrated through the description of the participants' demographics and the audio recordings and

transcripts of the interviews, which are to be kept for the required length of time in compliance with the ICH/GCP guidelines. It could also be supported by the evidence from the reflective diary kept by the researcher (LP) and the inclusion of direct quotes in the study results.

Transferability

Transferability of the study's findings is supported by the use of purposive sampling and a detailed description of the participant selection framework (Bradshaw et al., 2017). One of the limitations of this study was that only participants from the East Midlands area were recruited, so there is a possibility that their views may not reflect the experience of people from other UK regions. Nevertheless, this study used a purposive sampling strategy, which aimed to maximise the representation of a range of perspectives on the topic in question

The last admission date for participants with dementia had to be within the last 12 months, which is a broad timeframe but aided study recruitment. However, there was a delicate balance between people with dementia having reflected on their experience of admission and minimising recall bias. It may have been beneficial to interview people with dementia during their hospital admission. However, this could have added to the already challenging experience of being hospitalised for a medical reason.

Description of the research setting, participants and the research processes also enhances transferability of the study's findings by allowing the reader to make an assessment of the similarity of the study's context to their own environment (Polit and Beck, 2010).

3.7 Conclusion

This study explored the opinions of key stakeholders on the essential components of OcTPAP and their context. Three main themes emerged which will contribute to developing of OcTPAP intervention.

The first is to make sure the intervention includes the promotion of participation. This includes purposeful and meaningful activity, setting goals, keeping the patient's home routine, providing environmental cues and encouraging the patient's independence.

The second is by setting expectations, which comprises of considerations about the acceptability of risk, knowing what the rules of the setting are, valuing patient voice, carer involvement and support, and staff training and awareness.

The third is by matching the need, which focuses on adapting the approach for people with dementia, knowing what is usual for them, sharing information, providing the right amount of support as well as having enough staff and time.

The findings of the study, together with finding from the systematic review (Chapter 2), informed the next step in the development of the rehabilitation programme for people with dementia during hospital admissions.

This study's participants raised concerns about difficulties with appropriately adapting the activities and the environment to fluctuating abilities of hospitalised people with dementia. This study highlighted the need for further research into which staff groups in acute hospital may struggle to accurately match the level of support provided to patients with dementia to facilitate patient's participation at the optimal level and how staff can be supported with this.

Chapter 4 - Occupational Therapy Personal Activity Programme Modelling

This chapter builds on the first two reported steps taken for the development of the Occupational Therapy Personal Activity Programme (OcTPAP):

(1) The review and assessment of best practice evidence and identification of potential OcTPAP components through a systematic literature review (Chapter 2).

(2) The identification of potential OcTPAP components, their context and context for OcTPAP through qualitative interviews with stakeholders (Chapter 3).

In this chapter (Figure 5) intervention modelling is presented. The third and the fourth steps in the OcTPAP development process are described:

(3) Theory development underpinning the OcTPAP including mechanism of action.

(4) The synthesis of the systematic review and qualitative interviews findings.

The proposed mechanism of action and the themes arising from the data synthesis are presented, followed by the discussion of the strengths and limitations of the completed intervention modelling.

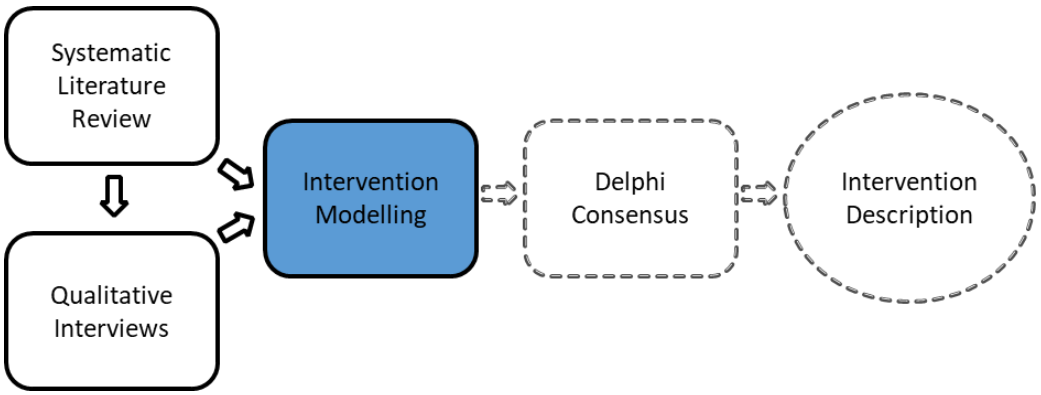

Figure 5 - Research Study Components - Intervention Modelling

4.1 The Theory behind the OcTPAP Intervention

It is vital to identify interventions that have the potential to be effective and are a priority for the people who will be affected by their implementation (Medical Research Council, 2006, Harris et al., 2016). When applied in clinical practice, interventions that are poorly designed and unevaluated can prove to be unproductive and ineffective (Wight et al., 2016). In addition, the evaluation of poorly designed complex interventions can lead to waste of public resources (May et al., 2007). Therefore, thorough, evidence-based, transparent intervention design is essential.

This section presents existing models and frameworks that informed the research in this thesis. The Medical Research Council (MRC) guidance for developing complex interventions was followed (Medical Research Council, 2006). The World Health Organisation's International Classification of Functioning (World Health Organisation, 2002) and Person-Environment-Occupation-Performance model (Duncan, 2011) provided an overarching framework for the initial intervention development of this complex intervention. Principles of the biopsychosocial model of illness (World Health Organisation, 2002, Wade and Halligan, 2017) and person-centred care (NICE, 2018) were also applied alongside good dementia care recommendations.

4.1.1 Guidance for Developing Complex Interventions

Two approaches to intervention development were considered, intervention mapping and the Medical Research Council Guidance for Developing and Evaluating Complex Interventions. These will now be discussed.

Intervention Mapping

Intervention mapping is a framework for intervention development, implementation and intervention evaluation (Fernandez et al., 2019). In intervention mapping, the first step is to complete a needs assessment to establish

personal and environmental determinants of the addressed behaviour (Hansen et al., 2017). The intervention mapping approach was considered but rejected as it is mostly aimed at behaviour modification and would be less suitable for answering the set research question. The aim of this study was to create an intervention, rather than viewing the loss of independence as a behaviour to be changed (Hansen et al., 2017).

Medical Research Council Guidance for Developing and Evaluating Complex Interventions

Healthcare interventions are often complex (Craig et al., 2008). The proposed OcTPAP fits the definition of a complex intervention by the Medical Research Council guidance (Medical Research Council, 2006). OcTPAP has several interacting components influenced by environmental and contextual factors resulting in longer and more complex causal link chains between the intervention and the outcome which is in line with Medical Research Council (2006). Components of a complex intervention can be described as characteristics of the intervention that are distinguishingly different from the whole of the intervention and compose the intervention in full or partly (Clark, 2013). These components can be micro or macro in nature, and they can be theoretical, social, procedural, human or material. An example of a micro component could be an occupational therapist completing a referral for the patient to access a specific community service. A change to an acute hospital policy to, for example, include quarterly reporting on the changes to ADL independence during admissions could be a macro component. Without pre-specified parts, the intervention could not be said to exist (Clark, 2013).

MRC guidelines have been widely used to design complex interventions for older people (Booth et al., 2019). The guidance aims to help the researcher with the intervention development, evaluation and implementation and has been recently updated to account for some of the previously raised criticisms (Medical Research Council, 2006). This framework was chosen to develop OcTPAP.

4.1.2 Frameworks and Theories Considered

Behaviour change theory (Ratz and Lippke, 2021), normalisation process theory (Davidoff et al., 2015), and World Health Organisation's International Classification of Functioning (WHO-ICF) were considered to underpin OcTPAP development. These are discussed below explaining why the latter was selected.

Behavioural Change Theory

There is a number of theoretical frameworks in health behaviour change research, such as the theory of planned change, the self-determination theory, health action process research (Ratz and Lippke, 2021). They share some overlapping concepts and aim to explain the mechanism of human behaviour change (Ratz and Lippke, 2021). For example, self-determination theory is based on the belief that people's motivation to grow and change is based on their needs for competence, connection and autonomy being fulfilled (Legault, 2017). The use of a behavioural change theory would provide insights into how OcTPAP could be delivered so that the stakeholders such as staff, patients and carers feel motivated to participate in it. For this research study the use of these theories was not suitable. It may have omitted addressing extrinsic factors that play a part in delivering rehabilitation intervention, such as the impact of the physical hospital environment on the person's range of daily activities.

Normalisation Process Theory

Normalisation Process Theory provides a conceptual framework for embedding practices into the social context and making them routine (Davidoff et al., 2015). It may be applicable at the next stage of this research once OcTPAP description has been developed as there is currently no intervention to embed. The potential feasibility and implementation issues were already taken into account in the chosen research design.

World Health Organisation's International Classification of Functioning

WHO-ICF is a framework used to describe health and health-related states. The framework can be used to classify the impact of health on a person (World Health Organisation, 2002). The main components of the WHO-ICF are body functions and structures, participation, activity and the personal and environmental contextual factors (World Health Organisation, 2002). Representation of the WHO-ICF model of disability is presented in Diagram 1 (World Health Organisation, 2002), and its components are explained in more detail below.

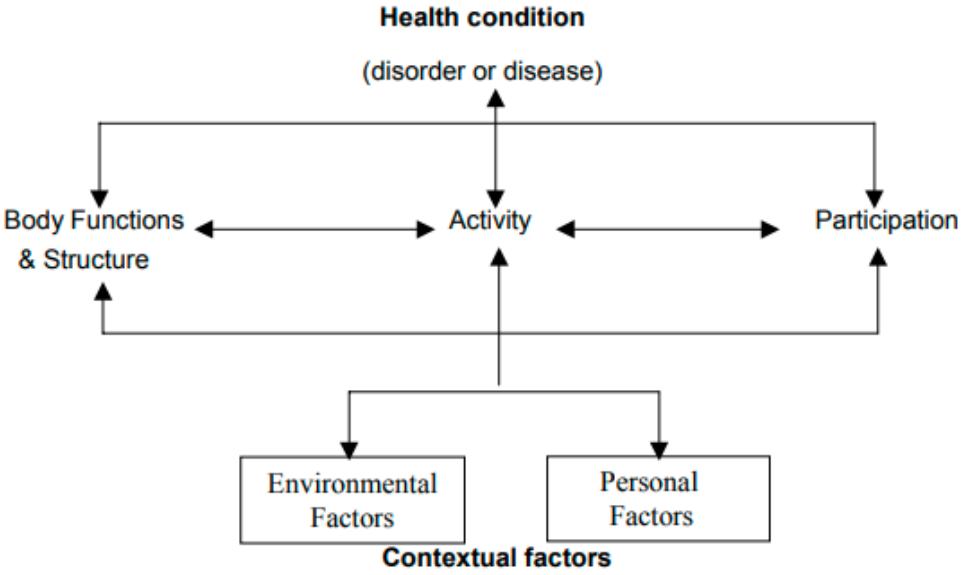

Diagram 1 – WHO-ICF Model of Disability, reproduced from World Health Organisation, 2002 p.9

Firstly, the body functions include the psychological and physiological functions of body systems; whereas the body structures are the anatomical parts of the body. Activities and participation cover all aspects of functioning (World Health Organisation, 2002).

Secondly, activities are defined as the execution of a task or action by a person, and participation refers to an individual's involvement in a life situation. The WHO-ICF describes difficulties an individual may experience with these activity limitations and participation restrictions, respectively (World Health Organisation, 2002). Importantly, the WHO-ICF lists performance and capacity as qualifiers for activity

and participation. Capacity refers to an individual's ability to execute a task in a given domain at a given moment. Whereas the performance describes what a person does in their own environment, including using aids or assistance.

Thirdly, the personal factors are internal to the individual and refer to factors such as gender, age, race, social background, habits, fitness levels and lifestyle. The environmental factors are external to the individual form their physical, social and attitudinal environment (Bonder et al., 2008).

One of the aims of the WHO-ICF is to establish a common language and provide the scientific basis for researching health and health determinants (Cole et al., 2007). Therefore, it helps to frame the understanding of the individuals' circumstances and provides common ground for communication and intervention planning in interprofessional and interagency working (McIntyre and Atwal, 2005). The WHO-ICF uses terms such as activity limitations and participation restrictions. The former refers to difficulties in executing activities, and the latter describes problems the person may experience during involvement in life situations (World Health Organisation, 2002).

The WHO-ICF adopts a bio-psychosocial approach. The medical model views disability as a direct result of disease, a health condition or trauma which can be fixed by treatment from a healthcare professional (Wade and Halligan, 2004). In contrast, the social model of disability does not attribute the disability to an individual but views it as a socially created problem (World Health Organisation, 2002). The biopsychosocial model proposes integrating the medical and social models of disability, therefore accepting all the aspects of disability (Wade and Halligan, 2017).

This framework also provides a foundation for all aspects of rehabilitation as it is focused on the impact of health conditions and a person's experience of health on their function. The WHO-ICF domains do not interact in a linear manner and help produce an understanding of the person and their context (World Health Organisation, 2002). As an example, the WHO-ICF provides a framework for a rehabilitative intervention to focus on correcting or modifying intrinsic factors in an

attempt to decrease personal limitations at a societal level. Alternatively, this framework allows for strategies focused on performance context that may choose environment modification to improve function through eliminating environmental barriers or creating environmental facilitators. The framework also allows rehabilitation strategies aimed at increasing capacity levels as well as other approaches. Importantly, it helps highlight the barriers and facilitators to a person's functioning linking intrinsic and extrinsic factors. For example, an older person with dementia may not have any activity limitation or participation restrictions when completing a task in their own environment but have difficulties in hospital due to environmental factors such as staff's attitudes to risk enablement or the physical hospital environment.

In this thesis, the WHO-ICF provided a framework to view the factors that influence change in ADL independence for hospitalised people with dementia and therefore helped guide the selection and organisation of potential intervention components. As the WHO-ICF places activities and function as the main determinants of health, it aligns with the core skills of occupational therapists and puts them in an ideal position to lead on the development of this intervention (Cole et al., 2007).

4.1.3 Person-Environment-Occupation-Performance Model

The OcTPAP was developed from an occupational therapy perspective, and therefore an occupational therapy practice model was used alongside the WHO-ICF. Occupational therapy in itself is a complex intervention. Occupational therapy interventions consist of multiple elements such as the therapist, the patient, the therapist's actions and how these actions relate to each other, the environment and the context (Creek, 2009).

The Person-Environment-Occupation-Performance (PEOP) model demonstrates the complexity of the person-occupation-environment relationship and applies a top-down approach (Duncan, 2011). This model is based on environmental theory, general systems theory, neurobehavioral theories, and social and behavioural

psychology, including Maslow's motivational learning and personality theorists influences (Cole et al., 2007).

The PEOP complements the WHO-ICF as it also sees function as central to health and wellbeing, but PEOP uses terms such as occupation and performance. PEOP also puts greater emphasis on fostering a person-centred relationship (Cole et al., 2007). The individual is asked to identify which occupational performance issues are of importance. When assessing an individual, physiological, neurobehavioral, psychological, cognitive and spiritual are the intrinsic factors that are considered. Extrinsic factors include the physical and natural environment, culture and values, social and economic systems, social support levels. The key constructs of the PEOP model are listed in Table 9.

Table 9 - Constructs of the PEOP Model reproduced from Cole et al., 2007 p.129

The Four Major Constructs to the PEOP Model
1. The person is made up of a series of intrinsic factors that make up one's set of skills and abilities. 2. Participation is always impacted by the extrinsic characteristics of the environment in which it occurs. 3. Occupations are the activities and tasks done in managing a person's daily life. They are a set of tasks that are grouped in some meaningful way so that the person can perform life roles. They are goal-directed pursuits, have temporal meaning, are recognisable by others, have meaning to the person, and involve multiple tasks. 4. Occupational performance and participation is the culmination of doing occupations. It is the interaction of a person's intrinsic factors, the environment (extrinsic factors), and one's chosen activity (occupations) that all lead to occupational performance and participation. It is a complex phenomenon. It describes the actions that are meaningful to a person as he or she cares for him or herself and for others, works, plays, and participates in home and community life. It is the successful outcome of the transactions among the person, environment, and occupations that the person seeks.

The PEOP used alongside the WHO-ICF can provide the occupational focus to OcTPAP, as well as helping understand the interrelations among diverse personal and environmental factors and their impact on a person's quality of life (Cole et al., 2007). In addition, PEOP provides a detailed account of what each domain includes assisting in a holistic approach. For example, under psychological factors, the model highlights the importance of motivation and internal processes that influence what an individual does and how this contributes to the sense of self. According to PEOP, a person's sense of fulfilment comes from mastery and a sense of self-identity that come with meaningful participation in occupations (Cole et al., 2007). This aligns with Kitwood's ideas about person-centred care in dementia which will be discussed later in this chapter.

Alternative occupational therapy models were considered as the basis for the development of OcTPAP, such as Allen's Cognitive Disabilities Model (CDM), Model of Human Occupation (MOHO) and Canadian Model of Occupational Performance and Engagement (CMOP-E). While the CDM would be a useful tool when matching activities to the person's cognitive level, a broader and more detailed model was required (OTheory, 2021). The MOHO addresses occupational change over the lifespan and emphasises people's volition, roles and habits (Kielhofner, 2008b). However, less detailed attention is given to the environment and occupation itself (Kielhofner, 2008b). The CMOP-E placed spirituality at the heart of the model and its concepts aligned with theories of active ageing. However, the model does not address the adaptation and compensation for decreasing function (Barney and Perkinson, 2016) associated with dementia and older age. All of these models are not specific to ageing but could have made valuable contributions to the intervention development. The PEOP was selected as the most suitable as it is broad and detailed and therefore supports the person-centred holistic approach.

4.1.4 Person-Centred Care

The WHO-ICF fits with the ethos of person-centred practice as it considers the function of individuals and how it is impacted by extrinsic factors (McIntyre and

Atwal, 2005). Kitwood's theory of person-centred care challenged the medical model of care (Kitwood, 1997, Mitchell and Agnelli, 2015). It focused on preserving "personhood" of the person with dementia, which embraced entering into a partnership with the person with dementia and supporting them to maintain identity and worth through communication and interaction strategies (Innes et al., 2012). Kitwood highlighted that adverse psychological, social and environmental influences excessively disable the person with dementia (Downs and Bowers, 2014). Principles of person-centred care from NICE guidelines for dementia care are listed in Table 10 (NICE, 2018). Involving carers, supporting and enhancing their input, as well as accounting for their needs is also included in the person-centred care guidance.

Table 10 - Principles of Person-centred Care reproduced from NICE, 2018 p.10

Principles of person-centred care
• The human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers. • The individuality of people living with dementia, and how their personality and life experiences influence their response to dementia. • The importance of the person's perspective. • The importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

4.1.5 Occupational Therapy Personal Activity Programme Proposed Mechanism of Action

The proposed mechanism of change is based on the theories discussed above in the context of the overall research topic for this study.

The level of participation that people with dementia maintain while in acute hospital setting is impacted by the person's health condition, how well their body functions on the structural level, their personal factors, the environment they are in and their ability to complete certain activities (World Health Organisation, 2002). Therefore, change could be facilitated through holistic assessment of what is causing activity limitations and participation restrictions during hospital admissions and create a rehabilitation plan accordingly (World Health Organisation, 2002, Duncan, 2011).

Continuing participation in meaningful activities is part of managing a person's daily life and performing their life role (Duncan, 2011), it can be argues that participation in occupations builds one's identity (Kielhofner, 2008a). It could be assumed that people's motivation to continue completing the task is linked to how competent they perceive themselves at completing this task (Kielhofner, 2008b). It must be noted that having dementia effects motivation (Williams, 2005, Gibson et al., 2004). Improvements in activities of daily living independence may be facilitated through addressing factors that are impacting on the participation, such as physical and cognitive deterioration, restrictive environment etc. (Duncan, 2011). This would mean adapting and progressing (grading) the activity demands in line with the person's abilities and available resources (Cole et al., 2007). For example, if the person struggles with concentration, completing meaningful activities in a less busy and quieter environment may help facilitate independence. Developing dementia does not mean the person does not have the capacity for rehabilitation (Laver et al., 2020). Additional strategies in comparison to general rehabilitation for older people are necessary, for example to support adherence to the rehabilitation plan. Daily use of rehabilitative approach should be embedded into the ethos of the ward.

Maintaining participation in activities that are meaningful to the person with dementia helps this person maintain identity and worth (Duncan, 2011). It is therefore proposed that understanding and appreciating the individuality of people living with dementia and how their previous life experiences influenced them (Kitwood, 1997) is key to planning rehabilitation and implementing solutions.

Therefore, if setting of rehabilitation goals is guided by the person with dementia with assistance from their families and carers it is more likely to have positive outcomes.

The interactions that hospital staff and visitors have with people with dementia have potential to promote wellbeing of that person with dementia (Mitchell and Agnelli, 2015). Therefore, each interaction could be used as an opportunity to both to learn more about the person with dementia and promote their independence.

4.2 Methods

4.2.1 Methods Considered

Three methods were considered for data synthesis, such as following a thread, mixed methods matrix, and triangulation. In this context synthesis means combining different ideas and facts to create a whole (Collins Dictionary, 2022). The aim of the data synthesis was to integrate data from the systematic review study (Chapter 2) and the qualitative interviews study (Chapter 3) to produce draft description of the OcTPAP.

Following a thread

Following a thread is a method for integrating data gathered through several methods (O'Cathain et al., 2010). The authors of the approach suggest identifying key themes and questions that need exploring further in each data set first (Moran-Ellis et al., 2006). Then "a thread" is followed by selecting one of the themes or questions from a dataset and following it across the other data sets (Moran-Ellis et al., 2006). So, for example, for this research study, a theme from the systematic literature review, such as "falls prevention focus" would be followed to check what the qualitative interview participants said about patient falls. However, the aim of this research study was to produce a draft intervention description, and it was important to identify any disagreements between data sets so they could be resolved during the next component of this research study.

Mixed Methods Matrix

Mixed methods matrix method allows integration of qualitative and quantitative data on the same cases during the analysis stage of the mixed methods study (O'Cathain et al., 2010). The data collected in all of the components on a single case is examined, highlighting any paradoxes (Creswell and Plano-Clark, 2017). The data across all cases is analysed for overall patterns (Creswell and Plano-Clark, 2017). As data on the same cases was not available, the mixed methods matrix was not appropriate for this research study.

Triangulation

Triangulation of data refers to a process of drawing on a variety of data sources to facilitate the investigation of a phenomenon from different angles (O'Cathain et al., 2010). It aims to provide more certainty regarding the findings or gain further understanding of the phenomenon (Grix, 2018). The triangulation protocol is the most detailed description of how triangulation should be completed and the only one to include silence as a domain, adding depths to the understanding of the data (O'Cathain et al., 2010). Triangulation protocol examines the findings from separate data sets in relation to their convergence, complementarity, contradiction and silence (Farmer et al., 2006).

The triangulation protocol was therefore selected to synthesise the evidence from the systematic literature review and qualitative interviews to gain a more complete picture, highlight any contradiction and inform the development of the intervention components (O'Cathain et al., 2010, Farmer et al., 2006). Using the triangulation protocol allowed a systematic and transparent way of combining evidence from multiple sources to be completed.

4.2.2 Triangulation Protocol Steps

Farmer et al. (2006) lists six steps to be completed to apply the triangulation protocol method. These steps were applied for synthesising the data for OcTPAP and are described below (Farmer et al., 2006).

Step 1: Sorting

The data set from the systematic review containing the description and content of the included interventions was re-reviewed to identify key themes. Then the data set from the interview findings was re-reviewed to identify key themes. A unified list of themes from both datasets was created by sorting the themes into similarly categorised segments that address the research question. These themes formed the rows of convergence coding matrix.

Step 2: Convergence Coding

The two data sets were then compared in terms of meaning and interpretation of themes, the frequency and prominence of themes. Specific examples were provided for each theme. The following four labels were used to characterise the relation between the data from the two data sets around each theme: convergence, complementarity, contradiction and silence. Convergence in data sets is agreement of findings, complementarity is when one data set is offering additional information on the same issue, contradiction is when findings from or within the datasets appear to be in dissonance with each other. Silence is when the findings arise from one data set but not the other.

Step 3: Convergence Assessment

All compared segments were reviewed to reflect on the overall level of convergence between datasets. Findings were presented to the supervisory team (PL, RH, SG, JH) for discussion and checking LP's interpretations mid-way through analysis.

Step 4: Completeness Assessment

To enhance the completeness of the combined datasets information the nature and scope of the data produced by each source was considered. Key differences in scope and coverage were reflected on.

Step 5: Researcher Comparison

This step assumes comparison of the assessments of convergence or dissonance and completeness of the united set of findings between multiple researchers. Only segments of the convergence matrix were explored in depth with other researchers from the supervisory team, with LP completing all of the analysis and synthesis of the datasets.

Step 6: Feedback

The results of the triangulation were presented to the supervisory team for review and discussion.

4.3 Results

4.3.1 Themes

The results of using the triangulation protocol to synthesise the data from the systematic review (Chapter 2) and interview study (Chapter 3) were summarised in the convergence coding matrix. An extract from the convergence coding matrix is presented in Table 11 which considers the component of goal setting, the full matrix is available on request. Forty seven themes arising from the evidence synthesis are presented in Table 12 and are organised following the TIDieR headings (Hoffmann et al., 2014). These themes were later used in generating Delphi consensus statements.

Table 11 - Intervention Modelling - Extract from Convergence Coding Matrix

Theme	Goal setting
Number of the systematic review studies that mention this	5 out of 13
Number of the interview participants that mention this	11 out of 20
Convergence, complementarity, contradiction and silence	Convergence: Setting goals which were important to the patient, following them up and updating the goals throughout the hospital stay. Example quotes from the systematic review studies: "*Patients were encouraged, using the TLS-BasicADL protocol, to consider activities that were important to them to be able to perform at discharge. They were invited to answer the following question; "Which activities are important for you to achieve during your inpatient care?" The individual goals were followed up and adapted throughout the hospital stay using the TLSBasicADL protocol.*" (Asplin et al., 2017) "*Team planning of the patient's individual rehabilitation process and goals twice a week.*" (Stenvall et al., 2007) Example quotes from the interview participants: *"To have shared decision making, to include a holistic approach with family members around desired goals, it's around the enabling approach, to get the patient to do as much for themselves as they can do, within their own time that they would need to be able to do that."* Participant 4 " We would say to the nurses, or, "Can you get them to walk, maybe today walk to the toilet with supervision", but tomorrow, I'll assess them and if they can do it tomorrow, walk to the toilet tomorrow" Participant 3

	Complementarity: Goals need to be realistic and specific. Knowing the baseline and what the normal routines are and trying to recreate these during the hospital admission. Getting the information from a variety of sources to get the bigger picture. If able, patients should also take responsibility for completing their rehabilitation. Being aware of capacity issues. Example quotes from the systematic review study: "*ADL retraining individually focussed and goal specific*" (Shearer and Guthrie, 2013) Example quotes from the interview participants: "*I think we probably are quite prescriptive with that and I think, definitely, with goals, we're quite prescriptive. Because in our head, we know how our system works, so we probably do that in our own way, and it's more that we probably ask people, when we want to give an intervention, are they happy with the intervention that we're going to give them."* Participant 11 *"A patient who was eating themselves, but was getting in a real mess and taking forever to eat a meal. I wanted to go and intervene, and I talked to the nurse, and she said that that wouldn't help and he doesn't like being helped, and he prefers to get on with it and take forever and get himself in a mess, but he manages better. So it's actually knowing your patient and knowing what they want, and what helps and doesn't help them, as opposed to what you think they want."* Participant 14 "*They need to continue with things they've accustomed to doing, because, if they don't, when they come back home, they've lost all that still. And once that start going, it's gone. And it depends on the degree of the illness, the person's illness as well*." Participant 18 "*I suppose, there would be more of an emphasis on maintaining what you would do at home. So, washing and dressing for yourself, doing your hair. I think, having a more flexible approach to, particularly eating and drinking times, and sleep times, in the realms of what you know is good for that person, would be useful*." Participant 5

	"If it was going to be a hospital based thing, it might need to be simple things that we could put in place that they might be able to, that you might be able to do, or potentially, something that you could start that would then be to be continued" Participant 10
	Contradiction: [No evidence]
	Silence: [No evidence]
Theme descriptions for OcTPAP (numbering from the full list of themes retained for transparency)	43. Rehabilitation goals need to be important to the patient and relevant to their past life (baseline and routines). 44. Trying to mimic patient's home timetable verses having set hospital routines. 45. Carers to be part of rehabilitation discussions and setting goals. 46. Rehabilitation goals need to be achievable in the environment and within the timeframe. Focus on finding out what activities were important for the person for discharge. Having activities that are relevant to the patients on their return home. 47. Goals to be monitored and adapted to match ability throughout the hospital stay.

Table 12 - Intervention Modelling - Themes from Synthesis

Themes from the synthesis of systematic literature review and qualitative interviews data
What (procedures and materials) 1. Getting the information from various sources (family, paid and unpaid carers, hospital and community records) to get "the bigger picture". Information from carers to form part of the assessment. 2. Carers coming in to help with care if they feel able to, but may need a break. 3. Patients to continuously be given feedback concerning their progress. 4. Retraining in activities of daily living by practicing patient's usual daily routines. 5. Practicing with assistive equipment on the ward – e.g. stocking aid. 6. Exercises with the goal of improving performance in a chosen ADL. Active and passive exercises. Exercises aimed at preventing or correcting contractures. Exercises aimed at increasing range of motion. 7. Cognitive stimulation: pool of exercises with an objective of activating mental functions. Cognitive exercise aimed at increasing perceptual and cognitive skills, promoting positive self-image through purposeful activities, reality orientation. 8. Intense external stimulation with an objective of increasing the patient's level of alertness. 9. Positioning to increase body alignment, improve postural control, enhance upper extremity, and prevent contractures. 10. Use of devices and adaptations to prevent oedema and bedsores on vulnerable body areas. 11. Addressing falls risks, falls prevention and coping strategies. 12. Recommendations for how patient can maintain or increased independence at home, in activities of daily living, and social and occupational activities. Home visits and safety assessment. 13. Interventions aimed at community reintegration. 14. Rehabilitation assessment to be holistic (physical, functional, cognitive, social, neuropsychological and emotional assessment). 15. Appropriate leadership and culture on the ward. 16. Staff to have dementia training. Interprofessional learning. Continuous training for staff, not a one off. 17. "Dementia friendly" approach. Not stereotyping or making too many assumptions. Checking patient's understanding of their ability. Evidence based practice. 18. Enough staff and staff time to allow patients to encourage patients to complete the activities independently, at their own pace.

19. Ward environment designed to prevent disability and maximise independence (more homely and "dementia friendly" environment), having access to rehabilitation gymnasium.
20. Assessment for aids that would be used during hospital admission and at home.
21. Patient having their own belongings and familiar items in hospital and staff helping the patient to use them (even though these may get lost or soiled).
22. Using information gained during assessments in rehabilitation planning.
23. Written record of patient's rehabilitation progress. Effective handover of information.
24. Having activity groups (led by activity co-ordinators). Need for social activities on the ward.
25. Having not medically related activities available on the ward that are relevant to the patient group.

Who provided

26. Staff to have the skills to assess the need for ADL retraining accurately.
27. Staff to be able to adapt and update rehabilitation plan as situation changes. Unpicking what parts patients have difficulties with (activity analysis).
28. Having a professional assigned to each patient responsible for assessing the patient's specific needs daily and implementing protocols for the prevention of disability and for rehabilitation in addition to multidisciplinary input. Should there be a designated person or team for rehab, or is it a responsibility of all the team (including catering staff etc)?
29. Encouraging independence is everyone's responsibility including domestic staff and family carers or wider community.

How

30. Explaining to patients and carers what is expected from them during the admission in relation to rehabilitation. Having information that advises patients and their carers on how they can maintain their independence to avoid misconceptions. Addressing "patient role" misconceptions.
31. Provision of education for carers on what to expect during the admission and other relevant topics.
32. The patients to do as much as they can by themselves before they are helped. Every activity as rehabilitation, need to involve patient as much as possible. Patient having options to complete activities more independently.
33. If able, patients should also take responsibility for completing their rehabilitation. Being aware of capacity issues. Encouraging patient to take more responsibility for own recovery, practising without staff supervision if able.
34. One to one interactions.
35. Risk assessment to address potential consequences of increased activity.

36. Communication and referral to community services for after the discharge.

Where

37. Most of the intervention delivered in hospital, with outreach to community in a form of home visits.

When and how much

38. Starting from the day of admission or as soon as person is medically stable enough to participate in even minimal rehabilitation (or when the active period of disease has been managed).
39. Continuity of care to be achieved by more professions and specialities adopting seven day working.
40. The session to be 45-60 minutes, sometimes including the carer. Clinically determined by an OT.
41. A minimum of one weekly session by an OT, a maximum of two daily sessions.
42. Awareness of what services are actually funded to do.

Tailoring

43. Rehabilitation goals need to be important to the patient and relevant to their past life (baseline and routines).
44. Trying to mimic patient's home timetable verses having set hospital routines.
45. Carers to be part of rehabilitation discussions and setting goals.
46. Rehabilitation goals need to be achievable in the environment and within the timeframe. Focus on finding out what activities were important for the person for discharge. Having activities that are relevant to the patients on their return home.
47. Goals to be monitored and adapted to match ability throughout the hospital stay.

4.3.2 Areas of Contradictions and Silence

Data synthesis highlighted three areas of contradiction between the data sets and six areas of silence. Data sets did not agree on:

- Whether the rehabilitation should be led by a designated professional, a team or be everyone's responsibility. This contradiction was evident both within and across the datasets.
- The frequency of the rehabilitation provision, across and within the two data sets. It ranged from a minimum of one weekly session by an occupational therapist to three times a day.

- Whether following set hospital routines was beneficial for the patients. This contradiction was within the qualitative interviews data set.

Topics highlighted in the systematic literature review but not the qualitative interviews were:

- Exercises.
- Cognitive stimulation.
- Sensory stimulation.
- Falls management.
- Positioning.

The topic highlighted in the qualitative interviews but not in the systematic literature review dataset was:

- Managing risks related to increased patient activity.

4.4 Discussion

This study found forty seven themes which resulted from the data synthesis of the systematic review and qualitative interview findings. The synthesis results highlighted contradictions in data sets about who should be leading and delivering OcTPAP, frequency of its delivery, and whether there is a benefit to set hospital routines. Topics which were "silent" in one of the data sets were intervention components such as exercises, cognitive stimulation, sensory stimulation, falls management, positioning and risk management. In this section, the strength and weaknesses of the completed intervention modelling will be presented.

One of the strength of this component of the study is the transparency of the steps taken to develop the intervention. MRC guidelines have been widely used for the development of interventions for older adults (Booth et al., 2019). However, the intervention development phase is not described in sufficient detail and multiple sources of evidence attempting to expand on that guidance exist, some of which contain conflicting information (O'Cathain et al., 2019). The MRC guidance was

updated in September 2021, after this research study has concluded and is addressed in Chapter 6.

Using triangulation as a method of data synthesis enhanced the comprehensiveness and the validity of the conclusions, providing the robustness of the data from the two sources being combined (Farmer et al., 2006, Thurmond, 2001). However, the individual strengths and weaknesses of the two data sources must be considered, as the process of triangulation may amplify sources of error (Farmer et al., 2006). For example, studies identified through the systematic review may have not contained all the necessary details on the content and the context of the described interventions. The qualitative interviews may have represented only opinions of the participants from a specific geographical region. However, both data sets did not share the same weaknesses and were investigating the same phenomena which is needed for corroboration (Grix, 2018).

The synthesis results could have been reinforced by having multiple researchers complete and then compare the assessments of convergence or dissonance of the data to agree on interpretations (Farmer et al., 2006). However, the convergence matrix was presented to the supervisory team and extracts were discussed in depth, which strengthened the validity of the conclusions.

4.5 Conclusion

The MRC framework was used to develop the rehabilitation intervention. The proposed mechanism of action for OcTPAP was presented in this chapter. Potential OcTPAP components were identified through the completion of a systematic literature review and qualitative interviews. The data from these sources was them synthesised using triangulation protocol and added to the underlying theory of OcTPAP to be further refined using Delphi consensus study described in the next chapter.

Chapter 5 - A Delphi Consensus Study to Refine the Intervention Components for the Occupational Therapy Personal Activity Programme

This chapter describes the fifth step in the development of the Occupational Therapy Personal Activity Programme (OcTPAP) (Figure 6). The synthesised evidence from the previous stages of the research study needed to be refined and was therefore subjected to a Delphi consensus. Intervention components that reached the predefined consensus level were included in the final description of OcTPAP. Delphi consensus is reported in line with Guidance on Conducting and Reporting Delphi Studies (CREDES) (Jünger et al., 2017). The resulting full OcTPAP description, ready for testing in a proof of concept study is presented in Chapter 6.

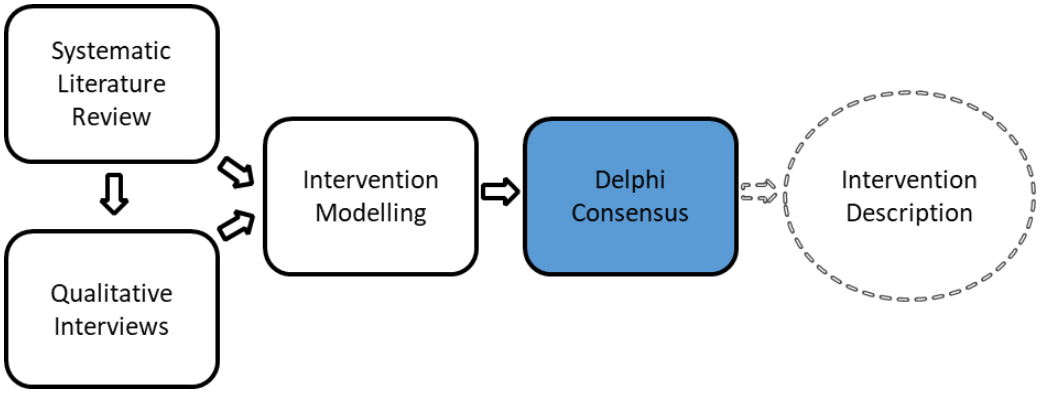

Figure 6 - Research Study Components - Delphi Consensus

5.1 Purpose and Rationale for Delphi Consensus

The initial OcTPAP components were generated by synthesising systematic review and qualitative interview evidence. Some of the evidence provided incomplete and divergent information for intervention description. Further clarification and refinement of OcTPAP components was necessary and was addressed by seeking consensus from experts. Methods such as consensus conference, nominal group

technique and Delphi consensus were considered for suitability to answer the research question.

5.1.1 Consensus Conference

A consensus conference provides a platform for evidence to be presented by the participants and facilitates in-person dialogue and debate (Halcomb et al., 2008). Consensus conferences mostly aim to identify research priorities for a discipline or reach an agreement about a specific policy issue. Such conferences start with presentations of the importance of the discussed issue and justifications for the need for having consensus and are followed by a group discussion about the topic's advantages and disadvantages. At the end of the conference, the participants are invited to vote on the discussed issues (Keeney et al., 2011). More resources may be needed to cover the costs of hiring a conference venue and organising the conference, in contrast to the remote consensus techniques (Keeney et al., 2011).

5.1.2 Nominal Group

A nominal group technique is a consensus method usually completed face-to-face. It starts with silent ideas generation, then participants take turns sharing one idea at a time with the group. Ideas are then clarified and grouped by themes. These ideas are ranked anonymously by the participants, and the outcomes are later presented to all participants (McMillan et al., 2016). The nominal group technique is very structured and moderator-led, which can be very productive, but limits discussion and therefore may not allow full development of ideas (Keeney et al., 2011, Dunham, 2006).

5.1.3 Delphi Consensus

The Delphi technique is a type of survey design with multiple stages that aims to achieve consensus on an important topic among a group of experts (Diamond et al., 2014). The technique is mainly used for either priority setting or to gain a consensus

on a set of issues. Differing forms of the Delphi technique exist, such as the "classical Delphi", the "technological Delphi" and the "modified Delphi" (Keeney et al., 2011) and are described in detail later in this section.

5.1.4 Strength and Limitations of These Methods

Both nominal group technique and consensus conference methods would have provided an opportunity for a face-to-face discussion and potentially could generate a better understanding of the context. However, lack of anonymity, group dynamics and opinions of dominant individuals could dictate the direction of the discussions and the outcome. Furthermore, practically, it is difficult to get a group of experts in a specific field together on a set date (Keeney et al., 2011). Strengths of the Delphi technique include anonymity, relieving participants of undue social pressure to agree with other group members. Delphi technique allows for ideas to be evaluated on their merit while still being informed of the other participants' views after each round (Skulmoski et al., 2007) and that the exercise can be completed at a convenient time for the participant. Therefore Delphi consensus technique was selected to seek consensus from experts on the essential components of OcTPAP.

5.1.5 Selecting Delphi Consensus Type

The technological Delphi, classical Delphi, and modified Delphi were considered for suitability. The technological Delphi involves participants reaching consensus in real-time using technology, which allows them to vote and then see instant feedback of the mean and/or median of the group answers and to re-vote with this information in mind (Keeney et al., 2011). This requires all of the participants to be available at the agreed time, and the experts could be in the same room (Keeney et al., 2011). In a classical Delphi, the first round is used to generate ideas that are then summarised and evaluated by the participants in the following rounds (McMillan et al., 2016). In a modified Delphi, the first round is replaced by a different data collection method, such as interviews (Keeney et al., 2011). The

classical Delphi and the modified Delphi can be completed remotely via post or electronically.

The modified Delphi technique was selected for this study as the systematic literature review, and the qualitative interview components provided the required data regarding potential OcTPAP components and their context replacing the first round of a classical Delphi. The first round of the Delphi built on the evidence synthesis, asking participants for their opinions and comments.

Guidance on Conducting and Reporting Delphi Studies (CREDES) was followed to clearly demonstrate the quality of the study conduct and transparency of reporting (Jünger et al., 2017). Clearly defined criteria for when consensus is regarded to have been achieved are essential (Jünger et al., 2017, Diamond et al., 2014). The number of rounds and the conditions on which Delphi terminates should be made clear. To improve rigour, these and other conditions specified in CREDES have been taken into account in the study's protocol before completing the Delphi consensus (Jünger et al., 2017).

The aim of the modified Delphi study described in this chapter was to reach an agreement on the content of the OcTPAP.

5.2 Methods

The flow chart of the Delphi process is presented in Figure 7 and the Delphi process is described in detail in the following sections.

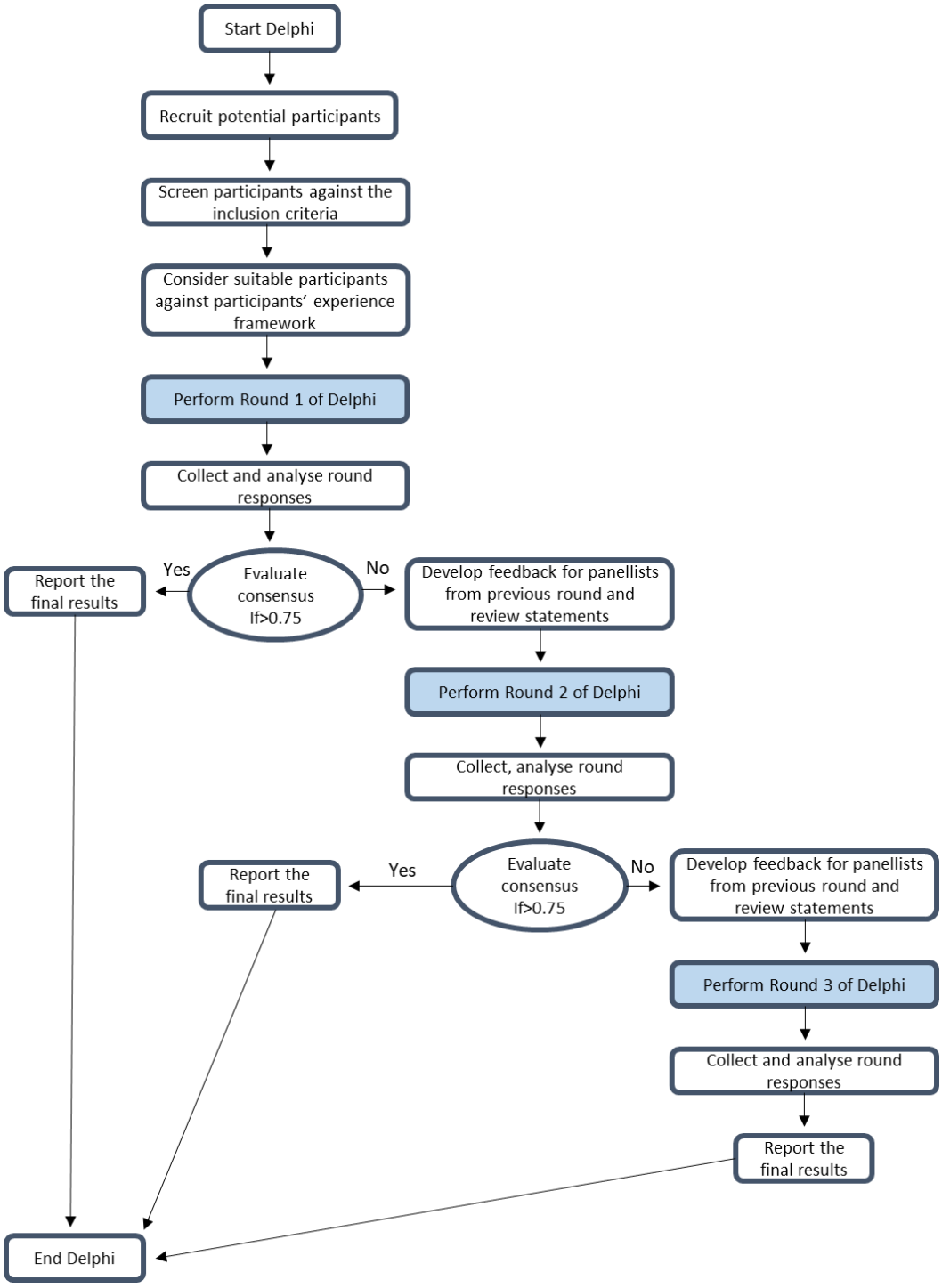

Figure 7 - Delphi Consensus Flow Chart

5.2.1 Ethical Approval

Detailed Delphi protocol was submitted to the Faculty of Medicine & Health Sciences Research Ethics Committee and received approval in March 2019, reference number 235-1902 (Appendix H), including an amendment in July 2020

(Appendix N). The amendment was submitted to change recruitment criteria from “academics and clinicians” with specific experience to “occupational therapists” with the same experience.

5.2.2 Statement Development

Delphi statements for the first round were generated from the convergence coding matrix themes with guidance and in discussion with the supervisory team (PL, RH, SG, JH). After discussion with the supervisory team a number of themes from the convergence coding matrix (Chapter 4) and underlying theory of OcTPAP were summarised in the introductory statement of the first Delphi questionnaire. The introductory statement clarified the assumptions that the participants could make about the OcTPAP and the environment it is being delivered in. The remaining statements were listed using the TIDieR (Template for Intervention Description and Replication) guidance headings for the Delphi consensus questionnaire (Hoffmann et al., 2014). Using TIDieR allowed a structured and logical presentation of the proposed components and ensured the developed intervention would be sufficiently described.

The phrasing of the statements was reviewed separately by the Patient and Public Involvement (PPI) collaborator and the Alzheimer's Society monitors for clarity and appropriateness. The supervisory team reviewed a number of iterations of statement phrasing until an agreement on phrasing was reached. Each statement and the themes that it was developed from are presented in Table 13. Theme numbering is retained in line with Chapter 4 synthesis themes to facilitate transparency.

Table 13 - Delphi Consensus - Statements against Themes from Data Synthesis

Statement for Round One	**Themes from the Data Synthesis**
Personal activity goals should be identified with the patient.	17. "Dementia friendly" approach. Not stereotyping or making too many assumptions. Checking patient's understanding of their ability. Staff following evidence based practice. 43. Rehabilitation goals need to be important to the patient and relevant to their past life (baseline and routines). 46. Rehabilitation goals need to be achievable in the environment and within the timeframe. Focus on finding out what activities were important for the person for discharge. Having activities that are relevant to the patients on their return home.
Family carers should be involved in helping set personal activity goals.	45. Carers to be part of rehabilitation discussions and setting goals.
Personal activity goals should be specific and measurable.	46. Rehabilitation goals need to be achievable in the environment and within the timeframe. Focus on finding out what activities were important for the person for discharge. Having activities that are relevant to the patients on their return home.
Personal activity goals should be achievable within the constraints of the hospital environment.	46. Rehabilitation goals need to be achievable in the environment and within the timeframe. Focus on finding out what activities were important for the person for discharge. Having activities that are relevant to the patients on their return home.
Personal activity goals should be relevant to patient's usual daily activities on return home.	46. Rehabilitation goals need to be achievable in the environment and within the timeframe. Focus on finding out what activities were important for the person for discharge. Having activities that are relevant to the patients on their return home.
Patients should have the same control over their daily routines as they would at home.	44. Trying to mimic patient's home timetable verses having set hospital routines.

Ward staff should never try to persuade a patient who is reluctant to practice self-care ADLs.	18. Enough staff and staff time to allow patients to encourage patients to complete the activities independently, at their own pace. 29. Encouraging independence is everyone's responsibility including domestic staff and family carers or wider community.
Personal activity goals should be monitored and adapted to match patient's ability throughout the hospital stay.	47. Goals to be monitored and adapted to match ability throughout the hospital stay.
Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records.	1. Getting the information from various sources (family, paid and unpaid carers, hospital and community records) to get "the bigger picture". Information from carers to form part of the assessment. 36. Communication and referral to community services for after the discharge.
If available, family carers should be involved in the rehabilitation process.	2. Carers coming in to help with care if they feel able to, but may need a break. 29. Encouraging independence is everyone's responsibility including domestic staff and family carers or wider community. 30. Explaining to patients and carers what is expected from them during the admission in relation to rehabilitation. Having information that advises patients and their carers on how they can maintain their independence to avoid misconceptions. Addressing "patient role" misconceptions. 40. The session to be 45-60 minutes, sometimes including the carer. Clinically determined by an OT. 45. Carers to be part of rehabilitation discussions and setting goals.
Patients should continuously be given feedback concerning their progress.	3. Patients to continuously be given feedback concerning their progress.
Independence in activities of daily living	4. Retraining in activities of daily living by practicing patient's usual daily routines.

should be maintained/regained through practising activities of daily living.	5. Practicing with assistive equipment on the ward – e.g. stocking aid.
OcTPAP must include physical exercises aimed at improving ability to complete activities of daily living independently.	6. Exercises with the goal of improving performance in a chosen ADL. Active and passive exercises. Exercises aimed at preventing or correcting contractures. Exercises aimed at increasing range of motion.
OcTPAP must include a component focusing on cognitive stimulation.	7. Cognitive stimulation: pool of exercises with an objective of activating mental functions. Cognitive exercise aimed at increasing perceptual and cognitive skills, promoting positive self-image through purposeful activities, reality orientation.
OcTPAP must include a component focusing on sensory stimulation.	8. Intense external stimulation with an objective of increasing the patient's level of alertness.
OcTPAP must include a component focusing on positioning.	9. Positioning to increase body alignment, improve postural control, enhance upper extremity, and prevent contractures.
OcTPAP must include a component focusing on pressure care.	10. Use of devices and adaptations to prevent oedema and bedsores on vulnerable body areas.
OcTPAP must include a component focusing on falls prevention.	11. Addressing falls risks, falls prevention and coping strategies.
OcTPAP should include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital.	12. Recommendations for how patient can maintain or increased independence at home, in activities of daily living, and social and occupational activities. Home visits and safety assessment. 20. Assessment for aids that would be used during hospital admission and at home.
OcTPAP should include goals that patient would continue working on after discharge.	12. Recommendations for how patient can maintain or increased independence at home, in activities of daily living, and social and occupational activities. Home visits and safety assessment. 13. Interventions aimed at community reintegration.

	20. Assessment for aids that would be used during hospital admission and at home.
OcTPAP should start as soon as the patient is well enough to participate in activities of daily living.	38. Starting from the day of admission or as soon as person is medically stable enough to participate in even minimal rehabilitation (or when the active period of disease has been managed).
Patients should be supported to participate in OcTPAP seven days a week.	39. Continuity of care to be achieved by more professions and specialities adopting seven day working.
There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence.	41. A minimum of one weekly session by an OT, a maximum of two daily sessions.
The length of occupational therapy personal activity sessions should be clinically determined by an occupational therapy worker.	40. The session to be 45-60 minutes, sometimes including the carer. Clinically determined by an OT.
The length of occupational therapy personal activity session should always be fixed to a minimum of 45 minutes.	40. The session to be 45-60 minutes, sometimes including the carer. Clinically determined by an OT.
Ward staff should wait for a registered occupational therapist assessment before allowing a patient to wash and dress.	28. Having a professional assigned to each patient responsible for assessing the patient's specific needs daily and implementing protocols for the prevention of disability and for rehabilitation in addition to muldisciplinary input. Whether there should be a designated person or team for rehabilitation, or is it a responsibility of all the team (including catering staff etc).

Ward staff should have the skills to adapt and update the rehabilitation plan.	26. Staff to have the skills to assess the need for ADL retraining accurately. 27. Staff to be able to adapt and update rehabilitation plan as situation changes. Unpicking what parts patients have difficulties with (activity analysis).
There should be a named key worker responsible for daily review of each patient's personal activity programme.	28. Having a professional assigned to each patient responsible for assessing the patient's specific needs daily and implementing protocols for the prevention of disability and for rehabilitation in addition to multidisciplinary input. Whether there should be a designated person or team for rehabilitation, or is it a responsibility of all the team (including catering staff etc).
The named key worker responsible for daily review of each patient's personal activity programme should be either a registered occupational therapist or an occupational therapy support worker.	28. Having a professional assigned to each patient responsible for assessing the patient's specific needs daily and implementing protocols for the prevention of disability and for rehabilitation in addition to multidisciplinary input. Whether there should be a designated person or team for rehabilitation, or is it a responsibility of all the team (including catering staff etc).
The named key worker responsible for daily review of each patient's personal activity programme must be a registered occupational therapist.	28. Having a professional assigned to each patient responsible for assessing the patient's specific needs daily and implementing protocols for the prevention of disability and for rehabilitation in addition to multidisciplinary input. Whether there should be a designated person or team for rehabilitation, or is it a responsibility of all the team (including catering staff etc).
Expectations about the OcTPAP should be discussed with patients and family carers.	30. Explaining to patients and carers what is expected from them during the admission in relation to rehabilitation. Having information that advises patients and their carers on how they can maintain their independence to avoid misconceptions. Addressing "patient role" misconceptions. 31. Provision of education for carers on what to expect during the admission and other relevant topics.
Patients should be encouraged to do as much as they can by themselves before they are helped.	30. Explaining to patients and carers what is expected from them during the admission in relation to rehabilitation. Having information that advises patients and their carers on how they can maintain their independence to avoid misconceptions. Addressing "patient role" misconceptions.

	32. The patients to do as much as they can by themselves before they are helped. Every activity as rehabilitation, need to involve patient as much as possible. Patient having options to complete activities more independently.
Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living.	29. Encouraging independence is everyone's responsibility including domestic staff and family carers or wider community. 32. The patients to do as much as they can by themselves before they are helped. Every activity as rehabilitation, need to involve patient as much as possible. Patient having options to complete activities more independently.
Patients should be encouraged to take more responsibility for their own recovery of independence.	33. If able, patients should also take responsibility for completing their rehabilitation. Being aware of capacity issues. Encouraging patient to take more responsibility for own recovery, practising without staff supervision if able.
OcTPAP should only be delivered through one to one interactions.	34. One to one interactions.
OcTPAP should include a documented risk assessment to address potential consequences of increased independent activity.	35. Risk assessment to address potential consequences of increased activity.
OcTPAP should include verbal and written communication with community services for information sharing and follow up.	36. Communication and referral to community services for after the discharge.
An occupational therapy worker should be able to assess/treat the patient in the patient's home following discharge.	37. Most of the intervention delivered in hospital, with outreach to community in a form of home visits.
Introduction to the first Delphi questionnaire.	14. Rehabilitation assessment to be holistic (physical, functional, cognitive, social, neuropsychological and emotional assessment).

	15. Appropriate leadership and culture on the ward. 16. Staff to have dementia training. Interprofessional learning. Continuous training for staff, not a one off. 17. “Dementia friendly” approach. Not stereotyping or making too many assumptions. Checking patient’s understanding of their ability. Staff following evidence based practice. 18. Enough staff and staff time to allow patients to encourage patients to complete the activities independently, at their own pace. 19. Ward environment designed to prevent disability and maximise independence (more homely and “dementia friendly” environment), having access to rehabilitation gymnasium. 21. Patient having their own belongings and familiar items in hospital and staff helping the patient to use them (even though these may get lost or soiled). 22. Using information gained during assessments in rehabilitation planning. 23. Written record of patient’s rehabilitation progress. Effective handover of information. 24. Having activity groups (led by activity co-ordinators). Need for social activities on the ward. 25. Having not medically related activities available on the ward that are relevant to the patient group. 42. Awareness of what services are actually funded to do.

The online questionnaire for round one of the Delphi was piloted with three clinicians unrelated to the study for functionality and clarity of the statements. This resulted in minor changes to the wording and the layout of the online questionnaire. The final version of Round one of the Delphi questionnaire can be found in Appendix O.

5.2.3 Expert Panel Size and Membership

Purposive sampling was selected to allow the inclusion of relevant experts. Working with patients on their ADL is well established in occupational therapy (American Occupational Therapy Association, 2020). Occupational therapists' core skills include performance analysis, functional activity analysis, teaching and coaching skills, environmental analysis skills (College of Occupational Therapists, 2016). Research question of this Delphi study aligns well with the knowledge and expertise as well as core values and beliefs of occupational therapy (Curtin et al., 2009, WFOT, 2021). While the opinions of other clinicians could have been beneficial in OcTPAP refinement, these have already been explored in some depth during the qualitative study (Chapter 3) and formed foundation of this complex intervention. Only occupational therapists were selected as this study aimed to develop a rehabilitation programme to be delivered or led by occupational therapists, representing a professionally homogenous group.

A sample size of 10-15 participants is recommended for homogenous groups (Skulmoski and Krahn, 2007, Delbecq and Van de Ven, 1975). Homogenous expert panels allow for the validity of results with a smaller sample (Duncan et al., 2004, Atkins et al., 2015). A sample of 20 was proposed to account for the attrition of participants over the three rounds, ensuring that meaningful conclusions could be drawn from the data. Evans (1997) suggests that smaller panels tend to have lower or non-existent dropout rates.

For this research study, an expert was defined as an occupational therapist with three or more years of experience of work or research in the areas of rehabilitation and/or dementia from the community and/or acute hospital settings. Currently, there is no agreement in Delphi literature on the definition of an expert (Baker et al., 2006).

Jünger et al. (2017) found that experts in Delphi studies were mostly identified by belonging to a particular profession or stakeholder group, being associated with a particular field and having relevant clinical or academic expertise. Baker et al. (2006) considered knowledge, experience and ability to influence policy as common

characteristics attributed to experts included in Delphi studies. The latter was less relevant to the current stage of the development process. Knowledge is demonstrated through having a professional registration. In the UK, Occupational therapists qualify by completing a BSc or an MSc degree in occupational therapy (Royal College of Occupational Therapists, 2019) and then register to practice with Health and Care Professions Council (HCPC, 2022). Experience is often determined by having worked for a certain length of time in a relevant area (Baker et al., 2006). There is no agreed length of experience that is required. However, a study by Hardy et al. (2004) used having a specific professional qualification and a minimum of three years of clinical experience as criteria for their Delphi study.

The inclusion criteria were:

- Registered occupational therapist.
- Three or more years of experience of work or research in the areas of rehabilitation and/or dementia from community and/or acute hospital setting (self-reported).
- Able to give informed consent.
- Eighteen years of age or over.

The exclusion criteria were:

- Participants who are not fluent in written English.
- Unable to use email.

The potential participants who met the essential inclusion and exclusion criteria were considered against a participants' experience framework. This framework was developed with the supervisory team to reduce the risk of selection bias if too many volunteered to participate in the study (Figure 8). Participant characteristics such as work experience in an acute hospital setting, community setting, geriatrics and dementia care and current area of clinical practice were considered. A mixture of occupational therapists with experience from any of these areas were sought to provide a comprehensive input covering the whole patient pathway and a range of services. It was agreed that the therapists with experience of working with older

adults in an acute hospital setting have to form about 70% of the sample, as this was the setting where OcTPAP was to be used once developed. Occupational therapists who were working with older adults in acute care at the point of recruitment were invited to participate in the study in the order that they contacted the researcher. The selected participants received an electronic link to the first questionnaire. The potential participants whose expertise was already represented were advised that they would be contacted if there was space for more occupational therapists from their areas of expertise. The individuals who contacted the researcher but did not fit the inclusion criteria were thanked for their interest but did not take part in the study.

Participant code	**Current speciality**	**Experience (years)**				**Suitability**		
		Acute hospital setting	Community setting	Dementia	Rehabilitation for older people	No	Yes	Yes, but overrepresented

Figure 8 - Delphi Consensus Participants' Experience Framework

5.2.4 Recruitment Strategy

Participants for the Delphi consensus were recruited through existing clinical, academic and professional networks, including EMRAN (East Midlands Research into Ageing Network), the British Geriatrics Society, RCOT SS Older People (Royal College of Occupational Therapy Special Interest Group), EM CAHPR (East Midlands Council for Allied Health Professions Research), EM Clinical academic NMAHP (East Midlands Clinical academic Nursing, Midwifery and Allied Health) group. The composition of a group of participants impacts the validity, reliability, credibility and acceptability of the findings (Campbell and Cantrill, 2001). Therefore, professional networks, which could include occupational therapists working with older adults or who have an interest in research in this area, were accessed.

Members of these networks received a recruitment poster (Appendix P) via email explaining the study and were asked to contact LP if they wished to take part. The poster was reviewed by local clinicians for presentation and content clarity. A voucher was offered for participation on the condition of the participants completing all the Delphi study rounds. Those who responded were emailed a participant information sheet (Appendix Q) and were offered an opportunity to have their questions about the study answered by the researcher (LP). The response email also included questions to clarify their clinical experience and establish whether the potential participants fit inclusion and exclusion criteria.

5.2.5 Consent

Completion and submission of the online questionnaire was taken as informed consent.

5.2.6 Consensus Criteria

It is important for the trustworthiness of the Delphi outcome that there are pre-defined criteria for consensus and stopping the Delphi process (Diamond et al., 2014). For this study, the consensus threshold was set at 75% agreement, and the study would terminate if consensus was reached on all items or after Delphi's third iteration (Diamond et al., 2014). This is consistent with other studies where the consensus threshold has been set at ≥70% agreement among respondents (Hasson et al., 2000). In their systematic review of Delphi studies, Diamond et al. (2014) reported the median threshold in studies for reaching consensus was 75%. The pre-defined consensus success criteria for this study were agreed upon by the supervisory team and the researcher (LP) and are listed in Table 14.

Table 14 - Delphi Consensus - Pre-defined Consensus Criteria

Delphi study pre-defined consensus success criteria
• Combined median scores of strongly agree and agree or strongly disagree and disagree were used in demonstrating consensus. • Statements rated strongly agree or agree by 75% or more of the participants have achieved a consensus. These statements are included in OcTPAP. • Statements rated strongly disagree or disagree by 75% or more of the participants achieved a consensus. These are excluded from OcTPAP. • The Delphi is conducted over a maximum of three rounds, with Delphi terminating earlier if all statements have reached consensus. • A response rate of ≥70% between rounds was necessary.

A minimum of 70% response rate was expected for each round to maintain the rigour (Keeney et al., 2011, Diamond et al., 2014). To reduce attrition, the Delphi was limited to three rounds even if some of the statements had not reached an agreement (Hasson et al., 2000). To enhance the response rate, if the participant did not return the questionnaire within the specified timeframe without explanation, two email reminders were sent approximately a week apart. If after the two reminders no response was received, after a week it was assumed that the participant no longer wished to participate in the study. The data collected from the participant to that point was still used in the analysis.

5.2.7 Data Collection

Online survey creator software Microsoft forms was used to create and host the Delphi consensus questionnaire (Microsoft, 2022a). Microsoft forms which is a part of Office 365 used by the University of Nottingham met the General Data Protection Regulation requirements (Microsoft, 2022b). The online questionnaire was piloted with three clinicians unrelated to the study for accessibility and the layout was updated following their suggestions. Participants were asked about their experience to check their suitability for the study before receiving the

questionnaire link. However, three screening questions were also added as a precaution to the beginning of the first questionnaire to ensure that clinicians who did not meet the inclusion criteria did not spend time generating data that could not be used in this research.

To decrease respondent fatigue and improve participant retention, a five-point Likert scale was selected (Ben-Nun, 2008, Bouranta et al., 2009). Five-point scales permit the neutral midpoint answer, decreasing the occurrence of forced answers (Keeney et al., 2011). Furthermore, it is documented that scales with four or fewer response categories have the lowest correlations with the criterion and perform less well in relation to intertertile discriminating power and test-retest reliability coefficients (Preston and Colman, 2000). While scales with 7 to 10 points were reported as most reliable, scales with five response categories was rated as the easiest to use (Preston and Colman, 2000).

For the first Delphi round, selected participants received a link to the online questionnaire and an assigned identification code to enable completion tracking. Participants were asked to complete the questionnaire within two weeks. The introduction to the questionnaire explained the purpose of the study, how the statements were developed, stated the assumptions that the participants can make about the environment the OcTPAP will be delivered in, the definition of the key concepts and instructions for completion. This was followed by 38 statements that were split into the Template for Intervention Description and Replication (TIDieR) checklist headings (Hoffmann et al., 2014). An example of a statement and scoring can be found in Figure 9. Space for additional suggestions on the programme was provided after these sections. The questionnaire concluded with gathering demographic data (Appendix O).

In the following Delphi rounds, statements that did not reach the set consensus level were reviewed by the researcher (LP) and supervisory team and edited to be included in the next round.

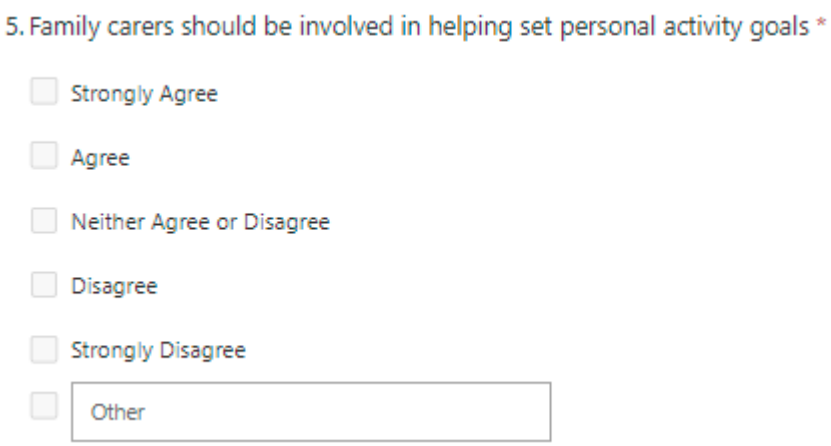

Figure 9 - Delphi Consensus Statement Scoring Example

In round two, the participants were sent a summary of the results of the previous questionnaire. This included a list of statements that reached consensus in round one and revised statements to be rated, with a rationale for the revisions. An example can be found in Figure *10*. Participants were asked to follow the same rating process as in the first round. If consensus was not reached for all statements in round two, the same process would have been repeated as for round two.

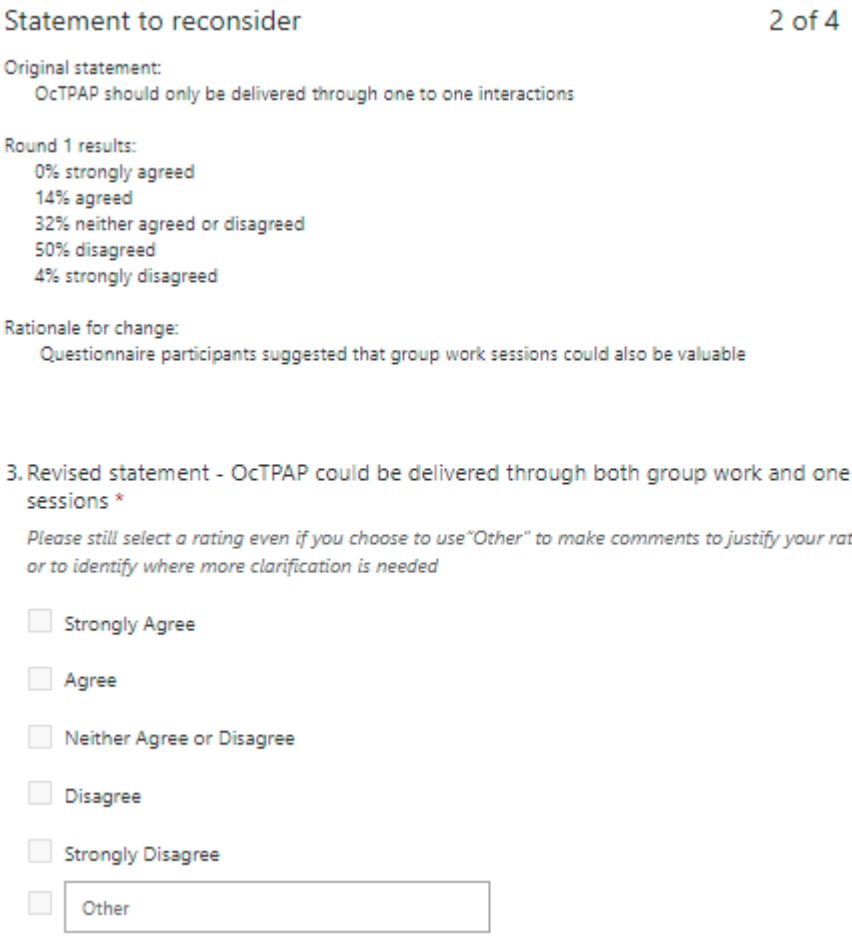

Figure 10 - Delphi Consensus Revised Statement Example

5.2.8 Data Analysis

Responses after each round were quantitatively analysed for levels of agreement using counts, percentages and median scores. The additional comments from the statements that did not reach 75% agreement were thematically analysed and then informed the revised statements for the next round.

After Delphi consensus completion, a researcher (SG) from the supervisory team validated 20% of the round one calculations and 100% of the round two calculations to increase transparency and rigor of the study.

5.3 Results

Between August 2020 and October 2020 twenty-eight participants completed round one of the Delphi study and twenty-seven completed round two achieving a 96% retention rate. Round three was not necessary as all the statements had reached agreement after the second round as per the a priori criteria for success.

Fifty-six potential participants responded to the recruitment advertisement and were contacted to establish whether they met the inclusion and exclusion criteria. Please see Figure 11 for the recruitment diagram. Ten were not eligible. One potential participant was qualified for less than three years, three had less than three years of experience of work or research in the areas of rehabilitation and/or dementia, four had less than three years of experience from community and/or acute hospital setting, one was based outside of the UK, and one was not a qualified occupational therapist. The remaining potential participants were contacted to enquire about their clinical experience to be added to the sampling framework. Thirty-seven participants were then sent the link to round one questionnaire, of which 28 completed the questionnaire. Nine participants were added to a waiting list as their clinical experience was primarily in a community mental health setting, which was already sufficiently represented in the selected sample. They would have been contacted to offer a place if an already selected participant with a similar expertise did not complete the first questionnaire.

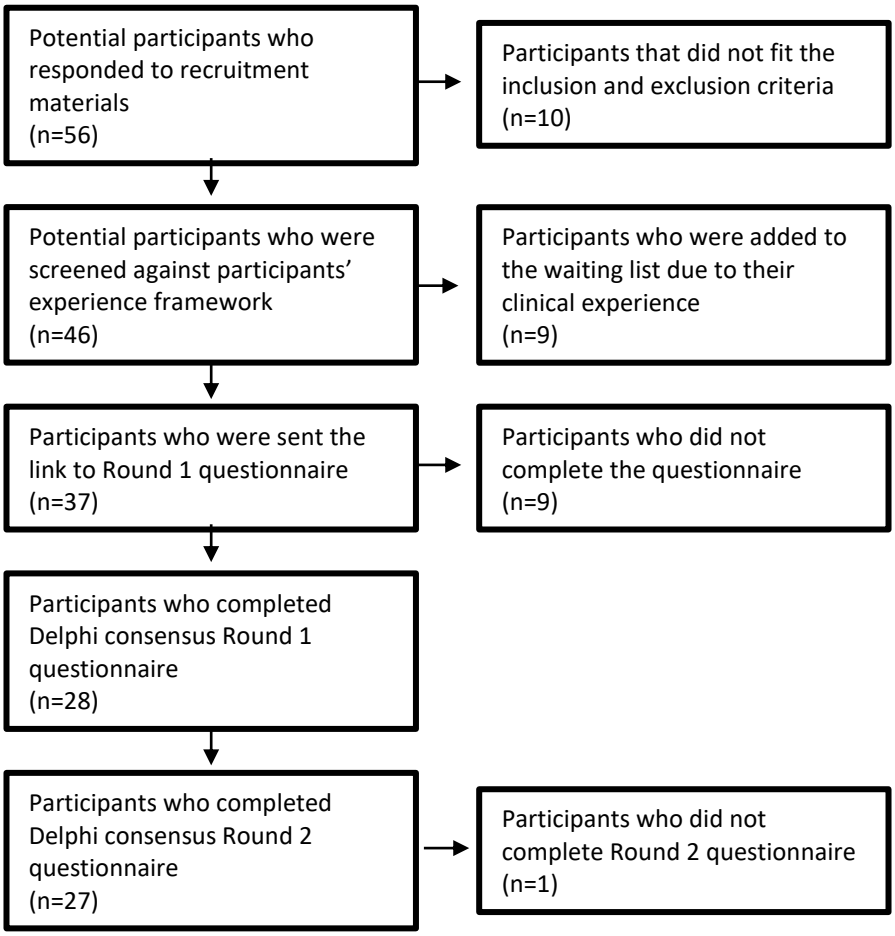

Figure 11 - Delphi Consensus - Participant Recruitment

Characteristics of the twenty eight participants are presented in Table 15. Seventy-one per cent of the selected participants worked in an acute hospital setting at the time of the Delphi completion, with half of these working on health care of older persons' wards. All participants were working in England. The participants were qualified occupational therapists for 3-26 years, with the mean being 13 years and the median 12.5 years. The median and mean lengths of working with people with dementia were eight years. The median years working in rehabilitation for older people was four years with mean being five years. The median and mean lengths of working in an acute hospital setting were seven years. The mean length of working in a community setting was five years, the median was two and a half years, with mode being one year.

Table 15 - Delphi Consensus - Participants' Characteristics

Gender	**N (%)**
Female	27 (96.43%)
Male	-
Prefer not to say	1 (3.57%)
Years as a qualified Occupational therapist	**N (%)**
3-10 years	10 (35.71%)
11-20 years	15 (53.57%)
21-30 years	3 (10.71%)
Years of experience working with people with dementia	**N (%)**
1-5	4 (14.29%)
6-10	17 (60.71%)
11-15	7 (25%)
Years of experience working in rehabilitation for older people	**N (%)**
0-5	17 (60.71%)
6-10	7 (25%)
11-15	4 (14.29%)
Years of experience working in an acute hospital setting	**N (%)**
0-5	10 (35.71%)
6-10	11 (39.29%)
11-15	7 (25%)
Years of experience working in a community setting	**N (%)**
0-5	19 (67.86%)
6-10	4 (14.29%)
11-15	3 (10.71%)
16-20	1 (3.57%)
21-30	1 (3.57%)
Highest professional qualification	**N (%)**
Degree	20 (71.43%)
Masters	6 (21.43%)
PhD	-
Other	2 (7.14%)
Current county of work	**N (%)**
Nottinghamshire	13 (46.43%)
Northamptonshire	3 (10.71%)
Somerset	3 (10.71%)
Leicestershire	2 (7.14%)
South Yorkshire	2 (7.14%)
Cambridgeshire	1 (3.57%)
Derbyshire	1 (3.57%)
Oxfordshire	1 (3.57%)
Somerset	1 (3.57%)
West Sussex	1 (3.57%)
Current clinical setting of work	**N (%)**
Acute hospital	20 (71.43%)
In-patient rehabilitation	1 (3.57%)
Community based	7 (25%)
University	-
Other	-

Current occupational therapy speciality of work	N (%)
Acute hospital	**20 (71.43%)**
Health Care of Older Persons	10 (35.71%)
Stroke rehabilitation	3 (10.71%)
Medicine and Oncology	3 (10.71%)
Integrated discharge team	2 (7.14%)
Dementia and Delirium service	1 (3.57%)
Acute Inpatient Mental health services for older adults	1 (3.57%)
Community	
Community Mental health Team	**7 (25%)**
Integrated Community Team	2 (7.14%)
Older people community	2 (7.14%)
Memory assessment service for older people	2 (7.14%)
	1 (3.57%)
In-patient rehabilitation	
Intermediate care	**1(3.57%)**
	1(3.57%)

5.3.1 Round One

In round one, the participants were asked to rate thirty eight statements. Summary of the agreement levels for statements in Round One is presented in

Table 16, statements that did not reach consensus are highlighted. Detailed agreement level breakdown is presented in (Appendix R). Thirty three statements reached consensus after this round. Two of these thirty three statements reached consensus by over 75% of participants disagreeing with these statements. Therefore these two statements were excluded from OcTPAP description and were not revised for the second Delphi round as per protocol for this study. The remaining five statements did not reach the required level of consensus.

Table 16 - Delphi Consensus - Agreement Levels for Round One Statements

Round One Statement	Consensus level
Personal activity goals should be identified with the patient.	100% agreed
Family carers should be involved in helping set personal activity goals.	93% agreed
Personal activity goals should be specific and measurable.	89% agreed

Personal activity goals should be achievable within the constraints of the hospital environment.	89% agreed
Personal activity goals should be relevant to patient's usual daily activities on return home.	100% agreed
Patients should have the same control over their daily routines as they would at home.	75% agreed
Ward staff should never try to persuade a patient who is reluctant to practice self-care ADLs	61% agreed
Personal activity goals should be monitored and adapted to match patient's ability throughout the hospital stay.	100% agreed
Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records.	100% agreed
If available, family carers should be involved in the rehabilitation process.	96% agreed
Patients should continuously be given feedback concerning their progress.	89% agreed
Independence in activities of daily living should be maintained/regained through practising activities of daily living.	93% agreed
OcTPAP must include physical exercises aimed at improving ability to complete activities of daily living independently.	75% agreed
OcTPAP must include a component focusing on cognitive stimulation.	89% agreed
OcTPAP must include a component focusing on sensory stimulation.	82% agreed
OcTPAP must include a component focusing on positioning.	79% agreed
OcTPAP must include a component focusing on pressure care.	75% agreed
OcTPAP must include a component focusing on falls prevention.	93% agreed
OcTPAP should include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital.	100% agreed
OcTPAP should include goals that patient would continue working on after discharge.	100% agreed
OcTPAP should start as soon as the patient is well enough to participate in activities of daily living.	93% agreed
Patients should be supported to participate in OcTPAP seven days a week.	82% agreed

There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence.	75% agreed
The length of occupational therapy personal activity sessions should be clinically determined by an occupational therapy worker.	89% agreed
The length of occupational therapy personal activity session should always be fixed to a minimum of 45 minutes.	93% disagreed
Ward staff should wait for a registered occupational therapist assessment before allowing a patient to wash and dress.	93% disagreed
Ward staff should have the skills to adapt and update the rehabilitation plan.	89% agreed
There should be a named key worker responsible for daily review of each patient's personal activity programme.	86% agreed
The named key worker responsible for daily review of each patient's personal activity programme should be either a registered occupational therapist or an occupational therapy support worker.	57% disagreed
The named key worker responsible for daily review of each patient's personal activity programme must be a registered occupational therapist.	71% disagreed
Expectations about the OcTPAP should be discussed with patients and family carers.	100% agreed
Patients should be encouraged to do as much as they can by themselves before they are helped.	93% agreed
Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living.	96% agreed
Patients should be encouraged to take more responsibility for their own recovery of independence.	93% agreed
OcTPAP should only be delivered through one to one interactions.	54% disagreed
OcTPAP should include a documented risk assessment to address potential consequences of increased independent activity.	68% agree
OcTPAP should include verbal and written communication with community services for information sharing and follow up.	89% agreed
An occupational therapy worker should be able to assess/treat the patient in the patient's home following discharge.	79% agreed

The five statements that did not reach consensus and examples of participants' comments are presented below.

- Statement “Ward staff should never try to persuade a patient who is reluctant to practice self-care ADLs” reached 61% agreement.

Twelve out of twenty eight participants left comments in the space provided below this statement. Participants stated that encouragement is very important, as a patient may just be, for example, anxious. Participants however stated that the patient should still feel able to decline if they wish. For example one of the participants (OT3172004) who voted “disagree” wrote: “breaking the task down perhaps would help the pt [patient] to feel less overwhelmed with a task they don't like doing. Increasing/maintaining independence is important, but without impacting the therapeutic relationship”. Another participant (OT0782036) who voted “strongly agree” wrote: “positive persuasion yet without undue pressure - outline benefits and risks of not doing activity, give space and return;”

- Statement “OcTPAP should only be delivered through one to one interactions” reached 54% disagreement.

Seventeen participants left comments in the space provided below this statement. Participants suggested that group work sessions would also be valuable. For example, one of the participants (OT0582033) who voted “neither agree or disagree” wrote: “Should be personalised to the patient, group interactions can have a valuable contribution too”. Another participant (OT0882037) who voted “disagree” stated: “Certain activities could be group activities ie, ask patient's to sit together at table for meals - therefore allowing visual prompting and cues for mirroring. Hair/make-up grooming could be in small groups also.”

- Statement “OcTPAP should include a documented risk assessment to address potential consequences of increased independent activity” reached 68% agreement.

Six participants commented on the statement. Participants expressed that occupational therapy workers (occupational therapists and occupational therapy support workers) should be constantly reassessing risk. However, the participants pointed out that this does not have to be documented or could be included in the general risk assessment paperwork to reduce time taken for documentation

completion. One of the participants (OT1782045) who voted “neither agree or disagree” stated: “Depends on the type of activities being undertaken. More than likely should actually be a care plan with the risk incorporated, and also incorporating the limitations that may arise as their dementia progresses”. Another participant (OT3072003) who voted “strongly agree” wrote: “It is our duty of care to discuss this with patients/family/carers. Enabling risk and empowering choice will be an important element to the rehab programme. The risk assessment must be holistic and dynamic and not just merely focusing on risk only.”

- Fifty seven percent of the participants disagreed with statement “The named key worker responsible for daily review of each patient’s personal activity programme should be either a registered occupational therapist or an occupational therapy support worker”.

Twelve participants have left a comment about this statement. They stated that while it would be preferable to have an occupational therapy key worker, this may be difficult to operationalise. Participants also raised the point that other professions can be key workers for OcTPAP with some suggesting that occupational therapist still should oversee the process. The need for appropriately skilled staff was highlighted. One of the participants (OT0782040) who voted “neither agree or disagree” stated: “I'm not sure how this would work in practice”. Another participant (OT0582034) who voted “disagree” explained: “I think this depends on how involved and highly trained the ward are.; I feel if ward staff are appropriately trained and involved it would also be beneficial to ask them to complete with OT staff overseeing the process.”

- Seventy one percent of the participants disagreed with statement “The named key worker responsible for daily review of each patient’s personal activity programme must be a registered occupational therapist.”

Participants left eleven comments under this statement. The comments suggested that this would depend on how skilled other staff are at reviewing patient’s personal activity programme. A participant (OT0782036) who voted “disagree” wrote: “an educative role should be part of an OTs role as there are insufficient

numbers to deal with patient demand, therefore reablement and rehabilitation should". Another participant (OT1982047) who voted "disagree" stated: "This could be a member of the MDT or a support worker under supervision."

5.3.2 Round Two

Five statements together with thematically summarised qualitative comments were reviewed with the researcher (LP) and the supervisory team. Revised statements and the rationale for their revision were included in round two of the questionnaire and are presented in Appendix S. Two of the original statements were combined into one for round two of the Delphi study as they addressed the same issue of who the named key worker should be. Therefore, there was four statements for participants to score in round two.

Detailed round two results are presented in Appendix S. All four statements reached a pre-defined consensus level of 75% or more meaning round three of the Delphi study was not needed. The full list of statements that reached agreement after two rounds and was included in OCTPAP can be found in Table 17.

Table 17 - Delphi Consensus - Full List of Statements that Reached Consensus and were included in OcTPAP

Statement	Consensus level	Reached consensus in
1. Personal activity goals should be identified with the patient.	100% agreed	Round 1
2. Family carers should be involved in helping set personal activity goals.	93% agreed	Round 1
3. Personal activity goals should be specific and measurable.	89% agreed	Round 1
4. Personal activity goals should be achievable within the constraints of the hospital environment.	89% agreed	Round 1
5. OcTPAP should include goals that patient would continue working on after discharge.	100% agreed	Round 1

6. Personal activity goals should be relevant to patient's usual daily activities on return home.	100% agreed	Round 1
7. Patients should have the same control over their daily routines as they would at home.	75% agreed	Round 1
8. Personal activity goals should be monitored and adapted to match patient's ability throughout the hospital stay.	100% agreed	Round 1
9. Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records.	100% agreed	Round 1
10. If available, family carers should be involved in the rehabilitation process.	96% agreed	Round 1
11. Patients should continuously be given feedback concerning their progress.	89% agreed	Round 1
12. Independence in activities of daily living should be maintained/regained through practising activities of daily living.	93% agreed	Round 1
13. OcTPAP must include physical exercises aimed at improving ability to complete activities of daily living independently.	75% agreed	Round 1
14. OcTPAP must include a component focusing on cognitive stimulation.	89% agreed	Round 1
15. OcTPAP must include a component focusing on sensory stimulation.	82% agreed	Round 1
16. OcTPAP must include a component focusing on positioning.	79% agreed	Round 1
17. OcTPAP must include a component focusing on pressure care.	75% agreed	Round 1
18. OcTPAP must include a component focusing on falls prevention.	93% agreed	Round 1
19. OcTPAP should include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital.	100% agreed	Round 1
20. OcTPAP should start as soon as the patient is well enough to participate in activities of daily living.	93% agreed	Round 1
21. Patients should be supported to participate in OcTPAP seven days a week.	82% agreed	Round 1

22. There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence.	75% agreed	Round 1
23. The length of occupational therapy personal activity sessions should be clinically determined by an occupational therapy worker.	89% agreed	Round 1
24. Ward staff should have the skills to adapt and update the rehabilitation plan.	89% agreed	Round 1
25. There should be a named key worker responsible for daily review of each patient's personal activity programme.	86% agreed	Round 1
26. Expectations about the OcTPAP should be discussed with patients and family carers.	100% agreed	Round 1
27. Patients should be encouraged to do as much as they can by themselves before they are helped.	93% agreed	Round 1
28. Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living.	96% agreed	Round 1
29. Patients should be encouraged to take more responsibility for their own recovery of independence.	93% agreed	Round 1
30. OcTPAP should include verbal and written communication with community services for information sharing and follow up.	89% agreed	Round 1
31. An occupational therapy worker should be able to assess/treat the patient in the patient's home following discharge.	79% agreed	Round 1
32. Ward staff should encourage patients who are reluctant to practise activities of daily living	96% agreed	Round 2
33. OcTPAP could be delivered through both group work and one to one sessions.	96% agreed	Round 2
34. A risk assessment for increasing independent activity should be included in the ward's general risk assessment.	89% agreed	Round 2
35. An appropriately skilled member of ward staff could be the named key worker responsible for daily review of each patient's personal activity programme with support from a registered occupational therapist.	93% agreed	Round 2

5.4 Discussion

5.4.1 Findings in Relation to Existing Literature

This modified Delphi study aimed to reach consensus on the content of the OcTPAP. Thirty five statements have reached agreement in two rounds.

A Delphi study of Australian occupational therapists explored occupational therapy service delivery and interventions in inpatient rehabilitation which are commonly used with older adults who deconditioned during a hospital admission for a medical illness (Timmer et al., 2015). Twenty four out of twenty six participants completed all three rounds. Timmer et al. (2015) acknowledged the role of other team members such as nurses, physiotherapists, family members and the deconditioned individuals themselves in the rehabilitation process. Similarly to OcTPAP, Timmer et al. (2015) reported that the interventions should be provided by an occupational therapist or under the direction of an occupational therapist. While this Delphi study suggested OcTPAP intervention could be delivered by an appropriately skilled worker without specifying professional background, Timmer et al. (2015) stated this should be an allied health assistant. Similarly to OcTPAP, Timmer et al. (2015) suggested that occupational therapy interventions should be delivered daily, however they defined “daily” as Monday to Friday. The importance of providing seven day rehabilitation has been highlighted in the qualitative interviews study (Chapter 3). In contrast to OcTPAP which includes both one to one and group intervention components, Timmer et al. (2015) concluded only individual occupational therapy interventions were seen as common.

Timmer et al. (2015) identified fifteen commonly used occupational therapy interventions and grouped them into four categories: impairment based interventions, execution of task interventions, participation and wellbeing interventions, and environmental interventions (Timmer et al., 2015). Commonly used execution of task interventions included showering and dressing, light meal preparation, falls prevention, home assessment and pacing educations, which is in line with findings of the Delphi study reported in this thesis. Pressure care and seating (positioning) interventions which were included in OcTPAP, were not

identified as commonly used interventions by Timmer et al. (2015). This could be explained by the differences in the setting, with acute hospitals having patient who are admitted for an acute illness and therefore are more physically unwell (Care Quality Commission, 2013). Cognitive retraining and specific strengthening interventions also did not reach consensus as commonly used in Delphi study by Timmer et al. (2015). Cognitive stimulation component has reached consensus for inclusion in OcTPAP. Cognitive stimulation is recommended for people with mild to moderate dementia by NICE (2018). Environmental interventions such as referral to community services and participation and wellbeing interventions such as working with the individual and their carers were included in both Delphi completed for OcTPAP refinement and Timmer et al. (2015) studies. While Timmer et al. (2015) looked at occupational therapy interventions at post-acute setting which were not specific to people with dementia. However many similarities were noted with the OcTPAP.

It was agreed by the Delphi participants (Chapter 5) that practise of activities of daily living should be encouraged by the ward staff even if patients are reluctant. There is a difference between encouraging and forcing a person participate in an activity, understanding reasons for declining to participate would assist with selecting the approach. CLEAR Dementia Care model could provide understanding on why the patients with dementia may express distress (Duffy, 2019). CLEAR stands for Cognition, Life story and personality, Emotional and physical wellbeing, Activity and environment and Relationships. The model suggests that behaviours of people with dementia which other people may find challenging are expressions of unmet needs, for example being in pain but not being able to communicate that (Duffy, 2019). These behaviours may start becoming prominent in people with moderate dementia (Alzheimer's Association, 2022, NHS, 2021) and staff need to be appropriately skilled to support people with dementia.

5.4.2 Strengths and Limitations

This Delphi study has been reported using CREDES to increase the transparency. Setting a pre-defined consensus criteria as well as clear plan detailing the conditions under which the study would terminate enhanced the rigor of the study (Diamond et al., 2014, Jünger et al., 2017).

The rigor of Delphi studies also depends on the composition of the panel (Campbell and Cantrill, 2001). All the Delphi participants were occupational therapists creating a professionally homogeneous group. Having other professional groups represented in the Delphi may have added to the understanding of the wider context, but would have increased heterogeneity of the group producing greater variation and reducing accuracy (Hasson and Keeney, 2011). In addition, research has found that the role of occupational therapists is mostly associated with assessments that inform safe discharge planning in acute hospitals (Kingston et al., 2019). Kingston et al. (2019) also noted that occupational therapists were seen to provide rehabilitative treatments on the acute medical wards (Kingston et al., 2019). Nursing staff have also reported occupational therapy assessments not being integrated in the patient's care plan during the acute hospital admission (Kingston et al., 2019). Having only occupational therapists on the panel would ensure a wide range of occupational therapy intervention strategies could be considered. It must be noted that the study sample was heavily skewed to female workforce. However, this is in line with Health and Care Professions Council data from 2019 which reported female occupational therapists being almost 92% (28,857 out of 31,419) of the OT workforce in England (HCPC, 2019).

Having a larger number of participants is known to effect the retention rates between rounds (Keeney et al., 2011). The drop out of the participants between rounds is a common issue effecting the rigor of Delphi studies. It is recommended that a response rate of 70% should be maintained between rounds (Atkins et al., 2015). This study has achieved a 96% retention rate, increasing confidence in the study's rigor (Keeney et al., 2011).

The recruitment strategy allowed for a variety of practising occupational therapists to volunteer to participate, but did not target occupational therapists working in academia or researchers who publish on dementia care. Including researchers and academics could have contributed up-to-date evidence based knowledge to the process. However, the overall research study had pragmatic underpinnings and aimed to produce an intervention that would be accepted in clinical practice, and therefore views of the front line clinicians were essential. There is an ongoing debate in the literature as to the definition of "an expert"(Hasson et al., 2000).

A strength of the Delphi study was having a participant experience framework to aid the participant selection and therefore support the credibility of the results (Campbell and Cantrill, 2001). The framework ensured representation of occupational therapists from all specialities and settings that are part of the services that older people with dementia may use, yet kept the focus on the acute hospital setting. This provided contribution from clinicians with wider insight into rehabilitation services, enhancing the transferability and validity of the findings.

The Delphi statements were developed based on the current literature and in-depth interviews with practicing clinicians, commissioners, patients and carers. Thinking about how the intervention would be delivered in the clinical settings from the beginning of the intervention development process is advised (Medical Research Council, 2006). Involving the key stakeholders early is likely to increase the chances for the successful implementation of the intervention in clinical practice (Croot et al., 2019). Using a model, such as BRUSO (Peterson, 2000), when writing the Delphi questions could have helped minimise unintended effects on participant's responses (Price, 2017). BRUSO model of writing effective questionnaire items suggests making sure that the questionnaire items are brief, relevant, unambiguous, specific and objective (Peterson, 2000).

One of the weaknesses of the modified Delphi method is a lack of opportunity for participants to discuss issues or further explain their views (Keeney et al., 2011). A space for comments was provided at the end of the questionnaire to provide an opportunity to make suggestions and facilitate consensus. However, the length of text was fixed to 1000 characters and may have prevented in-depth explanations.

Anonymity of Delphi participants is often cited as an advantage as it mitigates against the impact of strong personalities on the group (Keeney et al., 2011). However it must be noted that anonymity also could promote the lack of accountability for the expressed opinions and rushed not thought through comments (Goodman, 1987).

Delphi consensus results are representative of the knowledge and views of the participating experts and are time-specific. Therefore, it is recommended to validate and refine the findings further through additional research (Keeney et al., 2011). It must be acknowledged that Delphi consensus study data collection was between August 2020 and October 2020, while the UK was effected by the Coronavirus disease (COVID-19). While the required number of participants with relevant experience was recruited despite the health services being affected by COVID-19, the finding may have been effected in some way. For example, the settings in which the participants were working may have been under excess pressure, resulting in participants rushing to complete the questionnaire. However, having occupational therapists complete the questionnaire during such a phase may make the findings more implementable and relevant to current clinical practice.

5.5 Conclusion

This chapter covered the completion of the Delphi consensus study which sought to seek agreement on the content of OcTPAP and the Delphi study strengths and limitations. The description of the OcTPAP was produced and is presented and discussed in light of existing literature in Chapter 6, which concludes the research completed for this PhD thesis.

Chapter 6 - Occupational Therapy Personal Activity Programme Description and Discussion

In this chapter, the overall methodology and methods used in this research study will be re-stated and a resulting OcTPAP description presented. The findings will be discussed in relation to existing literature. This chapter will address the study's overall strength and limitations, research implications for clinical practice and future research areas. It will consider the findings in light of the coronavirus disease which will be followed by the study's conclusions. The overall study design is presented in Figure 12.

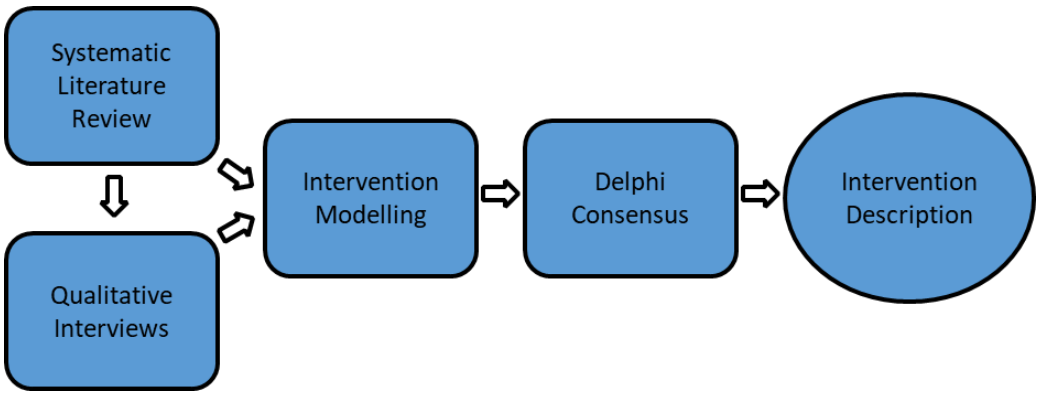

Figure 12 - Completed Research Study Components

The overall aim of this thesis of developing an occupational therapy rehabilitation intervention for hospitalised people with dementia was achieved. The resultant Occupational Therapy Personal Activity Programme (OcTPAP) was designed by collecting reliable and rigorous data from published literature, NHS clinicians, commissioners, people with dementia and carers. The OcTPAP intervention was informed by the World Health Organisation's International Classification of Functioning (World Health Organisation, 2002), Person-Environment-Occupation-Performance model (Duncan, 2011), principles of biopsychosocial model (World Health Organisation, 2002, Wade and Halligan, 2017) and principles of person-

centred care (NICE, 2018). Rigorously and transparently synthesised data from the systematic review (Chapter 2) and qualitative interviews (Chapter 3) was subjected to Delphi consensus study to achieve agreement on the OcTPAP components. Producing an intervention in this way and following the MRC guidelines (Medical Research Council, 2006) provides the best context for the programme to feasible in any acute NHS hospital setting. This thesis forms an original piece of work in that it was the first time that an occupational therapy intervention aimed at improving the ability of hospitalised people with dementia to be independent in their activities of daily living was developed. The resulting OcTPAP description is presented in the next section.

6.1 Occupational Therapy Personal Activity Programme Description

The OcTPAP is described (Table 18) following the structure of the Template for Intervention Description and Replication (TIDieR) guidelines (Hoffmann et al., 2014). TIDieR are guidelines aimed at improving the quality of reporting of complex healthcare interventions (Eldh et al., 2017).

Table 18 - Intervention Description Following TIDieR Guidelines

Item	Description	Source of the information
Brief name	OcTPAP (Occupational Therapy Personal Activity Programme)	• Discussions with the Patient and Public Involvement (PPI) collaborator and input from the research supervisory team.
Why	People with dementia over the age of 65 occupy up to one-quarter of hospital beds, they have longer hospital stays and are more likely to be readmitted. Having dementia was found to be significantly associated with having an adverse event in an acute hospital. For all older adults hospital admissions are likely to be deskilling, and for people with dementia hospital admissions present additional challenges. Dependence in activities of daily living has a negative impact on the quality of life of people with dementia, limits their choices about the future and has adverse effect on relationships. There is a need for an evidence-	• Review of the background literature (Chapter 1). • PPI input.

	based intervention to help people with dementia improve their independence in activities of daily living during hospital admissions.	
What	**Procedures:** Holistic assessment of patients which covers physical, functional, cognitive, social, neuropsychological, and emotional areas. Where possible, OcTPAP should be delivered in an environment where ward leadership values maintenance of patient independence. Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records. OcTPAP should include verbal and written communication with community services for information sharing and follow up. Expectations about the OcTPAP should be discussed with patients and family carers. Personal activity goals should be: • Identified with the patient; • Set with support of family carers; • Specific and measurable; • Achievable within the constraints of the hospital environment;	• Review of the background literature (Chapter 1). • Systematic literature review (Chapter 2). • Qualitative interviews (Chapter 3). • Intervention modelling (Chapter 4) • Delphi consensus study (Chapter 5).

	• Focused on self-care activities of daily living and cover areas such as personal hygiene/grooming, dressing, toileting/continence, transferring/mobilising, and eating; • Relevant to patient's usual daily activities on return home; • Monitored and adapted to match patient's ability throughout the hospital stay; • Include goals that patient would continue working on after discharge and include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital. The following components should be included in the rehabilitation programme: • Activities of daily living practice; • Physical exercises aimed at improving ability to complete activities of daily living independently; • Cognitive stimulation; • Sensory stimulation; • Positioning; • Pressure care; • Falls prevention. Rehabilitation process characteristics: • Patients should be encouraged to take more responsibility for their own recovery of independence. • Patients should have the same control over their daily routines as they would at home. • If available, family carers should be involved.	

	• Patients should continuously be given feedback concerning their progress. • Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living and patients should be encouraged to do as much as they can by themselves before they are helped. • Ward staff should encourage patients who are reluctant to practise activities of daily living. **Materials:** Materials for staff training would need to be developed once OcTPAP is finalised. Ward general assessment needs to address risk assessment for increasing independent activity.	
Who provided	Sufficient ward staff numbers to allow enabling patients to complete tasks more independently. Ward staff to have dementia awareness and follow principles of person centred care. Ward staff should have the skills to adapt and update the rehabilitation plan. There should be an appropriately skilled, named key worker responsible for daily review of each patient's personal activity programme with support from a registered occupational therapist.	• Systematic literature review (Chapter 2). • Qualitative interviews (Chapter 3). • Delphi consensus study (Chapter 5).

How	To be delivered through both face to face group work and one to one sessions.	• Systematic literature review (Chapter 2). • Qualitative interviews (Chapter 3). • Delphi consensus study (Chapter 5).
Where	Hospital environment to maximise independence and prevent disability, including environment which allows completion of group activities. Following discharge form an acute hospital, an occupational therapy worker should be able to assess/treat the patient in the patient's home.	• Systematic literature review (Chapter 2). • Qualitative interviews (Chapter 3). • Intervention modelling (Chapter 4) • Delphi consensus study (Chapter 5).
When and How much	OcTPAP should start as soon as the patient is well enough to participate in activities of daily living.	• Systematic literature review (Chapter 2).

	Patients should be supported to participate in OcTPAP seven days a week. There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence. The length of this session should be clinically determined by an occupational therapy worker.	• Qualitative interviews (Chapter 3). • Delphi consensus study (Chapter 5).
Tailoring	The intervention is tailored through using person-centred approach and individual goal setting.	• Intervention modelling (Chapter 4) • Research study supervisory group meetings. • Discussions with the PPI collaborator.
Modifications	Not applicable	-
How well	Not applicable	-

6.2 Strength and Limitations

The strength and limitations of the individual study components have been discussed in the relevant chapters. This chapter critically reflects on the strengths and limitations of the method and methodology of the study overall.

The main strength of this research study is its use of the MRC guidelines for development of complex interventions (Medical Research Council, 2006). Using a recognised framework helped ensure that appropriate considerations were given to the steps taken to systematically develop OcTPAP using appropriate theory and best available evidence (Craig et al., 2008). The 2006 version of the framework was used, which was the most recent one during this research study. In September 2021, an update was published. The key changes included an updated definition of complex interventions, added choice of perspectives that research can adopt, a slightly extended list of essential elements of the development and evaluation process, and having six core questions to consider at every stage listed in the framework (Skivington et al., 2021). The updated MRC framework's key elements of the process now include intervention identification or development, feasibility assessment and design evaluation, intervention evaluation and meaningful implementation. As previously, these are not linear or sequential. Based on the already available evidence and what is now needed, the updated framework suggests assuming theory-based, effectiveness, efficacy or systems perspective (Skivington et al., 2021). The next steps of testing OcTPAP in clinical setting should follow the updated MRC guidelines (Skivington et al., 2021).

The Medical Research Council (2006) recommend using different research methods that do not share the same weaknesses. Another strength of this study is the use of a sequential transformative mixed methods approach (Creswell, 2003). Mixed methods approaches are particularly valuable when addressing complex issues (Creswell, 2018) such as care of people with dementia and rehabilitation as was the subject of this thesis. Using mixed methods research produced a greater understanding of the research topic by combining the qualitative and quantitative methods than would not have been achieved by using a single method (Teddlie and

Tashakkori, 2009). Qualitative and quantitative data were analysed separately and later were merged to see if they support or disconfirm each other using triangulation. This is consistent with the objectives of sequential transformative design (Creswell, 2003). The interpretive consistency is demonstrated by both data sets finding first being reported separately and the finding being backed up with explanations and data extracts (Tashakkori and Teddlie, 2010).

Involving key stakeholders both as research participants and partners throughout the OcTPAP development is one of the study's strengths. A variety of clinicians participated in qualitative interviews, and occupational therapists took part in the Delphi consensus study. The Dementia, Frail Older People and Palliative Care PPI Advisory Group at the University of Nottingham and the Alzheimer's Society Research Network monitors were involved in refining the research question for the overall study and the development of the recruitment materials for the qualitative interviews. PPI collaborator (KS) was involved throughout the research study and added her views and expertise gained through experience to ensure the presence of "voice" of carers of people with dementia. The involvement of stakeholders as participants and collaborators can improve the usability, acceptability and utility of complex interventions (Hudson et al., 2020).

The research undertaken for the development of OcTPAP has been presented in this thesis, but OcTPAP will need further refinement and testing. A potential limitation in the applied research methods was inability to make a definite projection about the effectiveness of the combination of intervention components and how they will be operationalised. Not all of the OcTPAP components which originated from the systematic review studies have evidence of their effectiveness if considered independently from the larger interventions or programmes that they were part of. For example, Abizanda et al. (2011) had cognitive stimulation as part of their occupational therapy intervention, alongside other components such as retraining in activities of daily living. NICE (2018) recommended cognitive stimulation for people with mild to moderate dementia. In contrast, Álvarez et al. (2017) had sensory stimulation as one of their intervention components. While there is evidence of positive effect of sensory stimulation on activities of daily living

for people with dementia, it is limited (Mileski et al., 2018). OcTPAP is a complex intervention, which is evidenced through it having a number of interacting components (Medical Research Council, 2006). The same can be said for the interventions identified through the systematic review (Chapter 2). In complex interventions it is harder to extract which of the components are the "active ingredients (McCleary et al., 2013). Participants of a qualitative scoping study by Rabiee et al. (2005) raised concerns about how to isolate and measure the active ingredients of complex interventions. Therefore, it could be questioned whether for complex interventions such as OcTPAP, the effectiveness of individual components on its own guarantees the effectiveness of the rehabilitation programme.

To ensure comprehensive and robust description of OcTPAP, the TIDieR checklist and guide (Hoffmann et al., 2014) was used to inform data collection, data synthesis and to present the OcTPAP content. Using an additional tool to describe the OcTPAP content, such as Criteria for Reporting the Development and Evaluation of Complex Interventions in Healthcare guide (CReDECI2), could have been beneficial. CReDECI2 guidelines cover three stages: development, feasibility and piloting, and evaluation (Möhler et al., 2015). The development stage of CReDECI2 specifies the intervention's underlying theoretical basis, intervention components and their functions, their interactions and the wider context (Moher et al., 2009). While all of these stages were covered in this research study, TIDieR does not allow to explicitly demonstrate these.

To add transparency to actions taken and the robustness of the work undertaken in the development of OcTPAP under Medical Research Council (2006) guidance, O'Cathain et al. (2019) guidance can be used. O'Cathain et al. (2019) completed a consensus study to review which actions are needed to develop interventions for healthcare. This guidance elaborates on the complex intervention development phase of the MRC framework and was published after the research study had been planned. O'Cathain et al. (2019) suggest that the actions listed do not have to be completed in the presented order and could be addressed in a dynamic manner, and revisited as the intervention evolves. The actions are grouped under the following titles:

- Plan the development process.
- Involve stakeholders, including those who will deliver, use and benefit from the intervention.
- Bring together a team and establish decision-making processes.
- Review published research evidence.
- Draw on existing theories.
- Articulate programme theory.
- Undertake primary data collection.
- Understand context.
- Pay attention to future implementation of the intervention in the real world.
- Design and refine the intervention.
- End the development phase.

The steps taken in this PhD study are clearly presented below in Table 19 against the actions in this guidance (O'Cathain et al., 2019).

Table 19 - Actions for Intervention Development Recommended by O'Cathain et al. (2019)

Proposed action	Done	Details
Plan the development process		
- Identify the problem to be targeted and refine understanding of it throughout the process.	✓	- Identified through clinical experience, prior research completed by LP (Patrick, 2017) and local Patient Public Involvement (PPI) group meeting.
- Assess whether the problem is a priority.	✓	- Assessed through prior literature search by LP (Patrick, 2017), local PPI group meeting and working with PPI collaborator for the study. - Evidence on the importance of the topic discussed in Chapter 1.
- Consider which aspects of the problem are amenable to change.	✓	- Assessed through the review of the background literature (Chapter 1).
- Ask whether a new intervention is really needed and if the potential benefit of the new intervention justifies the cost of development.	✓	- Successfully gained research funding from the Alzheimer's Society and NIHR Applied Research Collaboration East Midlands to complete the study. - Proposed mechanism of action was described to articulate the potential benefit of the intervention.
- Determine the time needed to undertake intervention development. - Obtain sufficient resources/funding for the intervention development study.	✓ ✓	- Details of the time and resources required for the research study were submitted to and approved by the Alzheimer's Society and NIHR Applied Research Collaboration East Midlands.
- Draw on one or more of the many published intervention development approaches, recognising that there is no	✓	- Drawn on a widely used intervention development approach, MRC framework, and World Health

Proposed action	Done	Details
evidence about which approach is best and apply flexibly depending on the problem and context.		Organisation's International Classification of Functioning, Person-Environment-Occupation-Performance Model, Kitwood's theory of person-centred care.
- Involve stakeholders during the planning process (see next Action).	✓	- Involved PPI collaborator and local PPI group. - LP's discussions with fellow NHS staff, patients and their families.
- Produce a protocol detailing the processes to be undertaken to develop the intervention.	✓	- Specified the process of intervention development in a protocol prior to commencement of the study, part of which was submitted to the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics committee for review.
Involve stakeholders, including those who will deliver, use and benefit from the intervention		
- Work closely with relevant stakeholders throughout the development process: patients, the public, the target population, service providers, those who pay for health and social services or interventions, policymakers and intervention design specialists.	✓	- A variety of stakeholders was involved at all stages of the research study: Throughout the research study - PPI collaborator and the Alzheimer's Society Monitors. The qualitative interviews component - Occupational therapists, healthcare assistant, physiotherapists, physiotherapy assistant, geriatricians, dietitian, nurses, speech and language therapist, commissioners, people with dementia and carers.

Proposed action	Done	Details
- Develop a plan at the start of the process to integrate public and patient involvement into the intervention development process.	✓	- A detailed plan of PPI input was developed prior to the commencement of the study and submitted with the grant application.
- Identify the best ways of working with each type of stakeholder, from consultation through to coproduction, acknowledging that different ways may be relevant for different stakeholders at different times. - Use creative activities within team meetings to work with stakeholders to understand the problem and generate ideas for the intervention.	✓ ✓	- PPI collaborator (KS) was involved throughout the study and participated in data analysis for the qualitative interviews. - Alzheimer's Society Monitors regularly met with LP and supported the development of patient facing materials. - The qualitative interviews component of the study included a variety of clinicians who deliver care for hospitalised people with dementia, people living with dementia, carers as well as commissioners for such services.
Bring together a team and establish decision-making processes		
- Include within the development team individuals with relevant expertise: in the problem to be addressed by the intervention including those with personal experience of the problem, in behaviour change when the intervention aims to change behaviour, in maximising engagement of stakeholders and with a strong track record in designing complex interventions.	✓	- The research study supervisory team was constructed to include representatives from different disciplines (medicine, nursing, occupational therapy, rehabilitation, dementia) and with expertise in relevant research methods (complex intervention development, consensus studies and qualitative and quantitate research).

Proposed action	Done	Details
- It may be hard to make final decisions about the content, format and delivery of the intervention, so only some team members may do this. There is no consensus about the size or constituency of the team that makes these final decisions, but it is important early on to agree a process for making decisions within the team.	✓	- The research study supervisory team had oversight over the whole research process and reviewed the work for the study components relevant to their expertise.
Review published research evidence		
- Review published research evidence before starting to develop the intervention and throughout the development process for example, to identify existing interventions, to understand the evidence base for each proposed substantive intervention component. - Look for, and take into account, evidence that the proposed intervention may not work in the way intended.	✓ ✓	- A systematic literature review identified intervention components and the effectiveness and content of occupational therapy interventions in older adults population during hospital admissions (Chapter 2). - Completed as part of the data synthesis (Chapter 4).
Draw on existing theories		
- Identify an existing theory or framework of theories to inform the intervention at the start of the process, for example, behaviour change or implementation theory. - Where relevant, draw on more than one existing theory or framework of theories for example, both psychological and organisational theories.	✓ ✓	- World Health Organisation's International Classification of Functioning, Person-Environment-Occupation- Performance model, model of Person-centred care informed the development of this intervention (Chapter 4).

Proposed action	Done	Details
Articulate programme theory		
- Develop a programme theory. The programme theory may draw on existing theories. Aspects of the programme theory can be represented by a logic model or set of models.	✓	- Proposed mechanism of action was based on findings from the systematic literature review (Chapter 2), qualitative interviews (Chapter 3) and existing theories (Chapter 4) and is presented later in this chapter.
- Test and refine the programme theory throughout the development process.	✓	- The initial mechanism of action was refined through the Delphi consensus process (Chapter 5).
Undertake primary data collection		
- Use a wide range of research methods throughout, for example, qualitative research to understand the context in which the intervention will operate, quantitative methods to measure change in intermediate outcomes.	✓	- Systematic literature review, qualitative interviews, triangulation protocol and Delphi consensus, were used to develop the intervention.
Understand context		
- Understand the context in which the intervention will be implemented. Context may include population and individuals; physical location or geographical setting; social, economic, cultural and political influences and factors affecting implementation, for example, organisation, funding and policy.	✓	- To improve the understanding of the context in which the intervention will be implemented, qualitative interviews were completed with Occupational therapists, healthcare assistant, physiotherapists, physiotherapy assistant, geriatricians, dietitian, nurses, speech and language

Proposed action	Done	Details
		therapist, commissioners, people with dementia and carers (Chapter 3).
Pay attention to future implementation of the intervention in the real world		
- From the start, understand facilitators and barriers to reaching the relevant population, future use of the intervention, 'scale up' and sustainability in real world contexts.	✓	- Involving a range of stakeholders from the beginning will help to ensure the intervention can be successfully implemented in clinical practice. More development work is needed prior to finalising the intervention for implementation.
Design and refine the intervention		
- Generate ideas about content, format and delivery with stakeholders.	✓	- The components of the intervention, format and delivery were generated through a systematic literature review and qualitative interviews with stakeholders.
- Once an early version or prototype of the intervention is available, refine or optimise it using a series of iterations. Each iteration includes an assessment of how acceptable, feasible and engaging the intervention is, including potential harms and unintended consequences, resulting in refinements to the intervention. Repeat the process until uncertainties are resolved.	✓	- Initial intervention was refined and optimised through two rounds of Delphi consensus. Further refinement is to be completed following a proof of concept study outside the scope of this thesis.
- Check that the proposed mechanisms of action are supported by early testing.	×	- Outside of the scope of this thesis. A proof of concept study completion is needed.

Proposed action	Done	Details
End the development phase		
- There are no established criteria for stopping the intensive development phase and moving on to the feasibility/pilot or evaluation phases. The concepts of data saturation and information power may be useful when assessment of later iterations of the intervention produces few changes.	×	- Outside of the scope of this thesis. A proof of concept study completion is needed.
- Describe the intervention to facilitate transferability of an intervention outside the original team and location in which it was developed.	×	- Outside of the scope of this thesis. A proof of concept study completion is needed first.
- Write up the intervention development process so that judgements can be made about the quality of the process, links can be made in the future between intervention development processes and the subsequent success of interventions, and others can learn how it can be done.	✓	- Detailed information on the development of the intervention is presented in this thesis.

✓ - yes; × - no;

6.3 Context and Comparison to Other Literature

6.3.1 Organisation of Care

When considering both care of older people and care of people with dementia in acute hospital setting, it must be discussed how this is organised. Two examples of relevant acute hospital service models are wards which provide care for all older people and specialist wards which have patients with a specific health diagnosis. Examples of the latter include stroke units and specialist dementia wards. Guidelines for stroke patients state that patients with acute stroke should be directly admitted to a hyperacute stroke unit within four hours of arrival at a hospital (Royal College of Physicians, 2016). Recommendations for acute hospital care for people with dementia do not currently state whether the care should happen on specialist wards (Department of Health, 2009b). However, specialist acute hospital units or wards for people with dementia have been developed and tested (McCausland et al., 2019). McCausland et al. (2019) completed a systematic review of specialist inpatient dementia care services and standard inpatient dementia care in acute hospitals. The review was unable to draw any firm conclusions about the effects of specialist inpatient dementia units as the three studies that met the inclusion criteria had little consistency in their outcome measures (McCausland et al., 2019). Medical and Mental Health Unit (MMHU) is an example of an alternative model of care for hospitalised people with dementia and delirium (Tanajewski et al., 2015).

Another way to accommodate for the needs of people with dementia admitted to acute hospitals is provision of specialist services, such as old age psychiatry services or liaison psychiatry (Department of Health, 2009b). Depending on a hospital, the liaison psychiatry services may have separate teams to deliver care for children and younger people, for adults and older adults (Royal College of Psychiatrists, 2019b). Services such as old age psychiatry are not usually based on a ward, but the ward staff can access these for their patient by completing a referral (Mukaetova-Ladinska et al., 2011). Holmes et al. (2010) in a research report of liaison mental health services for older people found wide variations in the provision these

services for older people and reported that many parts of the UK did not have these. Holmes et al. (2010) concluded that further evaluative studies of liaison mental health services for older people are needed.

OcTPAP contains components which rely on multidisciplinary teamwork, and are therefore more in line with ethos of specialist inpatient dementia wards but with a stronger emphasis on ADL rehabilitation. In that, while there are similarities in approach, such as application of person-centres care concepts (Tay et al., 2018), there are also differences. For example, OcTPAP focuses more on specific targeted actions. OcTPAP emphasises the need for accurate assessment of person's abilities to complete ADL which may fluctuate throughout the hospital admission and adaptation of the rehabilitation plan in accordance with that.

6.3.2 Rehabilitation Process and Environment

Tijsen et al. (2019) in a narrative literature review identified seven main topics linked to environments with formalised rehabilitation process. These were: therapy time, carer involvement, team dynamics, a physical environment that promotes opportunities for engagement in activities, group training, task-oriented training and patient-regulated exercise. OcTPAP components addressed all of these except task-oriented training. Tijsen et al. (2019) review was not limited to people living with a specific diagnosis, but mostly included evidence related to people with stroke. Task-oriented training is mostly used in neurological rehabilitation and focuses on repetitive practice of a context-specific task (Hubbard et al., 2009). An example of using task-oriented practice with people with dementia is detailed in a trial protocol of an intervention developed by an occupational therapist (Ciro et al., 2016). Ciro et al. (2016) propose intervention that helps to achieve ADL goals through combining task-oriented practice concepts with "errorless learning" method, which requires preventing people from making mistakes during task completion (Voigt-Radloff et al., 2017). The outcomes of Ciro et al. (2016) trial have not been published.

OcTPAP emphasises the role of carers in the rehabilitation process and specifies their involvement. Involvement of both the person with dementia (care receiver) and their carer as active participants and decision makers is key characteristic of dyadic interventions (Whitlatch et al., 2006). Laver et al. (2016) completed a systematic review of systematic reviews of interventions used to delay ADL decline in people with dementia which covered non-pharmacological, pharmacological and alternative therapies. From the identified non-pharmacological interventions exercise and dyadic interventions demonstrated significant effect. The authors noted that due to low quality of evidence due to risk of bias, no concrete recommendations could be made (Laver et al., 2016). It is unclear if occupational therapy was part of these interventions, but the authors state that the dyadic interventions components included environmental adaptations, ADL and use of meaningful activities (Laver et al., 2016). Research into the interventions for reducing behavioural and psychological symptoms in people with dementia found interventions that are tailored and involve multiple components are most effective (Laver et al., 2014). Laver et al. (2014) in this review highlighted that several of the interventions which were found to be effective were developed with extensive input from occupational therapists or delivered by an occupational therapist.

6.4 Interpretation and Implications

6.4.1 Findings in Light of Coronavirus Disease

As previously stated, the Delphi consensus components of the study was completed during the time when coronavirus (COVID-19) was significantly impacting on both the National Health Service (NHS) and the lives and livelihoods of people in the UK and other countries (Prime Minister's Office, 2020). The potential impact of this on the recruitment and study results was discussed in Chapter 5. Below is discussed how the current and future provision of health and social care services may be impacted by COVID-19 and what does this mean for the OcTPAP intervention.

One of the effects of the COVID-19 pandemic was increased need for acute care, especially intensive care facilities (Propper, 2020). To increase availability of general

and acute hospital beds, patients who were medically fit got urgently discharged and many elective (planned) hospital care procedures such as joint replacements got postponed (Propper, 2020). The latter resulted in increased backlogs for elective care and a plan on how this will be addressed was published in February 2022 (NHS England, 2022). For older people longer waiting time for treatments may mean a more difficult and longer recovery resulting in independence loss (NHS England, 2022). Rehabilitation will also be needed by a large population of older people who experienced COVID-19 due to the direct consequences of the disease and the effects of social isolation and movement restrictions during lockdowns (De Biase et al., 2020). After hospitalisation for COVID-19, for people over 70 having dementia is associated with increased likelihood of readmission (Carrillo-Garcia et al., 2021). Therefore, there is likely to still be a need for acute hospital admission for people with dementia, and therefore OcTPAP.

COVID-19 may also cause symptoms which occur after the infection is gone and are referred to as “post-COVID-19 syndrome” or “long COVID” (NHS, 2022a). Some of the common long COVID symptoms are fatigue, difficulty sleeping, shortness of breath, depression, anxiety, problems with memory and concentration (NHS, 2022a). It is currently unclear how many people are effected by long COVID with confirmed and suspected number of cases range from 2.3% to 37.7% in different studies, and how many of these are people with dementia (Park, 2021). However, this must be considered as a potential additional factor during acute hospital admissions for people with dementia. OcTPAP interventions may be delivered alongside the strategies recommended when working with people with long COVID symptoms.

6.4.2 Implications for Clinical Practice

This research study findings provide evidence of the importance of implementing a person-centred care approach when working with people with dementia. This study has produced a new occupational therapy rehabilitation programme, based on research evidence, which could be used by clinical staff across the UK. However, clinicians should be made aware that the OcTPAP intervention has not been

evaluated in any clinical trials. While there has been a clear drive for only using evidence based interventions, it is unclear how many rehabilitation interventions for people with dementia that are presently delivered in NHS clinical settings have been rigorously developed and have shown to be effective. OcTPAP has been developed following MRC guidelines (Medical Research Council, 2006) and the process has been transparently and thoroughly described in this PhD thesis.

6.4.3 Implications for Future Research

The next step for OcTPAP would be the completion of the proof of concept study to test the acceptability of delivery of OcTPAP in an acute hospital setting. Research into the active components of the OcTPAP and their effect and interaction could also support the normalisation of the intervention in clinical practice.

The qualitative interviews component of this PhD study has found that ward staff are struggling to match the patient's fluctuating levels of independence with completing ADL. Further research into why this happens and identifying which staff groups are having most difficulties is required. Using activity analysis to identify what are the activity demands, its context, and the individual's abilities is one of the core skills of Occupational therapists (Atwal and McIntyre, 2013). Grading is then used to "pitch" the activity at the required level. Learning through observation and then modelling that behaviour is usually considered as essential components of clinical training of medical students (Mohammadi et al., 2020). However, this type of learning could also be happening between colleagues. Adopting the assumption that the Occupational therapists would be explicit about how activity analysis is applied to grade the tasks, they could be seen as "role models". When OcTPAP is trialled in a clinical setting it may be beneficial to explore the impact of working closely with an Occupational therapist on the other staff's confidence and ability to provide "just right" assistance and encouragement with ADL.

6.5 Conclusion

The aim of this thesis was to create an evidence-based occupational therapy intervention to help people with dementia retain independence in ADL during acute hospital admissions. This aim was achieved.

Appendices

Appendix A - Systematic Review Extraction Form

Reviewer			
Lead author		Year of paper	
Full paper ☐ Abstract only ☐			
Randomised Controlled Trial ☐ Non Randomised Controlled Trial ☐ Other study type (please state) ☐ ……			

Study aim	
Geographical location	
Setting (hospital type, ward type, patients)	
Participant Inclusion Criteria	
Participant Exclusion Criteria	
Experimental intervention - description of Occupational Therapy (Duration, frequency and description)	
Experimental intervention - description of other components	
Usual care/ conventional	

treatment delivered to the control group			
Participants	Control/ *Before intervention*	Experimental (Intervention)/ *After intervention implementation*	Notes
Age range and/or mean age			
No, participants recruited			
No, lost to follow up			
Final No. of participants evaluated/ analysed			
No. of participants with cognitive impairment or dementia (please indicate presence of these participants and numbers if unknown)			

OUTCOME MEASURES

Primary outcome measures	Outcome measure used and time/s of assessment (e.g admission, discharge, 3 months)
Activities of daily living independence	

Secondary outcome measures	Have these been measured? If yes, state outcome measure used.
Institutionalisation	
Re-hospitalisation	

Length of hospital stay	

Other outcome measures (specific to the study and not listed above)	Outcome measure used and time/s of assessment (e.g admission, discharge, 3months).

RESULTS

Primary Outcomes (results)	Control/ *Before intervention*	Experimental (Intervention)/ *After intervention implementation*
Activities of daily living independence (overall or individual ADLs) at the selected times of assessment		

Comments:

Secondary Outcomes (results) if measured	Control/ *Before intervention* N=	Experimental / *After intervention implementation* N=	Overall
Institutionalisation			

Re-hospitalisation			
Length of hospital stay			

Other outcome measures results (specific to the study and not listed above)	Control/ *Before intervention*	Experimental (Intervention)/ *After intervention implementation*

Comments:

Appendix B - Systematic Review - JBI Critical Appraisal Checklist for Randomized Controlled Trials



JBI Critical Appraisal Checklist for Randomized Controlled Trials

Reviewer_____Date_____

Author _____Year_____Record Number_____

		Yes	No	Unclear	NA
1.	Was true randomization used for assignment of participants to treatment groups?	☐	☐	☐	☐
2.	Was allocation to treatment groups concealed?	☐	☐	☐	☐
3.	Were treatment groups similar at the baseline?	☐	☐	☐	☐
4.	Were participants blind to treatment assignment?	☐	☐	☐	☐
5.	Were those delivering treatment blind to treatment assignment?	☐	☐	☐	☐
6.	Were outcomes assessors blind to treatment assignment?	☐	☐	☐	☐
7.	Were treatment groups treated identically other than the intervention of interest?	☐	☐	☐	☐
8.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	☐	☐	☐	☐
9.	Were participants analyzed in the groups to which they were randomized?	☐	☐	☐	☐
10.	Were outcomes measured in the same way for treatment groups?	☐	☐	☐	☐
11.	Were outcomes measured in a reliable way?	☐	☐	☐	☐
12.	Was appropriate statistical analysis used?	☐	☐	☐	☐
13.	Was the trial design appropriate, and any deviations from the standard RCT design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

_____

_____

_____

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Appendix C - Systematic Review - JBI Critical Appraisal Checklist for Quasi-Experimental Studies



JBI Critical Appraisal Checklist for Quasi-Experimental Studies (non-randomized experimental studies)

Reviewer_____Date_____.

Author _____Year_____Record Number_____.

		Yes	No	Unclear	Not applicable
1.	Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	☐	☐	☐	☐
2.	Were the participants included in any comparisons similar?	☐	☐	☐	☐
3.	Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	☐	☐	☐	☐
4.	Was there a control group?	☐	☐	☐	☐
5.	Were there multiple measurements of the outcome both pre and post the intervention/exposure?	☐	☐	☐	☐
6.	Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	☐	☐	☐	☐
7.	Were the outcomes of participants included in any comparisons measured in the same way?	☐	☐	☐	☐
8.	Were outcomes measured in a reliable way?	☐	☐	☐	☐
9.	Was appropriate statistical analysis used?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

_____

_____

_____

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Appendix D - Qualitative Interviews - Interview Guide Examples (patients, clinicians and commissioners)

Introduction

LP, a researcher at the UoN. Currently working on developing a rehabilitation programme for people with dementia during their hospital stay. It will be aimed at helping people with dementia (PwD) retain their independence in doing daily tasks (ADLs) during the admission.

ADLs are personal hygiene/grooming, dressing, toileting/continence, transferring/mobilising, and eating.

The aim of this interview is to gather information that will help to create an intervention, which could be delivered in a hospital setting. I am interested in talking to all involved to gather their views and ideas on how this intervention may look like. I'd like you to think that there is no limit on staff resources.

(Confirm that the participant has read and understood the Participant Information Sheet)

Any questions about the interview? Participant to sign the consent form if decides to proceed.

Gather relevant demographics:

e.g How long ago where you diagnosed with dementia?

When were you last in hospital?

Do you need full assistance with all tasks?

When you are ready I will switch on the recorder and we will start the interview.

The interview will last up to an hour. You can stop the interview at any time.

Main body

(relevant page from below)

Conclusion

Check if the participant would like to add anything else. Thank participant for their time. Explain that the interview will be anonymized and transcribed, the information will be kept strictly confidential.

Ask if they would like to receive the summary of the results.

(For patients) **Main body**

What a rehabilitation programme for hospitalized people with dementia might look like?

- **Please tell me about your general experience of hospital admissions for people with dementia**
- **How independent were you before the admission?**

  Possible prompts:

  - Did the admission make you better, worse or you stayed the same in terms of independence?
  - Was this something you expected? *talk through examples of ADLs*
  - What were the challenges?
  - What worked well and not so well?
  - Can you please tell me more about that?
  - What would make even a small difference?
  - **What would need to be in place for this to happen?**

hygiene/grooming
dressing
toileting/continence
transferring/mobilising
eating

- **Do you feel when you were being helped with *ADL* the cognitive impairment was taken into the account?**

  - What could have been done differently?
  - What can be done for this to be addressed?
  - Can you please give me a few examples?
  - What could be offered that isn't … ?
- When the **discharge** was mentioned, did you have any concerns?

- **What actions should be taken to help people with dementia maintain/regain their independence with daily activities in hospital?** (address any gaps from the previous question)
  - **And who should be helping these patients?**
  - **Tell me about what you think you would enjoy, or would like to work on to achieve?**
  - **What role do you think the patient has in their recovery?**
  - **What could clinicians do?**
  - How long could you do *activity* (e.g. getting dressed) before you have had enough?
  - Who should be helping you/these patients?

  - What do you think about the Environment, Equipment, Staffing, Training, Attitudes, Services
  - What would have been helpful?

(For carers) **Main body**

What is the participant's experience?

- Could you please tell me a bit about your experience of caring for someone with dementia?
- How long you have you been doing that for?

Possible prompts:

- Is there anything else you would like to add?
- Have any other past roles added to your experience?

What a rehabilitation programme for hospitalized people with dementia might look like?

- **Please tell me about your general experience of hospital admissions for people with dementia**
- **How independent was she/he before the admission?**

  - Did the admission make her/him better, worse or they stayed the same in terms of independence?
  - Was this something you expected? *talk through examples of ADLs*
  - What were the challenges?
  - What worked well and not so well?
  - Can you please tell me more about that?
  - What would make even a small difference?
  - **What would need to be in place for this to happen?**

hygiene/grooming
dressing
toileting/continence
transferring/mobilising
eating

- **Do you feel when she/he was being helped with *ADL* the cognitive impairment was taken into the account?**

  - What could have been done differently?
  - What can be done for this to be addressed?
  - Can you please give me a few examples?
  - What could be offered that isn't?

- When the **discharge** was mentioned, did you have any concerns?

- **What actions should be taken to help people with dementia maintain/regain their independence with daily activities in hospital?** (address any gaps from the previous question)
    - **And who should be helping these patients?**
    - **Tell me about what you think your relative/patient would enjoy, or would like to work on to achieve?**
    - **What role do you think the patient has in their recovery?**
    - **What clinicians could do?**

    - How long could your relative/patient do *activity* (e.g getting dressed) before your relative/patient have had enough?
    - Who should be helping these patients?

    - What do you think about the Environment, Equipment, Staffing, Training, Attitudes, Services
    - What would have been helpful?

(For clinicians) **Main body**

What is the participant's experience of hospital admissions?

- Could you please say whether you see yourself as a patient, carer, clinician or a commissioner?
- How long you have been in that role/s?
  Possible prompts:
  - Is there anything else you would like to add?
  - Have any other past roles added to your experience?

What a rehabilitation programme for hospitalized people with dementia might look like?

- **What are your expectations in terms of independence levels during hospital admissions for people with dementia?**
  - What are the challenges?
  - What works well and not so well?
  - Can you please tell me more about that?
  - What would make even a small difference?
  - How do you think this can be encouraged?
  - How do you think this can be supported?
  - **What would need to be in place for this to happen?**

hygiene/grooming
dressing
toileting/continence
transferring/mobilising
eating

- **Do you feel the cognitive impairment is taken into the account?**
  - What can be done for this to be addressed?
  - Can you please give me a few examples?
  - What could be offered that isn't already?

- What should the **expectations be on discharge** from the hospital in terms of independence with ADLs?

- **What actions should be taken to help people with dementia maintain/regain their independence with daily activities in hospital?**
  - **And who should be helping these patients?**
  - Tell me about what you think the patients would enjoy, or would like to work on to achieve?
  - **What role do you think the patient has in their recovery?**

- **What clinicians could do?**

- **Could you please give examples/options of what do you think is ideal to help maintain *specific skill from activities of daily living list*?**
  - How long could the patient do *activity* (e.g. getting dressed) before they have had enough?
  - Who should be helping these patients?

- What resources would be needed to do that?
  - What do you think about when we talk about resources? (e.g Environment, Equipment, Staffing, Training, Attitudes, Services)

(For commissioners) **Main body**

What is the participant's experience?

- Could you please tell me a bit about your commissioning role?
- How long you have been in that role/s?
  Possible prompts:
    - *What services were you commissioning?*
    - Is there anything else you would like to add?

    - How does the commissioning process look?

Influences

- **Have you ever funded or considered funding any therapeutic intervention?**
    - How would you decide what is funded?
    - Where would the funding come from?
    - What made them "commissionable"?
    - What made them not appealing?
    - What influenced your decision
    - What do you need to know about the intervention?

- **Tell me about your experience of funding an intervention for older people or people with dementia**
    - Could you tell me about what happened after you decided to fund this intervention?
    - What do you think would have happened if you did not fund it
    - What do you need to know about the intervention?

    - Are there any common themes on what the interventions would have to be funded?
    - Evidence shows that older people can get deconditioned during hospital admissions, is this an issue you ever came across in your career as a commissioner?

    - What would need to be in place for this to happen?
    - **What role does patients' voice have in the process?**

- Resources
    - Environment, Equipment, Staffing, Training, Attitudes, Services

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Interview Participant Information Sheet (for patients and carers)

(Final version 1.1: 1 February 2019)

Title of Study: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.

Name of Chief Investigator: Lisa Patrick
Local Researcher(s): Philippa Logan, Sarah Goldberg, Rowan Harwood, Jane Horne

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?

This study seeks to gather your thoughts on what a tailored rehabilitation programme might look like. The programme would be aimed at helping people with dementia maintain and regain independence in their daily activities (such as getting washed and dressed) while in hospital.

Why have I been invited?

You are being invited to take part because you are a person living with dementia or a carer for a person with dementia. We are inviting up to 20 participants overall including clinicians and commissioners to take part.

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?

1. You will be asked to carefully read this information sheet alongside a brief summary information sheet. You will be given the opportunity to ask any questions you may have about the study. You will be asked to sign a Consent Form to ensure you understand what you are agreeing to. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) and the Alzheimer's Society. The views expressed are those of the authors and not necessarily those of the Alzheimer's Society, the NIHR or the Department of Health and Social Care.

Alzheimer's Society

SUPPORTED BY NIHR | National Institute for Health Research

2. There will be an interview with the study lead. The discussion will be about your views on what a tailored rehabilitation programme could look like. The programme would be aimed at helping hospitalised people with dementia maintain and regain independence in their daily activities.

The interview is expected to last about an hour and is a one-off event. Depending on your preference, it will take place either at a meeting room in University of Nottingham, Nottingham or at your own home if it is within the East Midlands area. We will try our best to arrange a convenient date and time to suit you. The interview will be recorded on a voice recorder device and then typed up word by word.

Expenses and payments

You will receive a £20 voucher as a thank you for your contribution. If you decide to travel to be interviewed at the University of Nottingham, reasonable expenses, such as travel costs or costs of hiring a carer of up to £50 will be offered. In some circumstances costs in excess of £50 may also be covered. Please speak to the study lead about types of expenses that could be covered and how to claim them.

What are the possible disadvantages and risks of taking part?

There are no known risks or disadvantages of taking part.

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 to develop a rehabilitation programme to help people with dementia. Results of the study will be shared with you if you are interested, and may help you to increase your knowledge in this area.

What happens when the research study stops?

The gathered data will be analysed and used to inform the development of a rehabilitation programme to maintain or regain independence with activities of daily living for older people with dementia in an acute hospital setting. We plan to then test this rehabilitation programme.

If you wish to receive a summary of the conclusions drawn from this part of the study, please contact the study lead.

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 document. If you remain unhappy and wish to complain formally, you can do this by contacting the administrator of Faculty of Medicine and Health Sciences Research Ethics Committee c/o Faculty PVC office B floor, School of Medicine, QMC campus, NUH, Nottingham, NG7 2UH. Email: fmhs-researchethics@nottingham.ac.uk.

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 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 at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you join the study, some parts of the data collected for the study will be looked at and stored by authorised persons from the University of Nottingham, or the research funders - the NIHR Collaboration for Leadership in Applied Health Research and Care East Midlands, and the Alzheimer's Society. They may also be looked at by authorised people from regulatory organisations 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.

Although what you say to us 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.

Your contact information will be kept by the University of Nottingham for two years after the end of the study so that we are able to contact you about the findings of the study if you agreed to this. This information will be kept separately from the research data collected and only those who need to will have access to it. All other research data will be kept securely for seven 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 given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with other Universities and researchers, including those in other countries. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to

share identifiable information we will seek your consent for this. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

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 we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records. Should you withdraw more than 7 days after the interview has taken place then the information collected so far including during the interview cannot be erased and this information may still be used in the study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

The results of the study may potentially be used as part of service development projects, presented to relevant audiences, published in professional journals or used to identify future priorities for research. Direct quotations may be used, however these will be anonymised. A short video explaining the background and findings of the study for members of the public and healthcare professionals may be created. Findings will also be written up for a PhD thesis.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the Alzheimer's Society and the Collaboration for Leadership in Applied Health Research and Care.

Who has reviewed the study?

All research in healthcare 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 Nottingham University Faculty Research Ethics Committee.

Further information and contact details

Study lead:
Lisa Patrick
Clinical Doctoral Research Fellow at the University of Nottingham and Occupational Therapist
Tel: 0115 8230029, 07855518071
Email: lisa.patrick1@nottingham.ac.uk

Co-Investigator:
Professor Pip Logan
Professor of Rehabilitation Research and Occupational Therapist
Head of Division Rehabilitation and Ageing,
B108a, School of Medicine, UoN,
Nottingham, NG7 2UH
Tel: 0115 8230235, 07884318920
Email: pip.logan@nottingham.ac.uk

Interview Participant Information Sheet (for clinicians and commissioners)

(Final version 1.1: 1 February 2019)

Title of Study: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.

Name of Study lead: Lisa Patrick
Local Researcher(s): Philippa Logan, Sarah Goldberg, Rowan Harwood, Jane Horne

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?

This study seeks to explore the opinions on what a rehabilitation programme that helps hospitalised people with dementia maintain and regain independence in their daily activities might look like.

Why have I been invited?

You are being invited to take part because you are a clinician involved in patients' care of hospitalised patients with dementia or a commissioner of NHS or social services. We are inviting up to 20 participants including people with dementia and carers to take part.

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?

1. You will be asked to carefully read this information sheet and will be given the opportunity to ask any questions you may have about the study. You will be asked to sign a Consent Form to ensure you understand what you are agreeing to. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

2. There will be an interview with the study lead. The discussion will be about your views on what a tailored rehabilitation programme could look like. The programme would be aimed at helping hospitalised people with dementia maintain and regain independence in their daily activities (such as washing and dressing and transferring).

The interview is expected to last about an hour and is a one-off event. Depending on your preference, it will take place either at a University of Nottingham meeting room in Nottingham, a meeting room in your workplace or at your own home if they are within East Midlands. We will try our best to arrange a convenient date and time to suit you. The interview will be recorded on a voice recorder device and transcribed.

This project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) and the Alzheimer's Society. The views expressed are those of the authors and not necessarily those of the Alzheimer's Society, the NIHR or the Department of Health and Social Care.

Expenses and payments

If you decide to travel to be interviewed at the University of Nottingham, travel expenses of up to £50 will be offered. Please speak to the study lead about types of expenses that could be covered and how to claim them. If you are unable to participate in the interview in your work time and therefore have to be interviewed in your own time, you can claim a £20 voucher for the inconvenience.

What are the possible disadvantages and risks of taking part?

There are no known risks or disadvantages of taking part.

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 to develop a rehabilitation programme to help people with dementia with activities of daily living independence during acute hospital admissions. Results of the study will be shared with you if you are interested, and may help you to increase your knowledge in this area.

What happens when the research study stops?

The gathered data will be analysed and used to inform the development of a rehabilitation programme to maintain or regain independence with activities of daily living for older people with dementia in an acute hospital setting. We plan to then test this rehabilitation programme.

If you wish to receive a summary of the conclusions drawn from this component of the study, please contact the study lead.

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 administrator of Faculty of Medicine and Health Sciences Research Ethics Committee c/o Faculty PVC office B floor, School of Medicine, QMC campus, NUH, Nottingham, NG7 2UH. Email: fmhs-researchethics@nottingham.ac.uk

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 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 at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you join the study, some parts of the data collected for the study will be looked at and stored by authorised persons from the University of Nottingham, or the research funders - the NIHR Collaboration for Leadership in Applied Health Research and Care East Midlands, and the Alzheimer's Society. They may also be looked at by authorised people from regulatory organisations 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.

Although what you say to us 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.

Your contact information will be kept by the University of Nottingham for two years after the end of the study so that we are able to contact you about the findings of the study if you agreed to this. This information will be kept separately from the research data collected and only those who need to will have access to it. All other research data will be kept securely for seven 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 given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with other Universities and researchers, including those in other countries. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

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 we will no longer collect any information about you or from you, but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records. Should you withdraw more than 7 days after the interview has taken place then the information collected so far including during the interview cannot be erased and this information may still be used in the study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

The results of the study may potentially be used as part of service development projects, presented to relevant audiences, published in professional journals or used to identify future priorities for research. Direct quotations may be used, however these will be anonymised. A short video explaining the background and findings of the study for members of the public and healthcare professionals may be created. Findings will also be written up for a PhD thesis.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the Alzheimer's Society and the Collaboration for Leadership in Applied Health Research and Care.

Who has reviewed the study?

All research in healthcare 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 Nottingham University Faculty Research Ethics Committee.

Further information and contact details

Study lead:
Lisa Patrick
Clinical Doctoral Research Fellow at the University of Nottingham and Occupational Therapist
Tel: 0115 8230029, 07855518071
Email: lisa.patrick1@nottingham.ac.uk

Co-Investigator:
Professor Pip Logan
Professor of Rehabilitation Research and Occupational Therapist
Head of Division Rehabilitation and Ageing,
B108a, School of Medicine, UoN,
Nottingham, NG7 2UH
Tel: 0115 8230235, 07884318920
Email: pip.logan@nottingham.ac.uk

Appendix F - Qualitative Interviews - Informed Consent Form

University of Nottingham
UK | CHINA | MALAYSIA

Interview Consent Form

(Final version 1.1: 1 February 2019)

Title of Study: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions

Name of Researcher: Lisa Patrick

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet version number 1.1 dated 1.2.2019 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 more than 7 days after the interview has taken place then the information collected so far cannot be erased and that this information may still be used in the study analysis. ☐

3. I understand that 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 interview will be audio recorded and that anonymous direct quotes from the interview may be used in the study reports. ☐

5. 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. ☐

6. I agree to take part in the above study. ☐

If you wish to be sent a summary of the research findings please provide the Study lead with your contact details and contact us if these need updating before you receive the summary of the findings.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

2 copies: 1 for participant, 1 for the project notes

Appendix G - Qualitative Interviews - Brief Participant Information Sheet

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Brief Interview Participant Information Sheet

(Final version 1.0: 1 February 2019)

Title of Study: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.

Name of Study Lead: Lisa Patrick
Local Researcher(s): Philippa Logan, Sarah Goldberg, Rowan Harwood, Jane Horne

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.

This is a brief version of the information sheet which contains only the key points, please read the full information sheet too.

What is the purpose of the study?

This study seeks to gather your thoughts on what a tailored rehabilitation programme might look like. The programme would be aimed at helping people with dementia maintain and regain independence in their daily activities (such as getting washed and dressed) while in hospital.

Do I have to take part?

It is up to you to decide whether or not to take part. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?

1. You will be asked to carefully read the full information sheet alongside this one. You will be given the opportunity to ask any questions you may have about the study. You will be asked to sign a Consent Form to ensure you understand what you are agreeing to. You will be given a copy of both to keep.

2. There will be an interview with the study lead. The discussion will be about your views on what a tailored rehabilitation programme could look like. The programme would be aimed at helping hospitalised people with dementia maintain and regain independence in their daily activities.

This project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) and the Alzheimer's Society. The views expressed are those of the authors and not necessarily those of the Alzheimer's Society, the NIHR or the Department of Health and Social Care.

Alzheimer's Society

SUPPORTED BY NIHR | National Institute for Health Research

The interview is expected to last about an hour and is a one-off event. Depending on your preference, it will take place either at a University of Nottingham meeting room in Nottingham or your own home if it is within East Midlands. We will try our best to arrange a convenient date and time to suit you. The interview will be recorded on a voice recorder device and then typed up word by word.

Expenses and payments

You will receive a £20 voucher as a thank you for your contribution. If you decide to travel to be interviewed at the University of Nottingham meeting room, reasonable expenses such as travel costs or costs of hiring a carer of up to £50 will be offered. In some circumstances costs in excess of £50 may also be covered. Please speak to the study lead about types of expenses that could be covered and how to claim them.

Will my taking part in the study be kept confidential?

Although what you say to us 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 we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained.

Further information and contact details

Study lead:
Lisa Patrick
Clinical Doctoral Research Fellow at the
University of Nottingham and Occupational Therapist
Tel: 0115 8230029, 07855518071
Email: lisa.patrick1@nottingham.ac.uk

Co-Investigator:
Professor Pip Logan
Professor of Rehabilitation Research and Occupational Therapist
Head of Division Rehabilitation and Ageing,
B108a, School of Medicine, UoN,
Nottingham, NG7 2UH
Tel: 0115 8230235, 07884318920
Email: pip.logan@nottingham.ac.uk

Appendix H - Ethical Approval Letter

University of Nottingham
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences
Research Ethics Committee
c/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

6 March 2019

Lisa Patrick
PhD Student/Research Occupational Therapist
Room B95, Floor B, The Medical School
Division of Rehabilitation, Ageing and Wellbeing
School of Medicine
QMC Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

Dear Ms Patrick

Ethics Reference No: 235-1902– **please always quote**	
Study Title: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.	
Chief Academic/Supervisor: Professor P Logan, Head of Division of Rehabilitation, Ageing and Wellbeing, School of Medicine	
Chief Investigator/student: Lisa Patrick, Alzheimer's Society and CLAHRC Clinical Doctoral Research Fellow, Division of Rehabilitation, Ageing and Wellbeing, School of Medicine.	
Other Key Investigators: Dr Sarah Goldberg, Associate Professor in older persons care, School of Health Sciences, Professor Rowan Harwood, Professor of Palliative and End of Life Care/Consultant Geriatrician, NCARE, Dr Jane Horne, Research Fellow and Occupational Therapist, Rehabilitation, Ageing and Wellbeing.	
Proposed Start Date: 01/01/2019	**Proposed End Date:** 31/10/2020

The Committee considered this application at its sub-committee meeting on 22.02.2019 and the following documents were received:

- FMHS REC Application form and supporting documents version 1.0: 01.02.2019

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A favourable opinion has been given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix I - Ethical Approval Amendment Confirmation (Qualitative Interviews)

University of Nottingham
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty PVC Office
Room E41, Faculty Hub
E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

23 May 2019

Lisa Patrick
PhD Student/Research Occupational Therapist
Room B95, Floor B, The Medical School
Division of Rehabilitation, Ageing and Wellbeing
School of Medicine
QMC Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

Dear Ms Patrick

Ethics Reference No: 235-1902– **please always quote**	
Study Title: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.	
Chief Academic/Supervisor: Professor P Logan, Head of Division of Rehabilitation, Ageing and Wellbeing, School of Medicine	
Chief Investigator/student: Lisa Patrick, Alzheimer's Society and CLAHRC Clinical Doctoral Research Fellow, Division of Rehabilitation, Ageing and Wellbeing, School of Medicine.	
Other Key Investigators: Dr Sarah Goldberg, Associate Professor in older persons care, School of Health Sciences, Professor Rowan Harwood, Professor of Palliative and End of Life Care/Consultant Geriatrician, NCARE, Dr Jane Horne, Research Fellow and Occupational Therapist, Rehabilitation, Ageing and Wellbeing.	
Proposed Start Date: 01/01/2019	**Proposed End Date:** 31/10/2020

Thank you for notifying the Committee of amendment no 1: 23.5.2019 which is to add a new inclusion criteria for recruitment as detailed and the following documents were received:

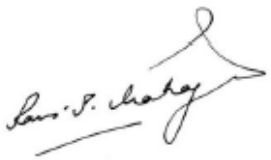
- FMHS REC Notice of minor amendment form and revised protocol version 1.1: 23.04.2019

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A favourable opinion has been given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely



Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix J - Qualitative Interviews - Example of Earlier Coding Frame

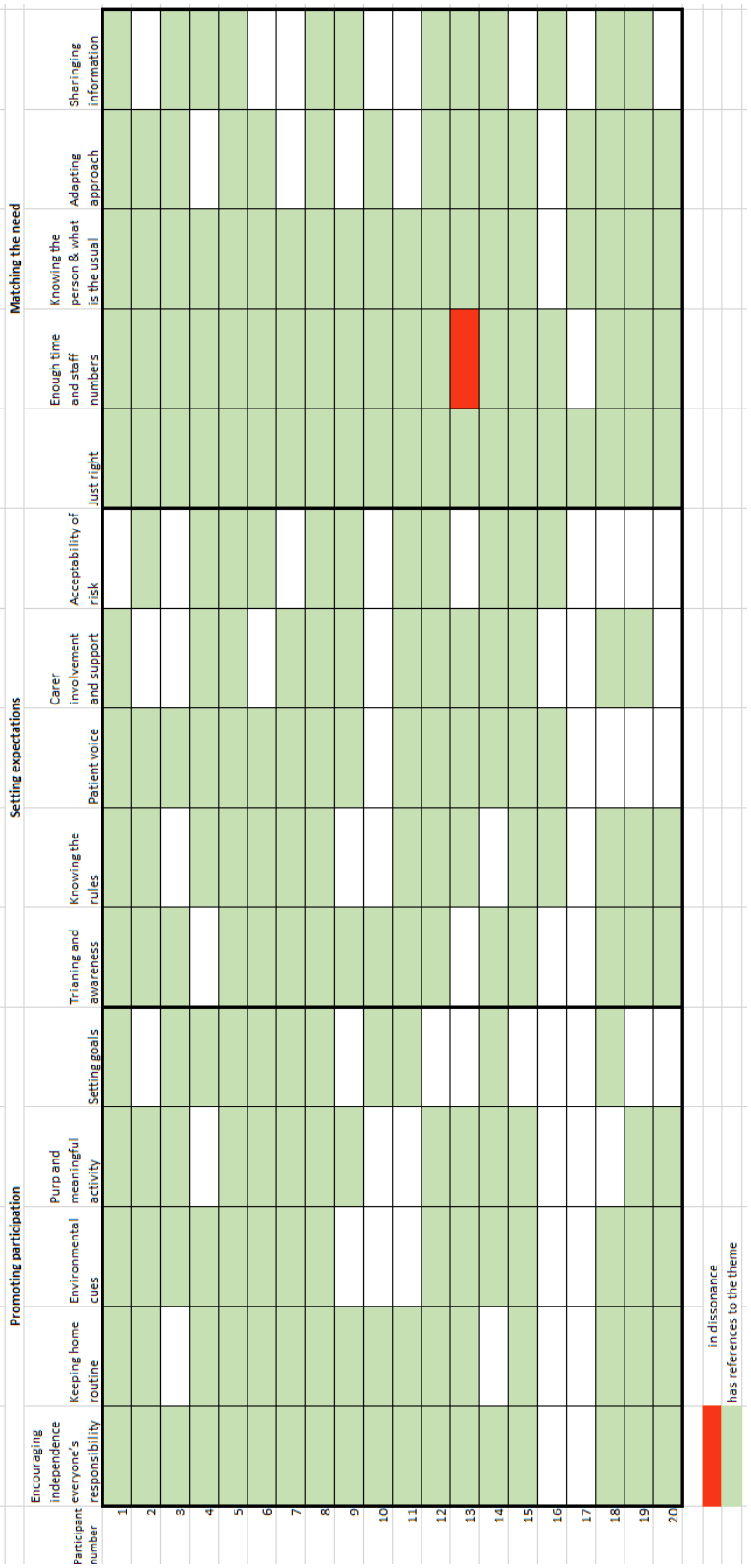
Code	Description
Adapting approach (for people with dementia)	
Communication	Dementia friendly way of communication, being patient. Using positive non-verbal language
Matching the need	Not over helping or under helping, adapting your approach. Often equipment is used to make it easier for staff.
Building a relationship	Patient having trust in staff, staff's expectations and "promises" to the patient coming true.
Encouragement/Empowerment	Motivating the patient, not doing things "to" someone, but "with" someone. Supporting/facilitating patients looking after themselves – "if we just let them". Not restricting function and choices.
Getting to know the patient	Sense of wellbeing for the patient. Knowing patient's values and believes. Not just a list on the form, but more of a discussion.
Avoiding negative labels	Not stereotyping.
Decrease change	Too much change in routines, need to decrease that. Changing wards can "backfire" and prolong stay.
Knowing "baseline"	Being aware of abilities and limitations. Maybe using strengths based approach, based on thorough assessment
Taking enough time	Not rushing the patient
Participation over the quality of outcome	

Environment	Unfamiliar environment is a hindrance. Having familiar things can be helpful. Having clear signage. Environmental clues – e.g eating in groups Having equipment to facilitate independence on the ward (e.g wheelchairs)
Opportunities for independence	Opportunities to do things for yourself (patient) Staff actively initiating interaction and creating opportunities.
Own belongings	Having familiar things around the patient.
Attention not just to medical and physiological needs is needed	Patients “loosing identity”.
Opportunities to do things which are more “normal”	Groups, having additional activities.
Familiarity	Working with the same staff members who got to know the patient, rather than a “new face every day”
Daily input	7 day working practices, returning to the patient every day. Decline of patients over weekend.
Continuity of approach	Differences between professions and staff members in terms of how much they encourage independence. Not coordinated.
Institutionalisation	Patient adopting a “sick role”. Decrease in motivation.
Goal setting	In preparation to returning home. Need to be individual and specific. Important to listen to patient, not just clinicians setting goals in line with hospital priorities. Letting patients make choices – “give control back”.

MDT input/ holistic assessment/ MDT effort	
Setting expectations	What is expected in terms of remaining independent during the admission. Patients continuing with rehab without active encouragement
Patients' own understanding /assessment of their abilities	How accurate/attitude. Patient's expectations of support levels in hospitals
Assessment as rehabilitation	Facilitating independence is an opportunity for further assessment.
Purposeful activity	Assessing through daily tasks, rather than aimless walk
Multidisciplinary team	
Roles within MDT	Each profession has own priorities
Communication within MDT	How the information is communicated. Use of technology.
Training and awareness	Professional background and previous training. Taking ownership of your job role and your practice. Confidence.
Ward culture/Cultural shift needed	Team approach, coordinated approach. Staff relationship. Under leadership of experts.
Risk averse/ acceptability of risk/ restricting function	Repercussions to the therapy team for "failed discharges"
Separate role to encourage independence	Some participants said it's everyone's responsibility, yet some said it should be a separate role.
Hospital priorities over patients' needs	
Staffing levels/Lack of staff time	Lack of time is restricting level of care that could be provided for a patient. Staff feel rushed. Pressures to discharge patients. Caseload/new patients - Therapists struggle to give rehab time to patients who have already been assessed.

Lack of funding	Funding restricts numbers of staff
	Patients returning to the hospital as a result of being discharged prematurely.
Staff morale	Staff feeling like they “can’t give your all” and fulfil their role due to time pressures.
Knowing the rules	Patient and carers knowing what they are “allowed” to do in hospital.
Hospital routines	Patients having to “fit” into hospital routines
Discharges are priority	
Other	
Carers input	Carers continuing to be involved in care. Carers knowing the person best, holding knowledge.
Use of technology to handover	How information is passed between the team.
Delivering evidence based interventions	
Flow through the hospital	During admission
Info from community systems	System 1 access
Rehab vs one off assessment	

Appendix K - Qualitative Interviews - Table of Subtheme Silences and Contradictions



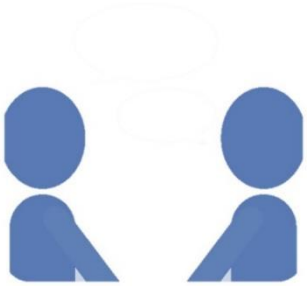
Appendix L - Qualitative Interviews - Recruitment Posters

Poster for clinicians and commissioners

Maintaining and regaining independence with daily people with dementia during hospital admissions

Can you help?

We are looking for people across the East Midlands region to talk to us about their views on **how we could help people with dementia retain their independence** with daily tasks during acute hospital admissions.

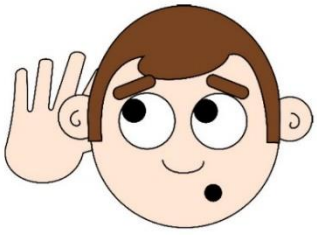




The informal interview will last for approximately an hour.

We would like to hear from you if you are:

- a clinician involved in the care of hospitalised people with dementia
- a commissioner





Please contact Lisa Patrick for more details:

Email: lisa.patrick1@nottingham.ac.uk

Telephone: 0115 8230029, 07855518071



This project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) and the Alzheimer's Society. The views expressed are those of the authors and not necessarily those of the Alzheimer's Society, the NIHR or the Department of Health and Social Care.

Alzheimer's Society United Against Dementia

SUPPORTED BY NIHR | National Institute for Health Research

Interview poster (persons with dementia and carers)

Maintaining and regaining independence with daily tasks for people with dementia during hospital admissions

Can you help?

We are looking for people across the East Midlands region to talk to us about their views on **how we could help people with dementia retain their independence** with daily tasks during their hospital stay.

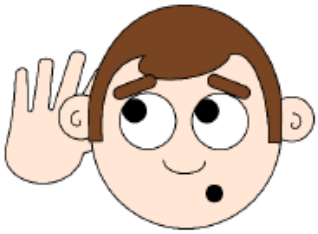




The conversation will last for approximately an hour.

We would like to hear from you if you are:

- a person diagnosed with dementia
- a carer for a person with dementia





Please contact Lisa Patrick for more details:

Email: lisa.patrick1@nottingham.ac.uk

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Alzheimer's Society

SUPPORTED BY NIHR | National Institute for Health Research

Appendix M - Qualitative Interviews – Theme summaries

Theme	Matching the need				
Theme description	This theme covers the importance of providing the exact amount of assistance to facilitate independence in activities of daily living. It also explains the need for having enough staff and for the staff to have sufficient time to deliver better care and the staff adapting their approach to working with people with dementia. Understanding of the individual patients and their circumstances and how this can be communicated is discussed.				
Subtheme	**Just right**	**Enough time and staff numbers**	**Knowing the person and what is the usual**	**Adapting approach**	**Sharing information**
Subtheme description	Staff not providing too much or not enough help. Staff being able to assess accurately what patient can and cannot do and progress/adapt that as situation changes.	Staff stating that they do not have time to encourage patients to do things for themselves, therefore staff may choose a less time consuming option. Having more staff and staff time to deliver better care.	Knowing the baseline and what the normal routines are and trying to recreate these during the hospital admission. Not knowing baseline delays the appropriate care. How the information is gained, recorded and communicated. Getting the information from a variety of sources (family, carers, records) to get "the bigger picture". Knowing about patient's	Understanding the impact having dementia can have on the patient and tailoring approach accordingly. "unpicking which part they have difficulties with". Presence of stereotypes is unhelpful. Patients not always aware of own ability.	Having access to previous information from community to understand the patient and their situation better. Communicating information about the ways to enable person during the admission in the way that works best for staff. Keeping carers up to date.

Theme	Setting expectations				
Theme description	This theme includes participant's views on the staff training and awareness, making sure the "patient voice" is listened to and the carers feel supported. The importance of setting expectation for the hospital admission in terms of independence and the associated risk is also covered.				
Subtheme	**Training and awareness**	**Knowing the rules**	**Patient voice**	**Carer involvement and suppo**	**Acceptability of risk**
Subtheme description	More understanding and staff training around dementia care is needed. Differences in training levels depending on type of the ward (e.g. geriatric vs orthopaedics). Evidence based practice is important. Leadership and reabling culture on the ward. Not just one off opportunities for staff training, continuous. Learning from colleagues from different professions.	Explaining what is expected from the patient and from staff "like a patient contract but it's not an enforceable" for during the hospital stay. Patients and carers need to be given information on how they can "keep their daily activities going" to avoid misconceptions. Perceptions around what patient role involves, "pyjama induced paralysis" from both patients and family. Often there is a certain routine to the ward. Carers need to know which facilities they can use and where things are and feeling	Valuing and respecting patient's choices and autonomy even if they are not what the staff would chose. Patient in control or "Having that ethos of a partnership", shared decision making. If able, patients should also take responsibility for completing their rehab. Being aware of capacity issues. Involving patients in decisions about changes to services as well as on individual bases about decisions about their care.	Involving family in decision making, valuing their knowledge about the patient, and keeping them updated. Carers coming in to help with care if they feel able to, but may need a break. Carers may need educating on what to expect or some care aspects. Information from and involvement of paid and unpaid carers.	Staff often risk averse as concerned about the consequences such as patient harm and complaints. Ideally keeping independence without increasing risk. Perceptions about risk levels in different environments

Theme	Promoting participation				
Theme description	This theme explores whose responsibility it is to help the patients retain independence in activities of daily living, the importance of recreating normal routines, and the role of environmental cues. Settings goals to promote participation and the application of purposeful and meaningful activities is discussed.				
Subtheme	**Responsibility of encouraging independence**	**Keeping home routine**	**Environmental cues**	**Purposeful and meaningful activity**	**Setting goals**
Subtheme description	Staff often chose the easier option for them instead of encouraging independence. Every activity as rehabilitation, need to involve patient as much as possible. Having designated person, team for rehab. Still an MDT effort. Start early on. Continuity and 7 days working for more specialities. Patient making decisions about how to be independent and taking responsibility for getting more active.	More flexible approach to the daily schedule to mimic patient's home timetable. Having set hospital routines has some benefit. Patient being able to practice daily routines in the most familiar way. Patient having their own belongings and familiar items in hospital and staff helping the patient to use them. Concerns around patient's items getting soiled/going missing.	Environmental cues that invite (creating context) and allow (better facilities) patients to do things for themselves and better environment layout. More homely and dementia friendly environment would help. Staff encouraging independence and offering an option for patient to do something more independently.	No stimulating activities for patients available. Social interactions on topics not related to clinical needs. Activities which are more "homelike" and relevant to that generation to be available. Staff being creative in coming up with meaningful activities for patients to get involved with that they "might be doing when they get home".	Need to set realistic and specific goals that are important to the patient and family "within the restriction of the setting". Setting a plan for everyday. A whole team effort on how to achieve it. Daily input. Using information gained during assessments for patient care during the hospital stay. Not just a paperwork exercise, but actioning the set goals.

Appendix N - Ethical Approval Amendment Confirmation (Delphi Consensus)

University of Nottingham
UK | CHINA | MALAYSIA

Email: FMHS-ResearchEthics@nottingham.ac.uk

Faculty of Medicine & Health Sciences
Research Ethics Committee
Faculty PVC Office
Room E41, Faculty Hub
E Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

21 July 2020

Lisa Patrick
PhD Student/Research Occupational Therapist
Room B95, Floor B, The Medical School
Division of Rehabilitation, Ageing and Wellbeing
School of Medicine
QMC Campus
Nottingham University Hospitals
Nottingham, NG7 2UH

Dear Ms Patrick

Ethics Reference No: 235-1902– **please always quote**	
Study Title: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.	
Chief Academic/Supervisor: Professor P Logan, Head of Division of Rehabilitation, Ageing and Wellbeing, School of Medicine	
Chief Investigator/student: Lisa Patrick, Alzheimer's Society and CLAHRC Clinical Doctoral Research Fellow, Division of Rehabilitation, Ageing and Wellbeing, School of Medicine.	
Other Key Investigators: Dr Sarah Goldberg, Associate Professor in older persons care, School of Health Sciences, Professor Rowan Harwood, Professor of Palliative and End of Life Care/Consultant Geriatrician, NCARE, Dr Jane Horne, Research Fellow and Occupational Therapist, Rehabilitation, Ageing and Wellbeing.	
Proposed Start Date: 01/01/2019	**Proposed End Date:** 31/10/2020

Thank you for notifying the Committee of amendment no 2: 24.6.2020 which is to update the eligibility criteria for component II (Delphi consensus) as detailed and the following documents were received:

- FMHS REC Notice of minor amendment form no 2: 24.6.2020
- Protocol v1.2 24.6.2020
- Delphi Participant Information Sheet v1.1 24.6.2020
- Delphi poster v1.1 24.6.2020

These have been reviewed and are satisfactory and the study amendment no 2: 24.6.20 is approved.

Approval is given on the understanding that:

1. The protocol agreed is followed and the Committee is informed of any changes using a notice of amendment form (please request a form).
2. The Chair is informed of any serious or unexpected event.
3. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

Dr Bethan E Phillips, Associate Professor
Clinical, Metabolic & Molecular Physiology, Medical Sciences & Graduate Entry Medicine
Acting Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix O - Delphi Consensus - Round One Questionnaire

OcTPAP Delphi questionnaire. Round 1

Thank you for agreeing to complete this questionnaire. The purpose is to reach agreement on the contents of a new occupational therapy personal activity programme (OcTPAP) which would be delivered in collaboration with the multidisciplinary team and in addition to the usual occupational therapy assessment and interventions.

The new programme is aimed at helping people with dementia stay independent with activities of daily living during hospital admissions, but does not have to be limited to in-hospital delivery. For all older people hospital admissions are likely to be deskilling, this is exacerbated for people with dementia, as they often have difficulties learning new skills or relearning the ones which are not used regularly.

OcTPAP has been developed from existing literature and interviews with people living with dementia, carers and healthcare professionals. You can assume that the OcTPAP takes place in an environment where the following is addressed: ward leadership values maintenance of patient independence, staff have reasonable dementia awareness and competence and follow principles of dementia friendly care, staffing levels allow enabling patients to complete tasks independently, hospital environment is adapted to prevent disability and maximise independence, a programme of ward group activities is available and there is a holistic assessment of the patient (physical, functional, cognitive, social, neuropsychological and emotional areas).

Definition of activities of daily living (ADL)
This research project focuses on self-care ADL. These include areas such as personal hygiene/grooming, dressing, toileting/continence, transferring/mobilising, and eating. Please use this definition when ranking the statements below.

Instructions
Please consider the following statements about concepts for inclusion in the new occupational therapy personal activity programme. Please rate each statement on a five point scale where items are ranked from Strongly Agree (1) that the item should be included in the programme to Strongly Disagree (5).

In addition to your rating please use "Other" option to make comments to justify your rating of the item should you wish or to identify where more clarification is needed.

* Required

Screening questions

1. Please type in your assigned identification code *

2. How many years of work or research experience in the areas of rehabilitation and/or dementia have you got? *

- ○ less than 3 years
- ○ 3 or more years

3. How many years of work or research experience in community and/or acute hospital setting have you got? *

- ○ less than 3 years
- ○ 3 or more years

Details on how the programme may be adapted.

Please remember to select a rating even if using "Other" option to make comments.

4. Personal activity goals should be identified with the patient *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

5. Family carers should be involved in helping set personal activity goals *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

6. Personal activity goals should be specific and measurable *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

7. Personal activity goals should be achievable within the constraints of the hospital environment *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

8. Personal activity goals should be relevant to patient's usual daily activities on return home *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

9. Patients should have the same control over their daily routines as they would at home *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

10. Ward staff should never try to persuade a patient who is reluctant to practice self-care ADLs *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

11. Personal activity goals should be monitored and adapted to match patient's ability throughout the hospital stay *

A record of rehabilitation progress detailing how best to help the patient stay independent would be available.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

What? Part 2 of 7

Procedures and materials for the programme.

Please remember to select a rating even if using "Other" option to make comments.

12. Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

13. If available, family carers should be involved in the rehabilitation process *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

14. Patients should continuously be given feedback concerning their progress *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

15. Independence in activities of daily living should be maintained/regained through practising activities of daily living *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

16. OcTPAP must include physical exercises aimed at improving ability to complete activities of daily living independently *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

17. OcTPAP must include a component focusing on cognitive stimulation *

This would include exercises aimed at increasing perceptual/cognitive skills, promoting positive self-image through purposeful activities and confusional syndrome prevention through reality orientation.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

18. OcTPAP must include a component focusing on sensory stimulation *

Sensory stimulation is the activation of one or more of the senses including taste, smell, vision, hearing, and touch, for example helping the patient to listen to a playlist of favourite music.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

19. OcTPAP must include a component focusing on positioning *

This would aim to increase body alignment, improve postural control, enhance upper extremity and prevent contractures.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

20. OcTPAP must include a component focusing on pressure care *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

21. OcTPAP must include a component focusing on falls prevention *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

22. OcTPAP should include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

23. OcTPAP should include goals that patient would continue working on after discharge *

For example, this could include recommendations about how to maintain or increase independence in activities of daily living, social and occupational activities after discharge from hospital.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

When and how much? Part 3 of 7

Timing and duration of the sessions.

Please remember to select a rating even if using "Other" option to make comments.

24. OcTPAP should start as soon as the patient is well enough to participate in activities of daily living *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

25. Patients should be supported to participate in OcTPAP seven days a week *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

26. There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence. *

This could be a registered occupational therapist or an occupational therapy support worker.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

27. The length of occupational therapy personal activity sessions should be clinically determined by an occupational therapy worker *

This could be a registered occupational therapist or an occupational therapy support worker.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

28. The length of occupational therapy personal activity session should always be fixed to a minimum of 45 minutes *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

Who? Part 4 of 7

Information about the clinician providing the OcTPAP programme.

Please remember to select a rating even if using "Other" option to make comments.

29. Ward staff should wait for a registered occupational therapist assessment before allowing a patient to wash and dress *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly disagree
- [ ] Other

30. Ward staff should have the skills to adapt and update the rehabilitation plan *

This would include ability of staff to identify what parts of the activity the patient is having difficulties with.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

31. There should be a named key worker responsible for daily review of each patient's personal activity programme *

When that worker is not in, a replacement key worker should take on the responsibility.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

32. The named key worker responsible for daily review of each patient's personal activity programme should be either a registered occupational therapist or an occupational therapy support worker *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

33. The named key worker responsible for daily review of each patient's personal activity programme must be a registered occupational therapist *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

How? Part 5 of 7

Details about the delivery of the programme.

Please remember to select a rating even if using "Other" option to make comments.

34. Expectations about the OcTPAP should be discussed with patients and family carers *

This would include a discussion about how independence can be maintained throughout the admission and addressing common misconceptions about hospital stays and independence.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

35. Patients should be encouraged to do as much as they can by themselves before they are helped *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree and Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

36. Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

37. Patients should be encouraged to take more responsibility for their own recovery of independence *

This would include staff being aware of capacity issues and patient's ability to practise without staff supervision.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

38. OcTPAP should only be delivered through one to one interactions *

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

39. OcTPAP should include a documented risk assessment to address potential consequences of increased independent activity *

For example, increased falls risk.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

40. OcTPAP should include verbal and written communication with community services for information sharing and follow up *

For example, communication with Social Services or voluntary organisations.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

Where? Part 6 of 7

Locations of where the programme will be delivered.

Please remember to select a rating even if using "Other" option to make comments.

41. An occupational therapy worker should be able to assess/treat the patient in the patient's home following discharge *

For example, this can be in the form of post-discharge visits.

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

42. Do you have any additional comments or feedback on the new occupational therapy personal activity programme?

43. Please list any name suggestions for the new occupational therapy personal activity programme

Demographics Part 7 of 7

44. Gender *

- ○ Female
- ○ Male
- ○ Prefer not to say

45. Which county do you currently work in? *

(e.g Nottinghamshire, Leicestershire, Hertfordshire)

46. Please indicate which setting best describes where you currently work? *

- ○ acute hospital
- ○ in-patient rehabilitation
- ○ community based
- ○ university
- ○ Other

47. What OT speciality do you currently work in? *

(e.g Healthcare of Older People, Trauma and Orthopaedics, Community Mental health)

48. How long, in years, have you been a qualified occupational therapist? *

The value must be a number

49. How many years' experience do you have working with people living with dementia? *

The value must be a number

50. How many years' experience do you have working in geriatric rehabilitation? *

The value must be a number

51. How many years' experience do you have working in an acute hospital setting? *

The value must be a number

52. How many years' experience do you have working in a community setting? *

The value must be a number

53. What is your highest professions qualification *

- ○ Degree
- ○ Masters
- ○ PhD
- ○ Other

Appendix P – Delphi Consensus – Recruitment Poster

Maintaining and regaining independence with daily tasks for people with dementia during hospital admissions

Can you help?



This is an opportunity to refine a rehabilitation programme which could **help people with dementia retain their independence** with daily tasks during acute hospital admissions.

You will be asked to fill in **up to three short online questionnaires.**

We would like to hear from you if you are an **occupational therapist** with expertise in the areas of:

- rehabilitation and/or dementia
- community and/or acute hospital setting



Please contact Lisa Patrick for more details:

Email: lisa.patrick1@nottingham.ac.uk

Telephone: 07855518071

This project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) and the Alzheimer's Society. The views expressed are those of the authors and not necessarily those of the Alzheimer's Society, the NIHR or the Department of Health and Social Care.

Alzheimer's Society

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Appendix Q - Delphi Consensus - Participant Information Sheet

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Participant Information Sheet
(Delphi consensus)
(Final version 1.1: 24 June 2020)

Title of Study: Maintaining and regaining activities of daily living independence for people with dementia during hospital admissions.

Name of Study lead: Lisa Patrick

Local Researcher(s): Philippa Logan, Sarah Goldberg, Rowan Harwood, Jane Horne

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 answer any questions you have in relation to the participation in the study. 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?

This study is a part of a larger study. It seeks to refine a rehabilitation programme which has been designed to help people with dementia maintain or regain independence in their daily activities during acute hospital admissions.

Why have I been invited?

You are being invited to take part because you are an occupational therapist with expertise in the areas of rehabilitation and/or dementia from community and/or acute hospital setting. We are inviting other participants like you to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. Completion and subsequent return of the questionnaires will be taken as informed consent and separate written informed consent will not be sought. 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?

1. You will be asked to carefully read this information sheet and will be given the opportunity to ask any questions you may have about the study over the phone or email.

2. A Delphi consensus technique will be used. This technique seeks to obtain consensus or agreement on the opinions of experts through a series of structured questionnaires. As part of the process, responses are summarised and returned anonymously to the participants who then can respond to the feedback. Therefore, you will receive an electronic questionnaire listing rehabilitation programme components and asking you to rate each component on whether it should be included in the final intervention. There will be space to justify your responses or seek clarification. Amended questionnaire based on previous questionnaire ratings and comments will be sent out again, unless an agreement has been reached. You will receive up to three questionnaires over a period of about three months. We will remind you by email if you forget to return the questionnaire. It should take you about 20 minutes to fill in each questionnaire. You will remain anonymous to other participants.

This project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care East Midlands (CLAHRC EM) and the Alzheimer's Society. The views expressed are those of the authors and not necessarily those of the Alzheimer's Society, the NIHR or the Department of Health and Social Care.

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Expenses and payments

You will receive a £30 voucher as a thank you for your contribution after completing all the questionnaires.

What are the possible disadvantages and risks of taking part?

There are no known risks or disadvantages of taking part.

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 to refine an intervention to help people with dementia to regain or maintain independence with daily activities during acute hospital admissions. If you wish to be emailed a summary of the research findings please let the study lead know and contact us if your contact details need updating before you receive the summary of the findings.

What happens when the research study stops?

The overall aim of the larger study is to develop a rehabilitation programme to maintain or help regain independence with activities of daily living for older people with dementia in an acute hospital setting.

If you wish to receive a summary of the conclusions drawn from this component of the study, please contact the study lead.

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 administrator of Faculty of Medicine and Health Sciences Research Ethics Committee c/o Faculty PVC office B floor, School of Medicine, QMC campus, NUH, Nottingham, NG7 2UH. Email: fmhs-researchethics@nottingham.ac.uk

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 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 at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible. You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

If you join the study, some parts of the data collected for the study will be looked at and stored by authorised persons from the University of Nottingham, or the research funders - the NIHR Collaboration for Leadership in Applied Health Research and Care East Midlands, and the Alzheimer's Society. They may also be looked at by authorised people from regulatory organisations 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.

Although what you say to us 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.

Your contact information will be kept by the University of Nottingham for 2 years after the end of the study so that we are able to contact you about the findings of the study if you agreed to this. This information will be kept separately from the research data collected and only those who need to will have access to it. All other research data will be kept securely for seven 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 given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with other Universities and researchers, including those in other countries. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information we will seek your consent for this. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

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 we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to tamper with study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally-identifiable information possible.

What will happen to the results of the research study?

The results of the study may potentially be used as part of service development projects, presented to relevant audiences, published in professional journals or used to identify future priorities for research. Direct quotations may be used, however these will be anonymised. A short video explaining the background and findings of the study for members of the public and healthcare professionals may be created. Findings will also be written up for a PhD thesis.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being funded by the Alzheimer's Society and the Collaboration for Leadership in Applied Health Research and Care.

Who has reviewed the study?

All research in healthcare 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 Nottingham University Faculty Research Ethics Committee.

Further information and contact details

Study lead:
Lisa Patrick
Clinical Doctoral Research Fellow at the University of Nottingham and Occupational Therapist
Tel: 07855518071
Email: lisa.patrick1@nottingham.ac.uk

Co-Investigator:
Professor Pip Logan
Professor of Rehabilitation Research and Occupational Therapist
Head of Division Rehabilitation and Ageing,
B108a, School of Medicine,
University of Nottingham,
Nottingham, NG7 2UH
Tel: 0115 8230235, 07884318920
Email: pip.logan@nottingham.ac.u

Appendix R - Delphi Consensus - Round One Detailed Statistics

4. Personal activity goals should be identified with the patient

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	4	Strongly Agree	17	60.71%	60.71%	To include concept 100%
		Agree	11	39.29%	39.29%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

5. Family carers should be involved in helping set personal activity goals

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	7	25%	25%	To include concept 92.86%
		Agree	19	67.86%	67.86%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree				
		Strongly disagree				

6.Personal activity goals should be specific and measurable

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	6	Strongly Agree	10	35.71%	35.71%	To include concept 89.29%
		Agree	15	53.57%	53.57%	
		Neither Agree or Disagree	3	10.71%	10.71%	
		Disagree				
		Strongly disagree				

7. Personal activity goals should be achievable within the constraints of the hospital environment

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	5	Strongly Agree	8	28.57%	28.57%	To include concept 89.29%
		Agree	17	60.71%	60.71%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree	1	3.57%	3.57%	
		Strongly disagree				

8. Personal activity goals should be relevant to patient's usual daily activities on return home

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	3	Strongly Agree	20	71.43%	71.43%	To include concept 100%
		Agree	8	28.57%	28.57%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

9. Patients should have the same control over their daily routines as they would at home

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	5	Strongly Agree	7	25%	25%	To include concept 75%
		Agree	14	50%	50%	
		Neither Agree or Disagree	5	17.86%	17.86%	
		Disagree	2	7.14%	7.14%	
		Strongly disagree				

10. Ward staff should never try to persuade a patient who is reluctant to practice self-care ADLs

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	12	Strongly Agree	3	10.71%	10.71%	60.71%
		Agree	4	14.29%	14.29%	
		Neither Agree or Disagree	4	14.29%	14.29%	
		Disagree	16	57.14%	57.14%	
		Strongly disagree	1	3.57%	3.57%	

11. Personal activity goals should be monitored and adapted to match patient's ability throughout the hospital stay

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	3	Strongly Agree	18	64.29%	64.29%	To include concept 100%
		Agree	10	35.71%	35.71%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

12. Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	4	Strongly Agree	17	60.71%	60.71%	To include concept 100%
		Agree	11	39.29%	39.29%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

13. If available, family carers should be involved in the rehabilitation process

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	13	46.43%	46.43%	To include concept 96.43%
		Agree	14	50%	50%	
		Neither Agree or Disagree	1	3.57%	3.57%	
		Disagree				
		Strongly disagree				

14. Patients should continuously be given feedback concerning their progress

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
27/28	3	Strongly Agree	13	48.15%	46.43%	To include concept 89.29%
		Agree	12	44.44%	42.86%	
		Neither Agree or Disagree	2	7.40%	7.14%	
		Disagree				
		Strongly disagree				

15. Independence in activities of daily living should be maintained/regained through practising activities of daily living

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	1	Strongly Agree	15	53.57%	53.57%	To include concept 92.86%
		Agree	11	39.29%	39.29%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree				
		Strongly disagree				

16. OcTPAP must include physical exercises aimed at improving ability to complete activities of daily living independently

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	5	Strongly Agree	8	28.57%	28.57%	To include concept 75%
		Agree	13	46.43%	46.43%	
		Neither Agree or Disagree	6	21.43%	21.43%	
		Disagree	1	3.57%	3.57%	
		Strongly disagree				

17. OcTPAP must include a component focusing on cognitive stimulation

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	4	Strongly Agree	15	53.57%	53.57%	To include concept 89.29%
		Agree	10	35.71%	35.71%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree				
		Strongly disagree	1	3.57%	3.57%	

18. OcTPAP must include a component focusing on sensory stimulation

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	6	Strongly Agree	10	35.71%	35.71%	To include concept 82.14%
		Agree	13	46.43%	46.43%	
		Neither Agree or Disagree	5	17.86%	17.86%	
		Disagree				
		Strongly disagree				

19. OcTPAP must include a component focusing on positioning

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	5	Strongly Agree	9	32.14%	32.14%	To include concept 78.57%
		Agree	13	46.43%	46.43%	
		Neither Agree or Disagree	5	17.86%	17.86%	
		Disagree	1	3.57%	3.57%	
		Strongly disagree				

20. OcTPAP must include a component focusing on pressure care

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	8	Strongly Agree	10	35.71%	35.71%	To include concept 75%
		Agree	11	39.29%	39.29%	
		Neither Agree or Disagree	7	25%	25%	
		Disagree				
		Strongly disagree				

21. OcTPAP must include a component focusing on falls prevention

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	5	Strongly Agree	14	50%	50%	To include concept 92.86%
		Agree	12	42.86%	42.86%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree				
		Strongly disagree				

22. OcTPAP should include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	3	Strongly Agree	17	60.71%	60.71%	To include concept 100%
		Agree	11	39.29%	39.29%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

23. OcTPAP should include goals that patient would continue working on after discharge

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	2	Strongly Agree	12	42.86%	42.86%	To include concept 100%
		Agree	16	57.14%	57.14%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

24. OcTPAP should start as soon as the patient is well enough to participate in activities of daily living

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	2	Strongly Agree	18	64.29%	64.29%	To include concept 92.86%
		Agree	8	28.57%	28.57%	
		Neither Agree or Disagree	1	3.57%	3.57%	
		Disagree				
		Strongly disagree	1	3.57%	3.57%	

25. Patients should be supported to participate in OcTPAP seven days a week

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	14	50%	50%	To include concept 82.14%
		Agree	9	32.14%	32.14%	
		Neither Agree or Disagree	4	14.29%	14.29%	
		Disagree	1	3.57%	3.57%	
		Strongly disagree				

26. There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence.

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	9	Strongly Agree	8	28.57%	28.57%	To include concept 75%
		Agree	13	46.43%	46.43%	
		Neither Agree or Disagree	4	14.29%	14.29%	
		Disagree	3	10.71%	10.71%	
		Strongly disagree				

27. The length of occupational therapy personal activity sessions should be clinically determined by an occupational therapy worker

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	11	39.29%	39.29%	To include concept 89.29%
		Agree	14	50%	50%	
		Neither Agree or Disagree	3	10.71%	10.71%	
		Disagree				
		Strongly disagree				

28. The length of occupational therapy personal activity session should always be fixed to a minimum of 45 minutes

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	14	Strongly Agree				Disagreement with concept 92.86%
		Agree	1	3.57%	3.57%	
		Neither Agree or Disagree	1	3.57%	3.57%	
		Disagree	23	82.14%	82.14%	
		Strongly disagree	3	10.71%	10.71%	

29. Ward staff should wait for a registered occupational therapist assessment before allowing a patient to wash and dress

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	11	Strongly Agree				Disagreement with concept 92.86%
		Agree	1	3.57%	3.57%	
		Neither Agree or Disagree	1	3.57%	3.57%	
		Disagree	17	60.71%	60.71%	
		Strongly disagree	9	32.14%	32.14%	

30. Ward staff should have the skills to adapt and update the rehabilitation plan

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	6	Strongly Agree	6	21.43%	21.43%	To include concept 89.29%
		Agree	19	67.85%	67.85%	
		Neither Agree or Disagree	1	3.57%	3.57%	
		Disagree	2	7.14%	7.14%	
		Strongly disagree				

31. There should be a named key worker responsible for daily review of each patient's personal activity programme

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	9	32.14%	32.14%	To include concept 85.71%
		Agree	15	53.57%	53.57%	
		Neither Agree or Disagree	3	10.71%	10.71%	
		Disagree	1	3.57%	3.57%	
		Strongly disagree				

32. The named key worker responsible for daily review of each patient's personal activity programme should be either a registered occupational therapist or an occupational therapy support worker

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	12	Strongly Agree	4	14.29%	14.29%	57.14%
		Agree	8	28.57%	28.57%	
		Neither Agree or Disagree	8	28.57%	28.57%	
		Disagree	8	28.57%	28.57%	
		Strongly disagree				

33. The named key worker responsible for daily review of each patient's personal activity programme must be a registered occupational therapist

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	11	Strongly Agree	5	17.86%	17.86%	71.43%
		Agree	3	10.71%	10.71%	
		Neither Agree or Disagree	7	25%	25%	
		Disagree	13	46.43%	46.43%	
		Strongly disagree				

34. Expectations about the OcTPAP should be discussed with patients and family carers

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	4	Strongly Agree	15	53.57%	53.57%	To include concept 100%
		Agree	13	46.43%	46.43%	
		Neither Agree or Disagree				
		Disagree				
		Strongly disagree				

35. Patients should be encouraged to do as much as they can by themselves before they are helped

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	17	60.71%	60.71%	To include concept 92.86%
		Agree	9	32.14%	32.14%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree				
		Strongly disagree				

36. Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	4	Strongly Agree	16	57.14%	57.14%	To include concept 96.43%
		Agree	11	39.29%	39.29%	
		Neither Agree or Disagree	1	3.57%	3.57%	
		Disagree				
		Strongly disagree				

37. Patients should be encouraged to take more responsibility for their own recovery of independence

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	4	Strongly Agree	16	57.14%	57.14%	To include concept 92.86%
		Agree	10	35.71%	35.71%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree				
		Strongly disagree				

38. OcTPAP should only be delivered through one to one interactions

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	17	Strongly Agree				53.57%
		Agree	4	14.29%	14.29%	
		Neither Agree or Disagree	9	32.14%	32.14%	
		Disagree	14	50%	50%	
		Strongly disagree	1	3.57%	3.57%	

39. OcTPAP should include a documented risk assessment to address potential consequences of increased independent activity

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	6	Strongly Agree	9	32.14%	32.14%	67.86%
		Agree	10	35.71%	35.71%	
		Neither Agree or Disagree	6	21.43%	21.43%	
		Disagree	3	10.71%	10.71%	
		Strongly disagree				

40. OcTPAP should include verbal and written communication with community services for information sharing and follow up

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	15	53.57%	53.57%	To include concept 89.29%
		Agree	10	35.71%	35.71%	
		Neither Agree or Disagree	2	7.14%	7.14%	
		Disagree	1	3.57%	3.57%	
		Strongly disagree				

41. An occupational therapy worker should be able to assess/treat the patient in the patient's home following discharge

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
28/28	7	Strongly Agree	14	50%	50%	To include concept 78.57%
		Agree	8	28.57%	28.57%	
		Neither Agree or Disagree	3	10.71%	10.71%	
		Disagree	3	10.71%	10.71%	
		Strongly disagree				

Appendix S - Delphi Consensus - Round Two Questionnaire

OcTPAP Delphi questionnaire. Round 2

Thank you for completing the first questionnaire. You rated 38 statements on the contents of a new occupational therapy personal activity programme (OcTPAP). Statements which scored 75% agreement or more were said to have reached consensus, and were included/excluded from the contents of the programme.

Thirty three statements reached consensus:

- Personal activity goals should be identified with the patient (100% agreed)
- Family carers should be involved in helping set personal activity goals (93% agreed)
- Personal activity goals should be specific and measurable (89% agreed)
- Personal activity goals should be achievable within the constraints of the hospital environment (89% agreed)
- OcTPAP should include goals that patient would continue working on after discharge (100% agreed)
- Personal activity goals should be relevant to patient's usual daily activities on return home (100% agreed)
- Patients should have the same control over their daily routines as they would at home (75% agreed)
- Personal activity goals should be monitored and adapted to match patient's ability throughout the hospital stay (100% agreed)
- Information for the OcTPAP should be gathered from a variety of sources, including family, paid and unpaid carers, hospital and community records (100% agreed)
- If available, family carers should be involved in the rehabilitation process (96% agreed)
- Patients should continuously be given feedback concerning their progress (89% agreed)
- Independence in activities of daily living should be maintained/regained through practising activities of daily living (93% agreed)
- OcTPAP must include physical exercises aimed at improving ability to complete activities of daily living independently (75% agreed)
- OcTPAP must include a component focusing on cognitive stimulation (89% agreed)
- OcTPAP must include a component focusing on sensory stimulation (82% agreed)
- OcTPAP must include a component focusing on positioning (79% agreed)
- OcTPAP must include a component focusing on pressure care (75% agreed)
- OcTPAP must include a component focusing on falls prevention (93% agreed)
- OcTPAP should include recommendations about how to maintain or increase independence in activities of daily living, after discharge from hospital (100% agreed)
- OcTPAP should start as soon as the patient is well enough to participate in activities of daily living (93% agreed)

- Patients should be supported to participate in OcTPAP seven days a week (82% agreed)
- There should be a minimum of one daily session delivered by an occupational therapy worker focusing on personal activities of daily living independence. (75% agreed)
- The length of occupational therapy personal activity sessions should be clinically determined by an occupational therapy work (89% agreed)
- The length of occupational therapy personal activity session should always be fixed to a minimum of 45 minutes (93% disagreed)
- Ward staff should wait for a registered occupational therapist assessment before allowing a patient to wash and dress (93% disagreed)
- Ward staff should have the skills to adapt and update the rehabilitation plan (89% agreed)
- There should be a named key worker responsible for daily review of each patient's personal activity programme (86% agreed)
- Expectations about the OcTPAP should be discussed with patients and family carers (100% agreed)
- Patients should be encouraged to do as much as they can by themselves before they are helped (93% agreed)
- Every activity should be considered as an opportunity to maintain or improve independence in activities of daily living (96% agreed)
- Patients should be encouraged to take more responsibility for their own recovery of independence (93% agreed)
- OcTPAP should include verbal and written communication with community services for information sharing and follow up (89% agreed)
- An occupational therapy worker should be able to assess/treat the patient in the patient's home following discharge (79% agreed)

* Required

Round 2 instructions

The results of the remaining 5 statements which did not reach consensus were analysed and findings have been incorporated into the reframes questions. In this questionnaire you will find:
1. The original statement.
2. Results from round 1
3. The rationale for the revised statement.
4. The revised statement

Please rate each statement on a five point scale where items are ranked from Strongly Agree (1) that the item should be included in the programme to Strongly Disagree (5).

In addition to your rating please use "Other" option to make comments to justify your rating of the item should you wish or to identify where more clarification is needed.

1. Please type in your assigned identification code *

Statement to reconsider 1 of 4

Original statement:

Ward staff should never try to persuade a patient who is reluctant to practice self-care ADLs

Round 1 results:

11% strongly agreed
14% agreed
14% neither agreed or disagreed
57% disagreed
4% strongly disagreed

Rationale for change:

Questionnaire participants stated that encouragement is very important, as patient may just be, for example, anxious, but patient should still feel able to decline if they wish.

2. Revised statement - Ward staff should encourage patients who are reluctant to practise activities of daily living *

Please still select a rating even if you choose to use"Other" to make comments to justify your rating of the item or to identify where more clarification is needed

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

Statement to reconsider

Original statement:

OcTPAP should only be delivered through one to one interactions

Round 1 results:

0% strongly agreed
14% agreed
32% neither agreed or disagreed
50% disagreed
4% strongly disagreed

Rationale for change:

Questionnaire participants suggested that group work sessions could also be valuable

3. Revised statement - OcTPAP could be delivered through both group work and one to one sessions *

Please still select a rating even if you choose to use"Other" to make comments to justify your rating of the item or to identify where more clarification is needed

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

Statement to reconsider 3 of 4

Original statement:

OcTPAP should include a documented risk assessment to address potential consequences of increased independent activity

Round 1 results:

32% strongly agreed
36% agreed
21% neither agreed or disagreed
11% disagreed
0% strongly disagreed

Rationale for change:

Questionnaire participants commented that Occupational therapy workers should be constantly re-assessing risk, but this does not have to be documented or could be included in general risk assessment to reduce time taken by completing documentation.

4. Revised statement - A risk assessment for increasing independent activity should be included in the ward's general risk assessment. *

Please still select a rating even if you choose to use"Other" to make comments to justify your rating of the item or to identify where more clarification is needed

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly Disagree
- [ ] Other

Statement to reconsider 4 of 4

Two original statements:
1) The named key worker responsible for daily review of each patient's personal activity programme should be either a registered occupational therapist or an occupational therapy support worker

Round 1 results:

14% strongly agreed
29% agreed
29% neither agreed or disagreed
29% disagreed
0% strongly disagreed

2) The named key worker responsible for daily review of each patient's personal activity programme must be a registered occupational therapist

Round 1 results:

18% strongly agreed
11% agreed
25% neither agreed or disagreed
46% disagreed
0% strongly disagreed

Rationale for change:

The two statements were combined as they address the same issue of who the named key worker should be.

Some questionnaire participants stated that an occupational therapy worker would be preferred but this may not be realistic. It was highlighted that another member of staff who has relevant skills can be a named key worker. Some questionnaire participants suggested a key worker can be another member of staff but be overseen by an occupational therapist.

5. Revised statement - An appropriately skilled member of ward staff could be the named key worker responsible for daily review of each patient's personal activity programme with support from a registered occupational therapist *

Please still select a rating even if you choose to use"Other" to make comments to justify your rating of the item or to identify where more clarification is needed

- [ ] Strongly Agree
- [ ] Agree
- [ ] Neither Agree or Disagree
- [ ] Disagree
- [ ] Strongly disagree
- [ ] Other

Additional comments

6. Do you have any additional comments or feedback on the new occupational therapy personal activity programme?

7. Do you have any suggestions that may help the implementation of OcTPAP into clinical practice? *

Appendix T - Delphi Consensus - Round Two Detailed Statistics

1. Ward staff should encourage patients who are reluctant to practise activities of daily living

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
27	4	Strongly Agree	13	48%	48%	To include concept 96%
		Agree	13	48%	48%	
		Neither Agree or Disagree	1	4%	4%	
		Disagree				
		Strongly disagree				

2. OcTPAP could be delivered through both group work and one to one sessions

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
27	1	Strongly Agree	14	52%	52%	To include concept 96%
		Agree	12	44%	44%	
		Neither Agree or Disagree	1	4%	4%	
		Disagree				
		Strongly disagree				

3. A risk assessment for increasing independent activity should be included in the ward's general risk assessment.

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
27	3	Strongly Agree	6	22%	22%	To include concept 89%
		Agree	18	67%	67%	
		Neither Agree or Disagree	2	7%	7%	
		Disagree				
		Strongly disagree	1	4%	4%	

4. An appropriately skilled member of ward staff could be the named key worker responsible for daily review of each patient's personal activity programme with support from a registered occupational therapist

N of responses	Number of comments	Options	Frequency	Percent out of responses	Percent including missing answers	Agreement reached?
27	2	Strongly Agree	10	37%	37%	To include concept 93%
		Agree	15	56%	56%	
		Neither Agree or Disagree				
		Disagree	2	7%	7%	
		Strongly disagree				

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