

Urinary incontinence in older women: exploring lived experiences and examining co-production

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Abstract

Rationale: Urinary incontinence (UI) is a common condition in women that leads to involuntary passing of urine. UI can impact social and mental wellbeing due to the associated stigma, which underlines the importance of inclusive research. Co-production research emphasises shared decision-making and collective knowledge; there is a lack of research into the realities of this approach, especially focused on physical illnesses. The Leeds Older women Urinary Incontinence Self-mAnagement (LOUISA) study is the wider project within which the current study is situated, bringing together these components through co-production of a self-management intervention for UI. The current study focuses on the individual perspectives in these areas, in terms of living with UI and stakeholder experiences of co-producing UI research.

Aims: 1) To explore older women's perceptions of living with UI (phase 1); 2) to examine the principles of co-production within the context of the LOUISA project (phase 2).

Method: Phase 1 utilised an interpretative phenomenological approach (IPA). A qualitative meta-synthesis was conducted to explore gaps in existing literature, supplemented by interviews with 3 women. For phase 2 a scoping review was conducted to map co-production literature and interviews with LOUISA stakeholders (academic, healthcare provider, service user, funder) and one meeting observation was conducted.

Results: The key themes from phase 1 are embarrassment and normalisation. Embarrassment characterised the lived experience of UI, permeating across several themes e.g. childhood experiences and coping strategies. The normalisation of UI as it relates to perceptions of age was another key finding, as UI was often believed to be an ordinary part of ageing. Key themes from phase 2 relate to concepts of co-production and power differentials. Barriers and facilitators to co-production were identified and tensions between theoretical and practical aspects were considered. Power differentials in the context of co-production were also identified as an important consideration.

Conclusion: This study provides insight into the lived experience of UI from the perspective of older women living in the UK who have either never sought professional help or have previously engaged with medical services but have since disengaged. Understanding the lived experience of UI is integral to providing appropriate support. This study also provides recommendations for co-producing research for stigmatised long-term conditions (LTCs) similar to UI, based on the experiences of stakeholders involved in an ongoing project.

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List of Abbreviations

AG	Advisory Group
FGD	Focus Group Discussion
HCP	Healthcare Provider/Professional
ICS	International Continence Society
IPA	Interpretative Phenomenological Approach
IUGA	International Urogynecological Association
LBSSL	Leeds Benevolent Society for Single Ladies
LOUISA	Leeds Older women Urinary Incontinence Self-mAnagement
LTCs	Long-Term Conditions
LUTS	Lower Urinary Tract Symptoms
MeSH	Medical Subject Headings
PCG	Patient and Carer Group
PI	Principle Investigator
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
SCIE	Social Care Online
SHREC	School of Healthcare Research Ethics Committee
UI	Urinary Incontinence

Chapter 1: Introduction

1.1 Introduction

This thesis presents a multi-phase qualitative study exploring urinary incontinence (UI) and co-production. This study focuses on the individual perspectives in these areas, both in terms of living with UI and in the ways in which stakeholders experienced co-producing UI research. Phase one aims to use interpretative phenomenological analysis (IPA) to explore older women's perceptions of living with urinary incontinence. Phase two aims to explore the principles of co-production within the context of a co-produced project focused on UI. It is expected that data from each phase of this study will be analysed independently and then synthesised together, using a thematic synthesis approach. This chapter will firstly outline the study context. Following this, background literature will be presented to contextualise the research aims of the current study. An outline of the thesis structure will also be provided.

1.2 Study Context

The current PhD is embedded within a wider project entitled Leeds Older women Urinary Incontinence Self-mAnagement (LOUISA); and both are funded by the Leeds Benevolent Society for Single Ladies (LBSSL). The charity was founded to assist elderly single women living in Leeds, and as part of this aim, LBSSL collaborated with members of the School of Healthcare to develop a research project focused on a specific health condition concerning older women. As a result of this collaboration, the current study was conceived. As the research was funded by LBSSL, the topics of study (UI and co-production) were decided in a priority setting exercise between the funders and the principal investigator/co-investigator (Professors Linda McGowan and Andrea Nelson).

However, the overall direction of the PhD study, along with the research aims, methods and analysis approach, were decided by myself in collaboration with my supervisors. Incorporating the two themes of UI and co-production into this study was challenging, and resulted in the research being designed in two phases with separate aims. Phase one of this PhD focuses on UI and phase 2 focuses on co-production. Due to the funder requirements, this thesis ultimately focuses on two separate parts of a debate on UI; firstly, the lived experiences of older women with UI and secondly, how co-production can be used to research UI. As the overall research design was split into two distinct phases, it was intended that data from each phase of the study would ultimately be synthesised. It was expected that the synthesis of the two phases would contribute to the development of a framework, to provide guidance to researchers who wish to undertake a co-production approach to research focused on long-term, physical health conditions (figure 1).

Prior to beginning this research, I had no previous knowledge of the areas of UI or co-production, which I believe enabled me to maintain an open-minded approach and uphold a reflexive stance throughout. I was also approaching this study with a social science background; however, as the research aims were focused towards experiences of UI and UI related research, rather than clinical symptoms or interventions, this was not problematic. My lack of clinical knowledge meant that I did not make assumptions about the research topics, which required me to be more inquisitive.

1.3 Background

1.3.1 Urinary Incontinence

1.3.1.1 Definitions and Types of UI

Urinary incontinence refers to a loss of bladder control, leading to the involuntary passing of urine. In a joint report by the International Urogynecological Association (IUGA) and the International Continence Society (ICS), urinary incontinence is defined as a ‘complaint of involuntary loss of urine’ (Haylen et al., 2010, p. 5). There are several types of urinary incontinence, including: stress incontinence, urgency incontinence, mixed incontinence, overflow incontinence and total incontinence (table 1). However, as Milsom et al. (2017) highlight, despite the general agreement on the symptoms and subtypes of UI, varying terminology is often used in questionnaires established to assess UI subtypes.

Table 1: Definitions of Urinary Incontinence

Stress Incontinence	Involuntary leakage of urine caused when the bladder is put under increasing pressure, for example when sneezing or exercising
Urgency Incontinence	Involuntary leakage of urine following an intense and sudden urge to urinate
Mixed Incontinence	Involuntary leakage of urine due to a combination of both stress and urgency incontinence
Overflow Incontinence	Involuntary leakage of urine caused by inability to fully empty bladder when urinating
Total Incontinence	Constant involuntary leakage of urine

1.3.1.2 Prevalence of Urinary Incontinence

Urinary incontinence is a problematic health condition worldwide, with an estimated 8.2% of the population thought to have been affected by urinary incontinence in 2008 (Irwin et al., 2011). Women are also more likely to suffer from urinary incontinence than men (Nitti, 2001), which can be attributed in part to factors such as pregnancy, childbirth and menopause (Foldspang et al., 1992; Milsom et al., 2017). Risk factors for UI include age, heredity, obesity, parity and pregnancy (Milsom and Gyhagen, 2019). Urinary incontinence rates are understood to increase with age (Hannestad et al., 2000; Hunskar et al., 2004). It is for this reason that the focus of this study is older women's experiences of urinary incontinence. In the EpiLUTS population study conducted in the UK, USA and Sweden, it was identified that lower urinary tract symptoms (LUTS), including UI, are 'highly prevalent' for those aged >40 (Coyne et al., 2009, p. 352). More specifically, older women appear to experience an increased prevalence of urgency incontinence, mixed incontinence, weak stream and nocturnal enuresis (Coyne et al., 2009; Milsom and Gyhagen, 2019).

It is estimated that in the UK, 3.5 million women experience urinary incontinence (Price and Currie, 2010). The prevalence rate of UI amongst women in the UK is thought to be approximately 42% (Hunskar et al., 2004). However, there are challenges in understanding the true prevalence of incontinence, as prevalence rates range from 25% to 45% in the majority of studies (Milsom et al., 2017, p. 18). Prevalence estimates often differ based on variances in definitions of urinary incontinence, sample and methodology (Thom, 1998; Hunskar et al., 2004). The lack of a 'unified definition' for UI is a problem that must be resolved to better understand the prevalence of UI

(Milsom and Gyhagen, 2019, p. 217). Furthermore, as Milsom et al. (2017, p. 35) highlight, 'there is no universally accepted threshold for clinically or biologically significant incontinence, and no objective tests that can be applied in the community', meaning that accurate prevalence rates may be difficult to establish. Additionally, urinary incontinence may be under-reported due to the fact that many women choose not to disclose their condition due to embarrassment or fear of stigma (Milsom et al., 2017). However, it is clear that UI is a common global health condition that is affecting the lives of many women.

1.3.1.3 Urinary Incontinence and Quality of Life

Whilst urinary incontinence is not a life-threatening condition, women living with UI have a considerably reduced quality of life in comparison to the quality of life experienced by continent women (Sinclair and Ramsay, 2011). One way that UI can negatively impact quality of life relates to emotional distress. Emotional distress has been recognised as more prevalent amongst adults with urinary incontinence compared to continent adults (Dugan et al., 2000). Such emotional distress resulting from UI can range from embarrassment (Hägglund and Wadensten, 2007) to depression and anxiety (Ko et al., 2005; North and Cooper, 2017) and has been identified as a key characteristic for many women living with the condition. Sexual relationships can also be negatively impacted by urinary incontinence (Nilsson et al., 2009). Reasons for the impact of UI on sexual relationships include low libido (Chaliha and Stanton, 1999), embarrassment (Srikrishna et al., 2009) and fear of leakage (Nilsson et al., 2009). Social relationships are another area of life impacted by urinary incontinence, often leading to isolation due to a lack of companionship (Yip et al., 2013). Restrictions to social life as a result of UI include travel restrictions

and limitations to socialising with friends (Srikrishna et al., 2009), which can contribute to a general decrease in quality of life.

1.3.1.4 Urinary Incontinence and Help-Seeking

Despite the impact that urinary incontinence can have on quality of life, often people suffering with urinary incontinence choose not to seek help (Roe et al., 1999; Shaw, 2001; Minassian et al., 2003; Hägglund and Wadensten, 2007; Agnew and Booth, 2009). However, as Milsom and Gyhagen (2019, p. 217) highlight, 'an increasing awareness of the problem has in recent years attracted more patients to seek advice'. The perceived non-seriousness of urinary incontinence is thought to be one of the factors affecting health seeking behaviour (Roe et al., 1999). As Teunissen et al. (2005, p. 776) highlight, patients are less likely to seek help if they perceive their condition as 'not very serious or distressing'. Hägglund and Wadensten (2007, p. 309) further this argument when stating that even when urinary incontinence causes disruption to a person's life, it is still often thought of as 'not enough of a problem to seek help for'. More specifically, for older people suffering with urinary incontinence, the condition is often thought of as a typical part of aging (Horrocks et al., 2004).

There is a negative societal stigma surrounding urinary incontinence (Elstad et al., 2010) which can lead to feelings of embarrassment about the condition.

These feelings of shame and embarrassment are also impacting help-seeking behaviour related to urinary incontinence (Roe et al., 1999; Minassian et al., 2003). Hägglund and Wadensten (2007) argue that for women with urinary incontinence, the fear of humiliation drives their choice not to seek professional help. Hägglund and Wadensten (2007, p. 308) also found that women with urinary incontinence would prefer healthcare providers (HCP) to initiate

discussions about the condition, as women often felt 'too ashamed' to raise the issue.

1.3.1.5 Treatment of Urinary Incontinence

There are both surgical and non-surgical treatments available for urinary incontinence, depending on the severity of symptoms. Non-surgical self-management treatments include bladder training, lifestyle changes and pelvic floor muscle training (NHS, 2016). Surgery and procedures include methods such as: tape procedures, sling procedures, Botox injections, and catheterisation (Thakar and Stanton, 2000; Schurch et al., 2005; Nilsson et al., 2008). Additionally, there are a range of pharmacological treatments available, such as anti-cholinergic medicines like oxybutynin (Chawathey, 2015).

1.3.1.6 Urinary Incontinence Summary

Urinary incontinence is a common condition that affects women worldwide. Living with urinary incontinence can have negative implications on physical, social and mental well-being. Negative societal stigma surrounding the condition can lead to feelings of shame and embarrassment. For this reason, many people living with urinary incontinence refrain from discussing their condition with doctors, family and friends. The significant prevalence of urinary incontinence along with the associated social stigma, make this condition a particularly important topic in need of further research. Whilst there are several existing studies exploring women's experiences of UI (e.g. Hägglund and Ahlström, 2007) and the experiences of both men and women with UI (e.g. Vethanayagam et al., 2017), there is a gap in the literature for research focussed specifically on the lived experiences of older women with UI in the UK. This study seeks to contribute to existing knowledge in this area, by illuminating the experiences of this under researched subset of women. Further gaps in the

literature will be addressed comprehensively in chapter 3, which presents the findings of a qualitative meta-synthesis of older women's experiences of UI.

1.3.2 Co-Production

1.3.2.1 Definitions and Principles of Co-Production

There are various terms and approaches that describe public involvement in research, such as: patient and public involvement (PPI), person-centredness, citizen engagement and user involvement. Public involvement in research refers to research that is conducted 'with' or 'by' the public, instead of research that is conducted 'for' or 'about' the public (INVOLVE, 2012). The benefits of public involvement include greater transparency and validation of information, improved recruitment, increased rates of follow-up and practical research outputs (Blackburn et al., 2018). Co-production is another approach to public involvement, which draws upon the principles of inclusive research and places emphasis on shared decision-making and collective knowledge of professionals and the public. Precise definitions of co-production vary, resulting in mixed understandings about the meaning and organisation of this approach. Alford and Yates (2015, p. 159) define co-production as 'the contribution of time and effort to the *delivery* of public services by service users and citizens, prompted by or in concert with public sector organisations'. Similarly, Brandsen and Honingh (2018, p. 14) differentiate between co-production and co-creation by emphasising that 'Co-production concerns the design and implementation of a service, whereas co-creation is about the initiation and/or strategic planning of a service'. Löffler (2009, p. 5) adds that 'Co-production views service users as active asset-holders rather than passive consumers'.

Boyle and Harris (2009, p. 3) argue that for co-production to really impact policy and public services, a '...stronger agreed understanding and evidence base' is needed. Although there is no definition of co-production that is universally agreed upon (Ewert and Evers, 2014), there are certain common principles that define co-production. INVOLVE, the national advisory group advocating for public involvement in health and social care research, define the key principles of co-production as: sharing power, embracing all perspectives/skills, respecting and valuing all knowledge, reciprocity and building/maintaining relationships (INVOLVE, 2018).

1.3.2.2 Co-Production in a Healthcare Context

Co-production research endeavours to include participants, service users and stakeholders in a study by encouraging participant involvement throughout the research process. The rising interest in co-production of research in health management (Alford, 2009; Realpe and Wallace, 2010), demonstrates the importance of this topic. Specifically, urinary incontinence in older women requires further research, as generic recommendations regarding co-production of research may not be applicable to this particular issue. A broad search of the literature in this area identified a strong emphasis on co-production within the field of mental health, with seemingly little co-production research focusing on long-term physical health conditions. There also appears to be limited information available about the experiences of being involved in a study centred on a co-production research approach. This study will address this issue by exploring the experiences of a co-production model of research from the perspectives of key stakeholders involved in an ongoing project aimed to develop a self-management intervention for urinary incontinence.

1.3.2.3 Co-Production Summary

Co-production in research emphasises the shared decision-making and collective knowledge of professionals and the public. Research studies adopting a co-production model can benefit from and be enriched by, the significant wealth of knowledge and experiences shared by participants. This study seeks to address the lack of existing research focused on the realities of using a co-production approach to research non-life-threatening physical conditions. This study will be uniquely positioned to observe the co-production research process in action throughout the LOUISA study, thus providing unique contributions to current co-production research.

1.4 Thesis Outline

Chapter 1

The current chapter introduces the aims of the study and provides background context to the topics of UI and co-production to situate the study.

Chapter 2

This chapter describes the theoretical and methodological underpinnings of the study. Justifications for the use of each methodological approach will be also be provided.

Chapter 3

This chapter presents findings from the qualitative meta-synthesis conducted to explore existing literature related to older women's experiences of UI.

Chapter 4

This chapter details the study design and methods used for phase one of the study.

Chapter 5

This chapter presents the findings from phase one of this study. The themes identified as characteristic of the lived experience of UI will be discussed.

Chapter 6

This chapter details the findings from the scoping review conducted to examine existing literature surrounding co-production in healthcare research.

Chapter 7

This chapter details the study design and methods used for phase two of the study.

Chapter 8

This chapter presents the findings from phase two of this study. Stakeholder experiences of being involved in a co-produced project will be explored.

Recommendations for conducting co-production research will also be presented.

Chapter 9

This chapter details the ethical principles underpinning both phases of this study.

Chapter 10

This chapter provides an interpretation of the findings from both phases of this study. The unique contributions from this study will be outlined. The strengths and limitations of the study will also be discussed.

Chapter 11

This chapter concludes the thesis by presenting an outline of the study and the key findings.

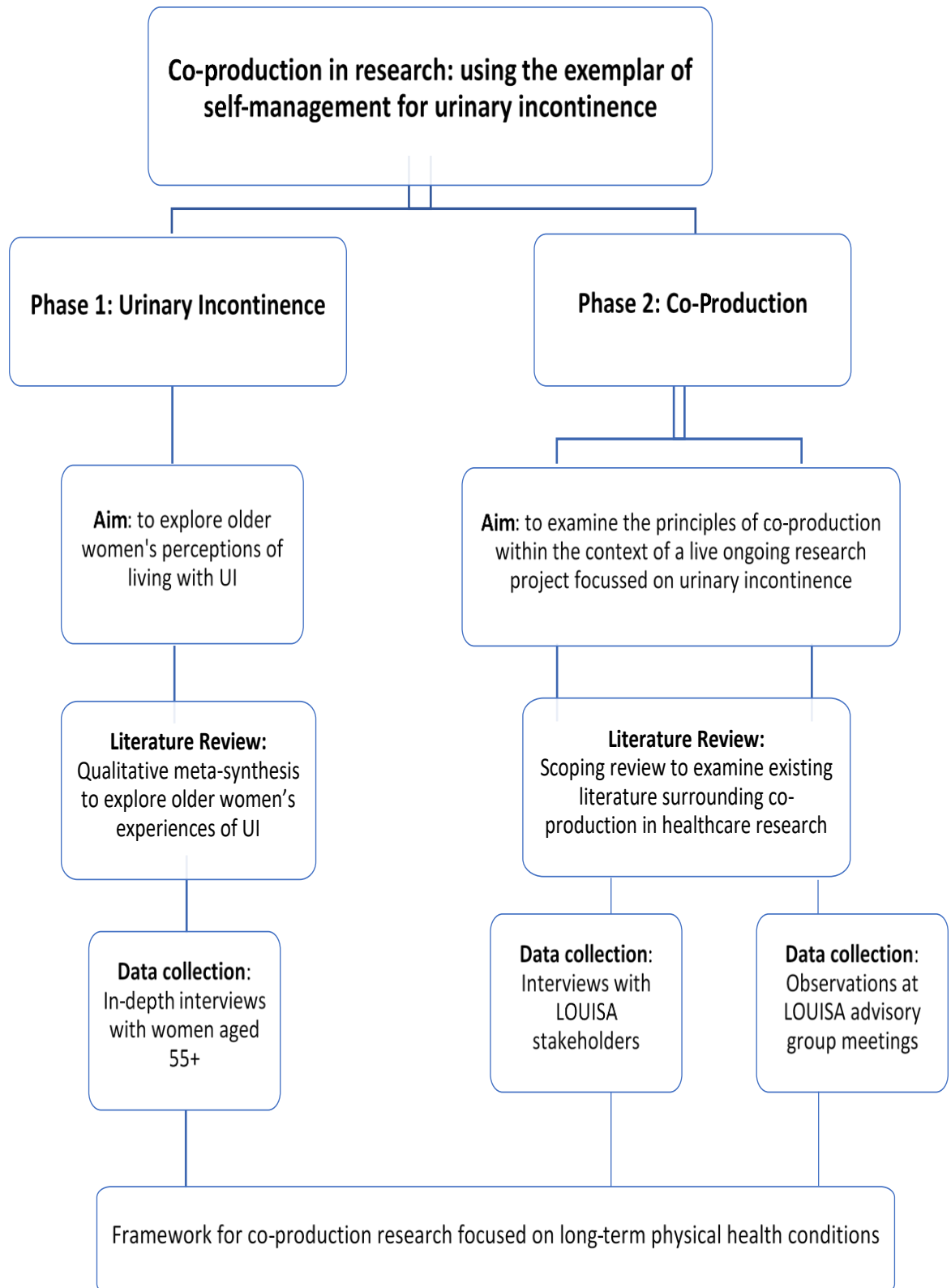


Figure 1: Research Design Overview

1.5 Summary

Phase One:

- Urinary incontinence (UI) refers to a loss of bladder control, leading to the involuntary passing of urine.
- UI is a stigmatised condition that can negatively affect physical, social and psychological well-being.
- **Phase one aims to use IPA to explore older women's perceptions of living with urinary incontinence.**

Phase Two:

- Co-production emphasises shared decision-making and collective knowledge of professionals and the public.
- There is a lack of research on the realities of using this approach for LTCs.
- **Phase two aims to explore the principles of co-production within the context of a co-produced project focused on urinary incontinence (LOUISA).**
- It is expected that data from each phase will be analysed independently and then synthesised together.
- This PhD is funded by the Leeds Benevolent Society for Single Ladies (LBSSL)
- This PhD is embedded within a wider project entitled Leeds Older women Urinary Incontinence Self-mAnagement (LOUISA)

Chapter 2: Methodology

2.1 Introduction

This chapter will discuss the methodological approaches underpinning this study. As this study has two aims with different emphases, separate methodological approaches will be adopted for each. Phase one of the study is focussed on exploring older women's experiences of living with urinary incontinence, therefore an interpretative phenomenological analysis (IPA) methodology will be used. Phase two of the study is focussed on co-production research in action; therefore, a case study methodology will be adopted. This chapter will first discuss the theoretical and philosophical positions underpinning this study. Despite the differing methodological approaches, the overall theoretic framework will underpin the study as a whole. Subsequently, the chosen methodological approaches will be discussed in relation to the current study.

2.2 Qualitative Approach

Due to the exploratory nature of this study, a qualitative research approach has been adopted. Qualitative research is a broad term that encompasses an extensive range of approaches (Ormston et al., 2014) and is thus difficult to define (Denzin and Lincoln, 2011). Miles and Huberman (1994, p. 1) argue that a central tenet of qualitative research is the focus on 'words rather than numbers'. Another central feature in qualitative research is the emphasis on the perspectives of the study participants (Bryman, 2008, p. 393). This is echoed by Ormston et al. (2014, p. 4), who argue that qualitative research should have:

'Aims and objectives that are directed at providing an in-depth and interpreted understanding of the social world of research participants by learning about the

sense they make of their social and material circumstances, their experiences, perspectives and histories’.

It is the intention in this research, to explore and interpret the experiences and perceptions of the participants in both phases of this study. The aim of phase 1 is to explore the lived experiences of older women living with urinary incontinence. The aim of phase 2 is to examine the experiences of participating in a co-produced research model, from the perspective of stakeholders involved in the LOUISA study. The focus in each phase of this study, is the experience as perceived by the participants. A qualitative methodological approach is therefore most applicable to achieve these aims.

Qualitative research is a popular approach within the area of healthcare, which is evidenced by the existence of specialised research journals such as *Qualitative Health Research* and dedicated research texts, e.g. Pope and Mays (2006) *Qualitative Research in Health Care*. Qualitative approaches are often used to research topics of illness (Jensen and Allen, 1994; Pierret, 2003; Morse, 2011), including: health seeking behaviours, experiences of illness, adjustment and coping strategies, experiences of healthcare providers or caregivers, and perspectives of healthcare providers or caregivers (Morse, 2011, p. 404). Qualitative research allows the experiences of illness to be explored from the narrative of those impacted. This is particularly pertinent to phase 1 of this study, which seeks to understand how older women experience living with urinary incontinence.

Although quantitative research allows for the collection of larger datasets and broader generalisation of results, the tightly focussed approach of quantitative research would not be appropriate for this research. Given the research

questions for this study, a qualitative approach was therefore a better fit.

Likewise, although mixed method approaches can be successful at providing different research viewpoints (Ritchie and Ormston, 2014); this approach is not a best fit for this study, as the potential 'loss of depth' would be detrimental to the exploratory research aims (Driscoll et al., 2007, p. 25). Instead, a solely qualitative approach will allow the complexities of the phenomenon to be explored in detail, using a thorough interpretative approach.

2.3 Paradigmatic Stance

Establishing a paradigmatic stance is an integral part of the research process.

Thomas Kuhn (1970) was one of the first philosophers to use the term 'paradigm', when referencing the common values and basis of knowledge shared by scientific communities. Guba (1990, p. 17) argues that a paradigm is a 'basic set of beliefs that guide action', characterised by ontological, epistemological and methodological beliefs. For this study, a qualitative interpretivist paradigm will underpin the research. This approach aligns with the exploratory nature of the research (Bryman, 2008), which seeks to explore older women's perceptions of living with urinary incontinence and examine the experiences of co-production research within the context of a live research project. An interpretivist paradigm is based on the belief that understanding of phenomena can be achieved through the interpretation of subjective insights. Interpretivists ultimately believe that understanding is attained through '...the joint construction/reconstruction of meaning of lived experience' (Lincoln et al., 2011, p. 106). This position conflicts with the principles of a positivist paradigm, which centre on the idea that there is a single objective reality which can be empirically measured (Lincoln et al., 2011). Conversely, an interpretivist

paradigm promotes the belief that there are multiple realities, all of which are constructed through interpretation from the subject and interpreter (Lincoln et al., 2011).

2.3.1 Epistemology

Epistemology is concerned with the nature of knowledge and provides a 'philosophical grounding for deciding what kinds of knowledge are possible' (Maynard, 1994, p. 10). The dominant epistemological perspectives are objectivism, subjectivism and constructionism (Crotty, 1998). An objectivist epistemology centres on the belief that a demonstrable truth exists '...apart from the operation of any consciousness' (Crotty, 1998, p. 8). In other words, truth exists independently of human sentience or interaction. Research underpinned by this epistemology therefore seeks to discover this objective truth. Subjectivism on the other hand, contends that meaning must be imposed on the object. As Crotty (1998, p. 9) argues, 'In subjectivism, meaning does not come out of an interplay between subject and object but is imposed on the object by the subject'. For subjectivism, the object does not play an active role in the creation of meaning. Constructionism, on the other hand, 'takes the object very seriously' (Crotty, 1998, p. 48). The underlying notion of a constructivist epistemology is that truth and meaning do not exist objectively, but are instead constructed through human experiences and engagement with the object. As Crotty (1998, p. 8) argues, a constructivist approach assumes that 'Meaning is not discovered, but constructed'. A constructivist epistemological stance is particularly relevant for this study, as researcher interpretations will be fundamental in understanding the lived experiences of urinary incontinence and exploring stakeholder perceptions on co-produced research.

2.3.2 Ontology

In addition to epistemology, ontological beliefs also feed into the theoretical perspective underpinning a research study (Crotty, 1998, p. 10). Ontology is concerned with the principles of being, i.e. 'things that exist' and 'what it is to exist' (Latsis et al., 2007, p. 2). However, due to the closely related emphases of ontology and epistemology, it can be difficult to distinguish between these concepts (Crotty, 1998, p. 10). Broadly speaking, the two overarching ontological positions are realism and idealism (Crotty, 1998; Ormston et al., 2014). The ontological beliefs of realism maintain that reality exists externally of human interpretation (Ormston et al., 2014, p. 24). Idealism on the other hand, is the belief that reality is dependent on human consciousness and '...what is real is somehow confined to the mind' (Crotty, 1998, p. 64).

A relativist ontology, which is positioned within the ontological branch of idealism, is best suited to constructivism (Guba, 1990; Lincoln et al., 2011). Relativism maintains that reality exists within the mind (Guba, 1990, p. 26) and is constructed through personal experiences. As Guba and Lincoln (1985, p. 73) argue, 'We put together our own personal reality'. This ontological position is most aligned with this study, which aims to explore individual lived experiences of phenomena. This ontological position recognises that there are several variations of 'co-constructed realities' (Lincoln et al., 2011, p. 100), which is the position most in line with the current research. Lived experiences of urinary incontinence will be experienced differently by everyone based on their interpretations of their experiences. It is therefore important to acknowledge the premise of constructed realities whilst conducting this research.

2.3.3 Methodology

Methodology refers to the research approach adopted in association with the theoretical framework underpinning a study (Mackenzie and Knipe, 2006).

Creswell (2007) outlines the five key methodological approaches to qualitative inquiry as: grounded theory, ethnography, narrative research, phenomenology and case study research. Each of these methodological approaches were considered in relation to this study.

Grounded theory research aims to generate theory from data (Creswell, 2007; Bryman, 2008). This research methodology follows an iterative process whereby data collection and analysis are repeated in a non-linear method until data saturation is achieved (Glaser and Strauss, 1967). Although this approach lends itself to inductive research, this study aims to gain an understanding of the experiences of specific individuals and groups, rather than generate theory.

Ethnographic research seeks to understand specific cultures through engaging with, and becoming absorbed in, their community. Ormston et al. (2014, p. 13) argue that ethnographic research involves exploring shared views and experiences through 'immersion in their community'. Although environmental and cultural factors may impact on individuals' experiences, this study seeks to capture the experiences from the perspectives of those being studied.

Furthermore, 'immersion' in the community was not feasible due to the nature of the research topics.

A narrative research methodology aims to understand individual stories as told by the participant. In narrative research, the focus is usually on a 'chronologically connected' series of experiences (Czarniawska, 2004, p. 17). Narrative research methodology is primarily concerned with the ways in which

these connected events combine to depict a narrative or story which is communicated by a participant. This study, however, seeks to explore and interpret the lived experiences of the phenomena under investigation in more depth.

Phenomenology is concerned with participants' lived-experience of a phenomenon (Van Manen, 1990), making it ideal for exploring urinary incontinence from the unique perspectives of older women. Specifically, interpretative phenomenological analysis (IPA) is a phenomenological approach which focuses on 'exploring experience in its own term' (Smith et al., 2009, p. 1). It is for this reason that IPA is the chosen methodological approach for phase one of this study.

Case study research is described by Creswell (2007, p. 73) as research that 'involves the study of an issue explored through one or more cases within a bounded system'. This approach often involves examination of a single case (Bryman, 2008, p. 52) which can impede the production of generalisable conclusions (Tellis, 1997, p. 3). However, this methodology can produce in-depth explorations of a topic (Flyvbjerg, 2011). Phase two of this study aims to explore the experiences and perspectives of stakeholders involved in the co-production research process adopted by the LOUISA project, therefore, a case study approach will be adopted.

2.4 Methodological Approach Phase One: Interpretative Phenomenological Analysis

Phenomenology is the chosen methodological approach for phase one of this study. This phase aims to explore older women's experiences of urinary incontinence, which fits with the focus on 'lived-experience' advocated by phenomenology (Van Manen, 1990). IPA is an interpretive research approach which aims to understand lived experiences and how people make sense of these experiences (Smith et al., 2009). IPA originated in the discipline of psychology, through the work of Jonathan Smith (1996), but has since been used across a range of disciplines, including healthcare (Smith et al., 2009). Smith et al. (2009, p. 3) argue that:

'When people are engaged with 'an experience' of something major in their lives, they begin to reflect on the significance of what is happening and IPA research aims to engage with these reflections' (Smith et al., 2009, p. 3).

IPA has a flexible approach to epistemological and ontological positions (Smith et al., 2009), however an interpretative phenomenological approach is compatible with the constructionist epistemology underpinning the theoretical framework of this study. As Crotty (1998, p. 12) states, 'Constructionism and phenomenology are so intertwined that one could hardly be phenomenological while espousing either an objectivist or a subjectivist epistemology'. This approach aligns with the aim of phase one of this study, which seeks to understand the lived experiences of older women living with urinary incontinence. It is for these reasons, that an IPA phenomenological methodology has been adopted for phase one of this study.

2.4.1 Theoretical Foundations

IPA has theoretical foundations related to phenomenology, hermeneutics and idiography. Each of these theories has influenced the development and application of IPA and will therefore be discussed in the following section of this chapter.

2.4.1.1 Phenomenology

Phenomenology can be described as 'a philosophical approach to the study of experience' (Smith et al., 2009, p. 11). Although the basic premise of phenomenology is to study human experience, several phenomenological approaches have been developed. Some of the key proponents of phenomenology include: Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty and Jean-Paul Sartre.

Edmund Husserl is thought to be the founder of phenomenology (Käufer and Chemero, 2016). Husserl's approach to phenomenology, often referred to as transcendental phenomenology, resonates with some of the core ideas of transcendental philosophy posited by Immanuel Kant; specifically, the belief that '...some important features of our experience are subjectively constituted' (Käufer and Chemero, 2016, p. 25). For Husserl, reflecting on our presupposed human experiences is key to understanding their essence. Husserl (1927) states that 'Focusing our experiencing gaze on our own psychic life necessarily takes place as reflection, as a turning about of a glance which had previously been directed elsewhere' (Husserl, 1927, para. 2). Husserl discussed phenomenological intentionality, which referred to conscious thought being internally levelled towards an object, meaning that, 'experience or consciousness is always consciousness of something' (Smith et al., 2009, p.

13). Transcendental phenomenology encourages researchers to ‘develop an objective “essence”’ (Moerer-Urdahl and Creswell, 2004, p. 32). This is done by “bracketing” previous experiences in order to provide a description of the lived experience of a phenomenon as perceived by the participants (Creswell, 2007). Ultimately, the transcendental phenomenological approach set out by Husserl, lays the groundwork for subsequent phenomenological thinking, through the emphasis on the examination of human experience.

Martin Heidegger further established the ideas of phenomenology, through the development of hermeneutic phenomenology. For Heidegger, the concept of ‘Dasein’ or ‘being-with’ is central to phenomenological inquiry (Heidegger, 1962, p. 156). Heidegger (1962, p. 150) argues that, ‘Dasein is an entity which is in each case I myself: its being is in each case mine’. Heidegger’s hermeneutic phenomenology differs from transcendental phenomenology most notably, in its interpretative rather than descriptive approach. Hermeneutic phenomenology has a focus on the ‘meaning-making activities’ of the people whose experiences are being examined (Smith et al., 2009, p. 18). Unlike transcendental phenomenology, a hermeneutic phenomenological approach does not believe that complete objectivity can be achieved and therefore rejects Husserl’s notion of “bracketing”. Instead, this approach considers data to be ‘based on a subjective reality’ (Mayoh and Onwuegbuzie, 2015, p. 94) and recognises the importance of researcher interpretations. For Heidegger, ‘the attitude of a detached observer misses fundamental features of the objects around us’ (Käufer and Chemero, 2016, p. 57).

Maurice Merleau-Ponty is another prominent phenomenologist, who draws on the works of both Husserl and Heidegger (Käufer and Chemero, 2016).

Merleau-Ponty discusses phenomenology in relation to embodiment, as he

argues that perception is a 'bodily process' (Käufer and Chemero, 2016, p. 94). For Merleau-Ponty, human experiences are individually understood because of their '...embodied position in the world' (Smith et al., 2009, p. 19). Merleau-Ponty argues that the first-hand experiences of one person are understood differently by another person, as 'For him these situations are lived through, for me they are displayed' (Merleau-Ponty, 1962, p. 415). This resonates with the interpretive phenomenological position held by Heidegger (1962).

Jean-Paul Sartre encouraged an existentialist phenomenological approach. Sartre's existential phenomenology is concerned with the complexity of consciousness, which cannot be conceptually reduced to uncomplicated 'building blocks' (Käufer and Chemero, 2016, p. 125). For Sartre, there is no fixed entity of 'self'; instead the self is developed through a dynamic process which is influenced by the world around us. As Smith et al. (2009, p. 19) argue, for Sartre, the concern is '...what we will be, rather than what we are'. 'Nothingness' is an important concept in Sartre's (1943) work, as he believes that our perceptions and sense of self are influenced even by things that are absent (Smith et al., 2009, p. 19).

2.4.1.2 Hermeneutics

Hermeneutics refers to the 'theory of interpretation' (Smith et al., 2009, p. 21). Originally, hermeneutics was used to study and interpret biblical texts (Crotty, 1998; Smith et al., 2009); however hermeneutic principles have become an integral feature of much modern-day research. As Rundell (1995, p. 10) states: *'Through hermeneutics, interpretation has become part of our cultural self-understanding that only as historically and culturally located beings can we articulate ourselves in relation to others and the world in general'*

The three most prominent hermeneutic philosophers related to IPA are Friedrich Schleiermacher, Martin Heidegger and Hans-George Gadamer (Smith et al., 2009). Friedrich Schleiermacher was one of the early hermeneutic theorists.

According to Schleiermacher, hermeneutics encompasses both grammar and psychology (Crotty, 1998; Smith et al., 2009). For Schleiermacher, readers can interpret text by understanding what the writer intended to express.

Schleiermacher recognises that there is an 'empathy in the speaker-listener interchange' which can be applied to textual interpretation (Crotty, 1998, p. 93).

Hermeneutics are also crucial to Martin Heidegger's interpretive strand of phenomenology. Heidegger's hermeneutic phenomenology highlights the importance of how people come to understand their own experiences through interpretation (Smith et al., 2009). Heidegger also recognises the importance of researcher interpretations. For Heidegger (1962, p. 192) 'An interpretation is never a pre-suppositionless apprehending of something presented to us'. Hans-George Gadamer is another key figure in the development of hermeneutics. For Gadamer, historical understanding is pivotal to hermeneutics. Gadamer (1989) discusses the 'fusion of horizons', whereby past and present are fused to construct historically situated understandings. According to Gadamer (1989, p. 290), the process of understanding should be understood as 'participating in an event of tradition'. For Gadamer (1989, p. 388), interpretation is crucial as it offers the interpreter '...an option and a possibility that one brings into play and puts at risk, and that helps one truly to make one's own what the text says'.

The hermeneutic circle is a key concept to consider in relation to IPA. Smith et al. (2009, p. 28) provide an example of how the hermeneutic circle operates when stating that, 'the meaning of the word only becomes clear when seen in the context of the whole sentence'. However, they go on to explain that 'the

meaning of the sentence depends upon the cumulative meanings of the individual words' (Smith et al., 2009, p. 28). This demonstrates the cyclical and iterative process of hermeneutic interpretation, where the interpreter must continuously shift between the part and the whole. This hermeneutic framework resonates with the concept of double hermeneutics. Double hermeneutics refers to the process whereby 'the researcher is making sense of the participants' sense making' (Tuffour, 2017, no pagination). This is particularly relevant to IPA research, where researchers' interpretations are central to understanding the lived experience (Smith et al., 2009).

2.4.1.3 Idiography

Idiography is the third theoretical underpinning of IPA research. Idiographic research emphasises specific cases and prioritises the appreciation of each case individually (Tuffour, 2017, no pagination). That being said, idiographic research is capable of making wider-ranging claims through cross-case analysis (Tuffour, 2017). Through the process of 'cautiously' generating such claims, researchers conducting idiographic research can locate any generalisations within the context of the particular (Smith et al., 2009, p. 29). As idiography focuses on specific cases, the importance of in-depth analysis in IPA research is therefore crucial (Smith et al., 2009). Ideography is a fitting theoretic foundation for IPA as the focus on 'the particular' (Smith et al., 2009, p. 29) resonates with the interpretive, phenomenological belief that events are uniquely experienced and contextually grounded.

2.4.2 Criticisms of IPA

One criticism of IPA is the lack of generalisability of findings (Charlick et al., 2016; Noon, 2018). Small sample sizes are a preferred option in IPA research

as this allows a richer depth of understanding and interpretation (Smith et al., 2009). Furthermore, IPA research seeks to understanding the lived experiences of individuals, drawing on the theoretical underpinnings of ideography which focuses on the 'particular'. These characteristics of IPA research mean that generalisability of findings is not feasible, unlike other research approaches e.g. grounded theory research. However, as argued by Noon (2018, p. 81) '...through the gradual accumulation of similar studies, more general claims can be made'. The aim of this study is to understand the lived experiences of women aged 55+ with urinary incontinence, who live in the Leeds area and are not currently seeking medical help for their condition. These are purposely selected criteria for inclusion and it is not the aim of the study to make broad generalisations about the lived experiences of all women with urinary incontinence based on the specific experiences of these women.

The role of language as a way of communicating lived experiences in IPA has also faced criticism. Willig (2013, p. 94) argues that '... an interview transcript or a diary entry tells us more about the ways in which an individual *talks about a* particular experience within a particular context, than about the *experience itself*. This conceptualisation of language stresses the meanings inherent in the words used to convey experiences, thus asserting the impossibility of uncovering 'direct access' to the experiences of others (Willig, 2013, p. 94). Additionally, Willig (2013) challenges the effectiveness of some participants at communicating their experiences to a researcher, questioning 'How many people are able to use language in such a way as to capture the subtleties and nuances of their physical and emotional experiences?' (Willig, 2013, p. 95). However, as Tuffour (2017, no pagination) highlights, such criticisms could be viewed as 'elitist' as the assumption is that participants can only communicate

their experiences accurately if they have 'access to the right level of fluency'. Although phenomenological approaches such as IPA focus on understanding lived experiences, many of the issues raised in arguments about the role of language also apply to other qualitative approaches seeking to understand participants' experiences.

Lastly, the inclusion of cognition in IPA has been criticised for its incompatibility with the central tenets of phenomenology (Tuffour, 2017). However, Smith et al. (2009, p. 188) argue that IPA '...is almost always concerned with; experiences where the individual is prompted to contemplate, take stock, worry, and try to make sense of what is happening'. Here, the emphasis is on how participants make sense of their experiences through the instinctive cognitive processes of reflection and meaning-making. To understand the lived experiences of older women with UI, it will be important to reflect on how they make sense of their experiences. In this sense, the role of cognition in IPA, as advocated by Smith et al. (2009) complements the process of interpreting and understanding participants' lived experiences.

2.4.3 Justification of IPA

Despite such criticisms, IPA has been chosen as the most appropriate methodological approach for phase one of this study. Firstly, the aim of phase one is to explore the lived experiences of older women living with urinary incontinence, and IPA is an approach that facilitates the exploration of lived experiences from the perspectives of those under inquiry. IPA is an approach that is frequently utilised for researching illness experiences due to its suitability (Smith, 2011). Specifically, Smith (2011, p. 14) highlights in his review of IPA studies, that 'urinary problems' were one of the prevalent conditions being

researched using IPA. Secondly, IPA is influenced by several strands of phenomenological thinking and draws on the works of numerous phenomenologists, which provides a comprehensive philosophical context. Unlike descriptive or interpretive phenomenology, which draw almost exclusively on the works of Husserl and Heidegger respectively, IPA acknowledges and makes use of the various phenomenological approaches and bases the methodology on these theoretical underpinnings. Thirdly, unlike most phenomenological approaches, IPA is also underpinned by the theoretical principles of idiography. Idiography focuses on the particular and is grounded in specific contexts, meaning that it offers an approach which explores how a phenomenon, in this case urinary incontinence, is experienced by specific people. This study is particularly interested in how urinary incontinence is experienced by older women, therefore the attention to specific cases advocated by idiography is fitting. Lastly, IPA offers a systematic approach to phenomenological research (Willig, 2013) and is an accessible methodological approach in comparison to other forms of phenomenological inquiry (Brocki and Wearden, 2006). Considering the arguments discussed here, an IPA approach was therefore a particularly appealing approach to adopt to explore the issues of urinary incontinent women.

2.5 Methodological Approach Phase Two: Case Study

Case study methodology was chosen for phase 2 of this study. A case study is a pragmatic and flexible methodology, which is applicable across various disciplines (Harrison et al., 2017). Case study can be regarded as both a method and a methodology (Creswell, 2007; Harrison et al., 2017) and definitions of what constitutes a case study often vary. Yin (2014, p. 16) regards a case study as an empirical approach that ‘investigates a contemporary phenomenon (the “case”) in depth and within its real-world context’. Stake (1995, p. xi) argues that the primary aim of case study research is to understand the ‘activity’ of the case within a setting that is significant to the case. Due to the exploratory aims of the research, the definition of case study that most resonates with this study, describes the approach as ‘... an in depth description and analysis of a bounded system’ (Merriam, 2009, p. 40)

2.5.1 Defining the Case

Defining the boundaries of the case under investigation is a crucial stage in case study research (Stake, 1995; Yin, 2014). Case studies can include single or multiple cases (Stake, 2006) depending on the research aims. The “case” itself is variable, often including; a single person, a small group of people or even a programme (Yin, 2014). For this study, the LOUISA advisory group is the “bounded system” (Creswell, 2007, p. 73) under investigation. The advisory group (AG) is relatively small, consisting of between 5-12 people depending on availability, making it a suitable “case” for this study. The group is advising on a self-management package for urinary incontinence, which is being developed using a co-production approach. The research will examine the principles of co-production within the context of a live ongoing project (LOUISA). The

experiences of key AG members will be explored, concerning their involvement in the project.

2.5.2 Philosophical Principles

Case study research can be qualitative or quantitative (Stake, 1995; Flyvbjerg, 2011; Yin, 2014), however for the purposes of this study, a qualitative case study approach is most appropriate. Due to the versatility of case study methodology, researchers are afforded flexibility regarding the epistemological and ontological underpinnings of the study (Rosenberg and Yates, 2007; Yin, 2014). This 'paradigmatic bridge' (Luck et al., 2006, p. 107) means that case study research offers an adaptable and pragmatic view of the often rigidly assumed philosophical underpinnings of research. Yin (2014) adopts a realist approach to case study research which centres on the belief that a single, objective reality exists (Yin, 2014, p. 17). Whereas Stake (1995, p. 102) assumes a constructivist approach to case study research, where constructed knowledge is crucial for 'sophisticating interpretations'. This approach is relevant to the current study, as each advisory group member could experience the project differently, therefore offering different constructs of reality related to these experiences. Stake (1995) also discusses the importance of the different roles played by the researcher in a case study. Stake (1995, p. 99) argues that the most central role that a researcher must occupy when undertaking a case study, is the role of interpreter. This resonates with the interpretivist paradigm underpinning this study, which emphasises the importance of the inquirer as a 'co-constructor' of meaning (Guba and Lincoln, 2005, p. 196). Stake's (1995) approach aligns with the epistemological and ontological positions underpinning the current study and will be drawn on for this study.

2.5.3 Case Study Approaches

Stake (1995) outlines three types of case study: intrinsic, instrumental and collective. Intrinsic case studies are conducted to understand only that specific case, rather than studying it to understand a wider problem or set of cases (Stake, 1995, p. 3). Instrumental case studies, on the other hand, do seek to provide insight into a wider issue or problem, through the examination of a specific case (Stake, 1995, p. 3). Collective case studies are the third form discussed by Stake (1995, p. 4), whereby several studies are encompassed within the single case. The case study research undertaken as part of this study is situated somewhere between the intrinsic and instrumental forms of case study advocated by Stake (1995). The case study is intrinsic in that the primary interest is to understand the experiences of the AG involved in this specific project; however, the expectation is that in studying this case, a wider understanding of similar projects may be achieved.

2.5.4 Criticisms of Case Study Methodology

Case study methodology is often criticised for the lack of generalisability it affords, due to the concentration on a single case (Stake, 1995; Tellis, 1997; Yin, 2014). However, as Stake (1995, p. 8) argues, 'The real business of case study is particularization, not generalization'. The aim of case study research is to reach a comprehensive understanding of the case, rather than producing overarching, generalisable theory. Case study research has also been criticised for lack of rigour within this methodology (Yin, 2014). Yin (2014, p. 20) argues that to avoid such criticism, researchers must follow 'systematic procedures'. The following chapters of this thesis will outline such procedures, by describing and rationalising the methods that will be used to address the aims of this case

study. Case studies can also be viewed as ‘unmanageable’ due to the potential time requirements and scope of data collection needed (Yin, 2014, p. 21). This issue is not applicable to the current study as only a selection of participants will be interviewed, to provide an understanding of the case without producing excessive amounts of data.

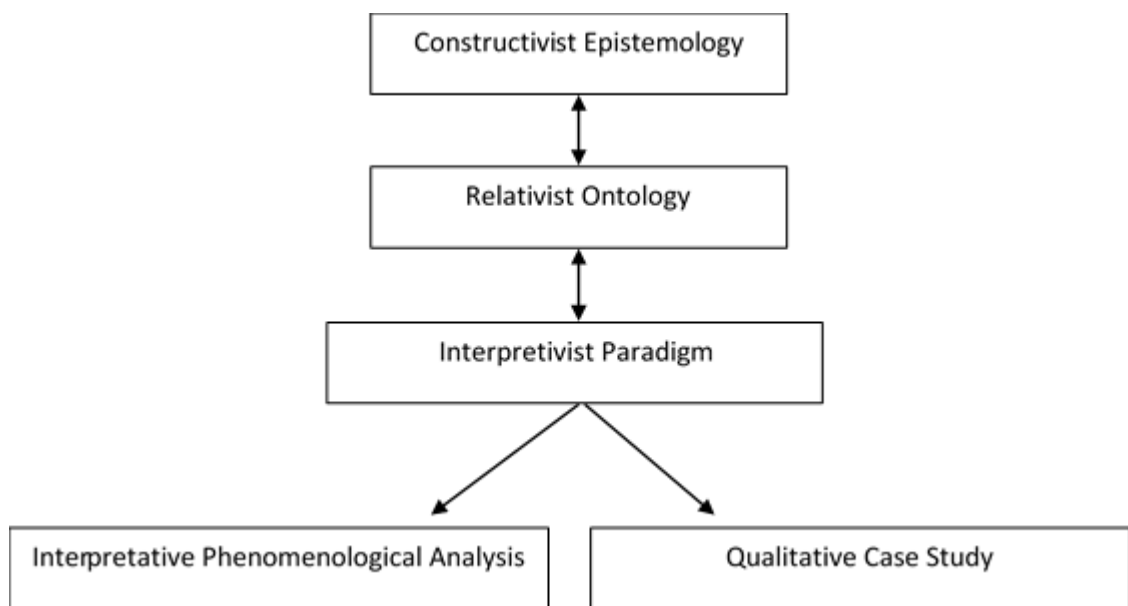


Figure 2: Theoretical Framework

2.6 Conclusion

This chapter begins by presenting a detailed account of the theoretical framework underpinning the study. Next, the potential methodological approaches considered for this study are discussed. The chapter concludes by discussing the chosen methodological approaches for this study – IPA and case study. The research methods chapters in this thesis (chapters 4 and 7) will describe the research methods employed for this study and will draw on the chosen methodological approaches outlined in the current chapter.

2.7 Summary

- This study uses a **qualitative methodological approach**.
- An **interpretivist paradigm** will underpin the research. This paradigm considers that understandings of phenomena can be realised through interpretation.
- A **constructivist epistemology** will be adopted, as researcher interpretations will be central in understanding experiences of UI and co-production.
- A **relativist ontology** is based on the belief that reality exists in the mind and is constructed through personal experiences. This is the approach most aligned with the aims of this research.
- **Phase one** will utilise an IPA methodology.
- IPA has foundations in phenomenology, hermeneutics and idiography:
 - Phenomenology emphasises the researching of experience.
 - Hermeneutics relates to the philosophy of interpretation.
 - Idiography focuses on the individuality of specific cases.
- IPA will facilitate the exploration of lived experiences from the perspectives of those under inquiry.
- IPA draws on several strands of phenomenological thinking.
- IPA provides a systematic approach to phenomenological research.
- **Phase two** will utilise a case study methodology.
- A qualitative case study approach is most appropriate for this study.
- The case is the LOUISA advisory group, consisting of between 5-12 people.
- A constructivist case study approach will be adopted, as different constructs of reality could be realised through the varied experiences of the AG members.

PHASE 1: URINARY INCONTINENCE

Chapter 3: Phase 1 Qualitative Meta-Synthesis

3.1 Introduction

Phase 1 of this study aims to explore older women's lived experience of urinary incontinence. A qualitative meta-synthesis of the literature surrounding women's experiences of living with UI was therefore conducted as part of phase 1. This chapter of the thesis will discuss the existing literature. The methods utilised in this qualitative meta-synthesis will first be detailed. The interpretations of the literature resulting from the synthesis will then be explored.

3.2 Qualitative Meta-Synthesis

There are several approaches that can be used to synthesise existing research. A meta-analysis approach focuses primarily on quantitative studies and seeks to add them together (Booth, 2006) with the intent of making estimates using the greater power of multiple studies and exploring heterogeneity. Similarly, systematic reviews may include quantitative literature and statistical analysis of results (Walsh and Downe, 2005). As this review is concerned with the interpretation of qualitative literature, a meta-synthesis is a more suitable approach. Alternatively, realist reviews are concerned with understanding complex interventions, including how they succeed or fail (Pawson et al., 2005, p. 21). The current study is focused on older women's experiences of UI, rather than the complex interventions surrounding the condition; therefore, a realist review would not be a suitable approach. Whilst narrative reviews are relevant for reviewing qualitative literature, the aim of a narrative review is to summarise and critique existing literature rather than providing new interpretations (Bryman, 2008).

Unlike the aforementioned approaches, a meta-synthesis involves systematically collating and synthesising qualitative literature, with the addition of in-depth interpretation surrounding a given topic. This approach aligns with the aim of this review, which is to examine and interpret older women's experiences of living with urinary incontinence. A qualitative meta-synthesis also provides an opportunity to identify gaps in knowledge (Erwin et al., 2011), due to the systematic and comprehensive synthesis of the literature. One criticism of synthesising qualitative literature is that it is reductionist in its approach, which can damage the integrity of the original findings (Sandelowski et al., 1997). However, opponents of this stance argue that if qualitative researchers fail to bring together knowledge '...they are doomed to irrelevant speculation' (Walsh and Downe, 2005, p. 205). In other words, for qualitative research to guide practice, it is important to demonstrate a broader interrogation and interpretation across qualitative studies (Erwin et al., 2011). The aim of this review is to provide a comprehensive synthesis and interpretation of the literature, surrounding older women's experiences of urinary incontinence.

3.3 Meta-Ethnographic Approach

To synthesise the literature, the 7-step meta-ethnographic approach described by Noblit and Hare (1988) was adopted. Meta-ethnography is a commonly used qualitative synthesis method (Dixon-Woods et al., 2007) to aid in the understanding and interpretations of a given topic. Meta-ethnography provides a structured approach to the synthesis of qualitative literature and involves cross-interpretation between studies, while preserving the context of the primary data. Noblit and Hare (1988, p. 11) argue that 'a meta-ethnography should be

interpretive rather than aggregative'; meaning that the aim is to surpass basic summations of the data, by providing unique interpretations grounded in data.

There is debate surrounding whether it is possible to synthesise studies with different methods or philosophical stances, due to the difficulty of translating meanings across studies (Jensen and Allen, 1996; Sandelowski et al., 1997; Walsh and Downe, 2005; Zimmer, 2006; Atkins et al., 2008; Ring et al., 2011).

Noblit and Hare (1988) proposed that a meta-ethnographic approach should be used exclusively for ethnographic research, to facilitate the 'translation' of studies (Noblit and Hare, 1988, p. 10). However, it is now argued that the exploration of translational relationships between studies is possible across a variety of qualitative study types, provided that these differences are made explicit (Sandelowski et al., 1997; Britten et al., 2002; Campbell et al., 2003; Walsh and Downe, 2005; Finlayson and Downe, 2013).

The meta-ethnographic methods developed by Noblit and Hare (1988) offer a structured approach to synthesising qualitative studies. The approach facilitates in-depth interpretations of the literature in a way that other approaches, such as thematic or narrative synthesis, do not. Whereas other approaches e.g. narrative synthesis, facilitate a systematic analysis of the literature findings, a meta-ethnographic approach also encourages rich interpretations of the literature by translating the studies into one another (step five). This was the chosen synthesis approach for review 1, as it fits with the overall purpose of the review which is to expand understanding and interpretations of the topic of older women's experiences of urinary incontinence.

Table 2: Meta-Ethnographic Approach

Step One	Getting started
Step Two	Deciding what is relevant to the initial interest
Step Three	Reading the studies
Step Four	Determining how the studies are related
Step Five	Translating the studies into one another
Step Six	Synthesising the translation
Step Seven	Expressing the synthesis

(Noblit and Hare, 1988, pp. 26-29)

3.3.1 Step One: Getting Started

The first step in the meta-ethnographic approach is 'getting started'. This step involves 'identifying an intellectual interest that qualitative research might inform' (Noblit and Hare, 1988, p. 26). At this stage, the topic of older women's experiences of urinary incontinence was decided as the focus of review. After reading around the topic, it was decided that an interpretive synthesis of qualitative studies would contribute to existing knowledge of older women's perceptions of living with urinary incontinence.

3.3.2 Step Two: Deciding Relevance

Step two focuses on deciding what is relevant to achieve the aims of the synthesis. This step consisted of the following stages: defining research questions, developing a search strategy, literature screening, data extraction and quality assessment.

3.3.2.1 Review Questions

The aim of this review is to synthesise existing published literature on older women's perceptions of living with urinary incontinence. The research questions framing the qualitative meta-synthesis are:

- What are older women's experiences of living with urinary incontinence?
- What do older women living with urinary incontinence consider to be important to their quality of life?
- What are women's experiences of seeking treatment for urinary incontinence?

3.3.2.2 Search Strategy

The SPIDER tool (Sample, Phenomenon of Interest, Design, Evaluation, Research type) was used to develop the key concepts of the research questions (appendix A), as this framework is well suited to qualitative research (Cooke et al., 2012). Once the key components were identified, a comprehensive list of keywords and synonyms were developed (appendix B). Subsequently, a search strategy was developed using truncations, wildcards, Medical Subject Headings (MeSH), and Boolean searching (appendix C). The search strategy was applied to the following databases: MEDLINE, PsycINFO, Embase, CINAHL, ASSIA and Sociological Abstracts. Databases were searched (June 2017) for literature published between 1991 and 2017. The date limits for searching were established due to the publication of a key paper in 1991 (Dowd, 1991); which was identified during a scoping search as being the first key paper to explore, using qualitative methods, the experiences of older women living with urinary incontinence.

3.3.2.3 Literature Screening

All results obtained from searching these databases (n=10,690) were imported into EndNote (v.8). Duplicates were removed in EndNote (n=4,316). The remaining 6,374 references were imported into Covidence; a literature screening and data extraction tool developed by Cochrane authors, for

streamlining the review process (www.covidence.org). An additional 68 references were identified as duplicates in Covidence, resulting in a total of 6,306 references requiring title and abstract screening.

Inclusion Criteria:

- Papers focused on experiences of urinary incontinence from the perspective of older women aged 55 or above
- Papers which used qualitative methods or had qualitative elements that captured the experiences of older women with urinary incontinence
- Primary or secondary research papers
- Papers written in English

Exclusion Criteria:

- Non-English language papers (due to lack of translation resources)
- Commentary or opinion papers
- Papers focused on the experiences of women with complicated urinary incontinence e.g. incontinence as a result of neurological conditions or other serious conditions such as pelvic prolapse

It was identified after the title and abstract screening that some key papers $n=8$ (Peake et al., 1999; Robinson, 2000; Horrocks et al., 2004; Hägglund and Ahlström, 2007; Hägglund and Wadensten, 2007; Siu and Lopez, 2012; Gjerde et al., 2013; Vethanayagam et al., 2017) were not identified in the original search. These were papers that had been flagged as potentially relevant during background reading for the thesis. It was therefore decided, in agreement with supervisors, that an additional search should be conducted to ensure a thorough examination of the literature. The additional search followed the same search strategy with the exclusion of age related search terms. This is because

some of these papers were not age-specific but might have still been relevant. The additional search produced 18,277 results after duplicates had been removed. After the papers from the original search had been removed from the additional search, the total number of new papers identified were 12,393. This is the total number of papers that were not identified in the original search. As such a large number of additional papers were identified, a random selection of 1,000 papers were screened using the eligibility criteria listed above. The yield of additional papers in this subset was 0.1%, meaning that an estimated 12 papers might be relevant for inclusion. As 8 of these papers had already been identified, there were only approximately 4 potential papers that might be relevant from the additional search. It was therefore decided after discussions with supervisors, that the papers from the additional search (n=12,393) would be discounted. Instead, the 8 papers identified as relevant were manually added into the database of literature.

A total of 110 full-text studies were assessed for eligibility, of which 45 studies were included. Reasons for exclusion included; inappropriate study design (n=36), inappropriate sample (e.g. women <55) (n=22), duplication of results (secondary publications where primary publication already included) (n=5) and inappropriate focus (e.g. not focused on participants' lived experiences) (n=2). Literature screening decisions were discussed with a supervisor throughout the process. The reference lists of all papers which underwent full-text screening were also hand searched; although no additional papers were added to the literature base. The literature screening process followed *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) guidelines (figure 3) (Moher et al., 2009).

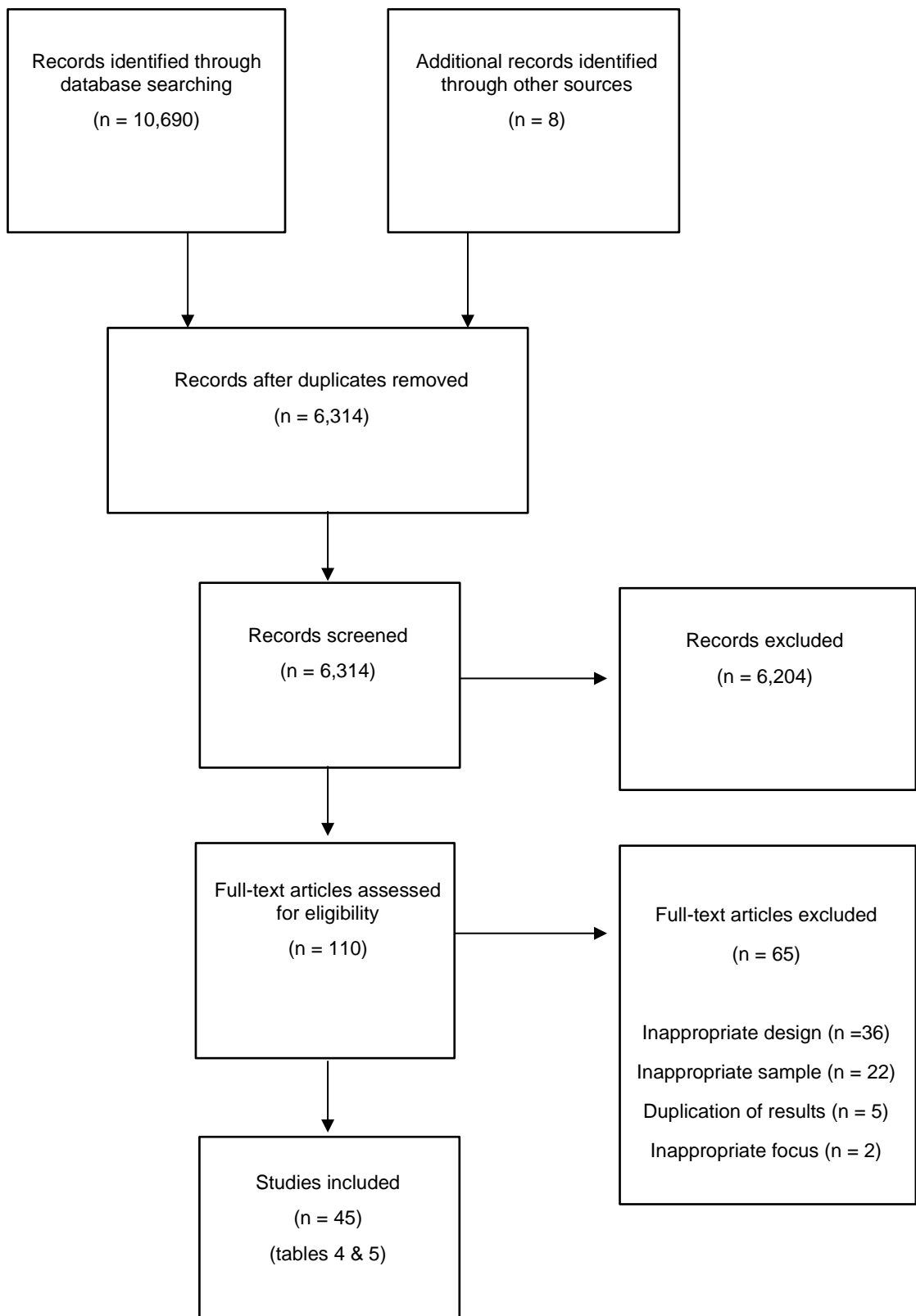


Figure 3: PRISMA Flowchart

Table 3: Reason for Exclusion of Studies

Reason for Exclusion	Number of Studies
Inappropriate study design	36
Inappropriate sample	22
Duplication of results	5
Inappropriate focus	2
Total	65

3.3.2.4 Data Extraction

Data was extracted from the 45 papers included in the study, using a data extraction table developed for this review (table 4 & 5). Relevant data was extracted including: author, setting, aim, sample size, sample age, sample gender, sample ethnicity, UI type, duration of UI, treatment received for UI, study design, data collection, analysis approach and results.

3.3.2.5 Quality Assessment

A meta-ethnographic approach is less concerned with quality assessment as an inclusion criterion than other synthesis approaches (Barnett-Page and Thomas, 2009; Ring et al., 2011). However, for this review each paper was assessed for quality, to provide an overview of the strengths and limitations of the studies. A quality assessment tool developed by Hawker et al. (2002) to assess various types of disparate data, was used to appraise the papers (appendix D). This assessment tool evaluates the quality of: abstract, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability/generalizability and implications and usefulness (Hawker et al., 2002, p. 1296). These 9 stages were assessed using a range of criteria and were given a result of either “good”, “fair”, “poor” or “very poor” (Hawker et al., 2002, p. 1292). On completion of quality assessment, 10% of papers (n=4)

were assessed by a member of the supervisory team using the same assessment tool (Campbell et al., 2003). The results of the quality assessment were then cross-checked with the results assigned by the researcher. Some discrepancies were identified, so the issues were discussed until an agreement was reached.

Using the Hawker et al. (2002) quality assessment tool, the scope of available quality scores ranged from 9 (very poor) to 36 (good). The lowest quality score of the papers included in this study was 21 and the highest score was 35, meaning that all papers were of good quality. Poor reporting of ethics and research bias were common amongst the papers, even those which scored highly on the quality assessment tool. Papers with a lower quality score often lacked sufficient details regarding sampling, which further impacted the score for 'transferability' on the assessment tool. Nonetheless, all papers included in this review had a quality score of at least 21, which is considerably higher than the lowest possible score of 9. Each paper was reviewed thoroughly and deemed suitable for inclusion (appendix E).

Table 4: Summary of Study Characteristics (Qualitative Only)

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Dowd, 1991)	Not specified	'To acquire an understanding of older women's experience of urinary incontinence' (p. 179)	7	58-79	Female	Not specified	Not specified	1.5-50 years	Not specified	Interviews	Grounded Theory
(Bjurbrant Birgersson et al., 1993)	Sweden	'To explore elderly women's feelings about being urinary incontinent, wearing napkins and the procedure of changing napkins when assisted by nurses' (p. 170)	6	65+	Female	Not specified	Not specified	Not specified	Not specified	Interviews & Observations	Grounded Theory
(Eisenhandler, 1993)	Not specified	To examine 'the experience of incontinence and continence as described by twelve community-dwelling older women' (p. 45)	12	64-84	Female	<ul style="list-style-type: none"> • White • Non-white (no details) 	Not specified	Not specified	Not specified (anecdotal information about 1 woman who sought medical help but stopped because she was dissatisfied)	Interviews	Not specified
(DuBeau et al., 1998)	USA	'To explore with older, urge incontinent individuals their own descriptions of the impact of UI on their QoL in order to determine valid content areas for a UI-related QoL questionnaire' (p. 684)	30 25 (F) 5 (M)	63-88	Mixed	White	Urge	Not specified	Not specified	Focus Groups	Content Analysis & Statistical Analysis
(Chaliha and Stanton, 1999)	UK	'To explore religious and cultural practices within ethnic minorities that may effect the experience and ideas sufferers have of incontinence' (p. 167)	34	32-74	Female	<ul style="list-style-type: none"> • Muslim • Hindu • Jewish • Buddhist • Christian 	Not specified	Not specified	8 women sought medical help	Interviews	Not specified

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Robinson, 2000)	USA	'To develop a substantive theory describing and explaining cognitive, psychosocial, and behavioural aspects of living with urinary incontinence in a nursing home' (p. 68)	43 33 (F) 10 (M)	69-93	Mixed	• White • Black	Not specified	Not specified	Not specified	Interviews & Observations	Grounded Theory
(Creech, 2002)	USA	'To examine factors that influence the experience of UI as it relates to sexual intimacy for older women' (p. 4)	10	65-81	Female	Caucasian	Not specified	Not specified	Not specified	Interviews	Thematic Analysis
(Peake and Manderson, 2003)	Australia	<ul style="list-style-type: none"> • To 'address how the construction of femininity affects women's understandings and experiences of UI' • To 'examine how women manage their incontinence in everyday public circumstances and in intimate settings' (p. 38) 	75	40-60	Female	Not specified	Not specified	Not specified	Not specified	Interviews	Thematic Analysis
(Bradway, 2004)	USA	'To examine the subjective, lived experience of women who suffer from long-term urinary incontinence and to show how a cultural model helps define that experience' (p. vi)	17	28-86	Female	• European-American • African-American	Any uncontrolled leakage	>5 years	<ul style="list-style-type: none"> • 15/17 had tried treatment or self-management • 11/15 had tried medical treatments e.g. surgery or UI medication 	Interviews	Narrative Analysis

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Horrocks et al., 2004)	UK	'To explore reasons why older people living in the community do not present for help with problems of urinary incontinence and to identify ways in which they may be assisted to access continence services' (p. 689)	20 11 (F) 9 (M)	66-94	Mixed	Not specified	Not specified	Not specified	<ul style="list-style-type: none"> • 6 people used the specialist continence service (but only 3 currently) • 3 participants were referred to a hospital urology department 	Interviews	Grounded Theory
(Komorowski and Chen, 2006)	China	'To understand the perceptions and experiences of Chinese women living with urinary incontinence (UI)' (p. 169)	15	24-81	Female	Asian	Stress, urge, mixed	Not specified	<ul style="list-style-type: none"> • 9 had sought previous treatment • 6 had not received previous treatment 	Interviews	IPA
(van den Muijsenbergh and Lagro-Janssen, 2006)	Netherlands	'To gain insight into the impact of urinary incontinence on the daily lives of Moroccan and Turkish women and their preferences for treatment' (p. 945)	30	25-65	Female	North-African & Middle-Eastern	Not specified	Not specified	17 women consulted GP	Interviews	Thematic Analysis
(Doshani et al., 2007)	UK	'To explore views and experiences of incontinence and perceptions of care among South Asian Indian Women in Leicester, UK' (p. 585)	24	36-82	Female	South Asian Indian	Women were not asked to disclose UI status	Women were not asked to disclose UI status	5 women sought help	Focus Groups	Grounded Theory
(Li et al., 2007)	Hong Kong	To examine 'community-dwelling women's experiences in coping with UI' (p. 610)	9	42-77	Female	Not specified	Stress UI	<5 - 16 years	All women sought treatment	Interviews	Content Analysis

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(MacDonald and Butler, 2007)	Canada	'To explore elderly women's experiences with UI while living in long-term care' (p. 16)	6	73-94	Female	Not specified	Not specified	At least 6 months	Not specified	Interviews	Thematic Analysis
(Andersson et al., 2008)	Sweden	'To describe experiences of living with urinary incontinence (UI) among persons who do not desire further assessment and treatment' (p. 115)	11	66-89	Female	Caucasian	Not specified	Not specified	<ul style="list-style-type: none"> • Participants did not want treatment • No information on whether they had previously 	Interviews	Phenomenology
(Sange et al., 2008)	UK	'To explore the religious and cultural influences on help-seeking behaviour and decision-making in South Asian Muslim women with UI' (p. 49)	9	21-70	Female	Muslim (Indian and Pakistan)	Not specified	Not specified	Participants all stated that they did not think their symptoms were severe enough for them to seek help	Interviews	Framework Analysis
(Andersson et al., 2009)	Sweden	'To describe the perception of urinary incontinence (UI) among Syrian women living in Sweden' (p. 296)	14	30-80+	Female	<ul style="list-style-type: none"> • Syrian • Christian 	Not specified	Not specified	Not specified	Focus Groups	Content Analysis
(Zeznock et al., 2009)	USA	'To explore Alaskan women's experiences of living with UI' (p. 158)	17	33-86	Female	<ul style="list-style-type: none"> • Caucasian • Alaska Native or Native American 	Stress, urge, mixed, overflow, functional	3 months - 'all my life' (p. 159)	4 women visited HCP regarding UI	Interviews	Thematic Analysis

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Elstad et al., 2010)	USA	<ul style="list-style-type: none"> • 'To characterize the stigma of urinary frequency and urgency and differentiate it from the stigma of incontinence' • 'To describe race/ethnic and gender differences in the experience of stigma among a diverse sample of individuals with LUTS' (p. 2460) 	151 75 (F) 77 (M)	31-80	Mixed	<ul style="list-style-type: none"> • Black • White • Hispanic 	Urinary frequency and urgency rather than incontinence	Not specified	Not specified	Interviews	Grounded Theory
(Hayder and Schnepf, 2010)	Germany	'To examine how people with UI in a German-speaking region organize and experience their everyday lives with incontinence' (p. 482)	32 22 (F) 10 (M)	38-83	Mixed	Not specified	Not specified	18 months-35 years	Not specified	Interviews	Grounded Theory
(Anger et al., 2011)	USA	'To assess women's perceptions of their OAB symptoms, treatment experience, and outcomes' (p. 1295)	33	39-91	Female	<ul style="list-style-type: none"> • Asian • Black • Caucasian 	Urge, nocturia	Not specified	5 women had previous treatment (no information about current help)	Focus Groups	Grounded Theory
(Smith et al., 2011)	USA	'To better understand aging women's experience with overactive bladder (OAB) symptoms and the care they receive' (p. 55)	33	39-91	Female	Not specified	OAB & urge UI	Not specified	Not specified	Focus Groups	Grounded Theory
(Wang et al., 2011)	Taiwan	'To generate descriptive theory on the basis of the lived experiences of Taiwanese women with lower urinary tract symptoms' (p. 66)	16	41-75	Female	Asian	UI, nocturia, urgency, increased daytime frequency	6-20 years	Not specified	Interviews	Grounded Theory

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Hayder, 2012)	Germany	'To investigate the impact of urinary incontinence (UI) on sexuality and intimate relationships' (p. 539)	32 22 (F) 10 (M)	38-83	Mixed	Not specified	Not specified	18 months-35 years	Not specified	Interviews	Grounded Theory
(Siu and Lopez, 2012)	Hong Kong	<ul style="list-style-type: none"> • To explore 'women's perceptions of the severity and impact of stress urinary incontinence, and of pelvic floor muscle exercises' • 'To compare factors that contribute to the understanding of the Chinese women's adherence or non-adherence to a pelvic floor exercise program' (p. 126) 	35	39-74	Female	Asian	Stress	Mean duration 5.09 years	<ul style="list-style-type: none"> • 18 women did a pelvic floor exercise program • No further details 	Interviews	Content Analysis
(Delarmelindo et al., 2013)	Brazil	'To understand Brazilian women's experience of urinary incontinence (UI) and design a representative theoretical model for the experience' (p. 1981)	18	41-81	Female	Not specified	Not specified	Not specified	7 women were undergoing conservative treatment and 4 had finished treatment	Interviews	Grounded Theory
(Gjerde et al., 2013)	Ethiopia	'To gain in-depth knowledge of women suffering from urinary incontinence (UI) in rural and semi urban settings in Ethiopia' (p. 953)	26	Not specified (but at least one woman aged 55+)	Female	Not specified	Mild-continuous leakage (type not specified)	Not specified	<ul style="list-style-type: none"> • Most had not disclosed UI to health workers • Participants in the health facility were referred for treatment by health workers 	Interviews	Systematic Text Condensation

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Avery et al., 2015)	Australia	'To explore the subjective experience of the burden of urinary incontinence in relation to mental health' (p. 94)	19	43-89	Female	Caucasian	Differing types of UI (types not listed)	Less than 5 years - 30+ years	10 women received treatment which improved or cured UI but unclear whether those still suffering had treatment	Interviews	Framework Analysis
(Hamid et al., 2015)	Iran	'To illuminate the experience of Muslim community-dwelling postmenopausal women who were living with urinary incontinence (UI)' (p. 514)	17	52-68	Female	Muslim	Any UI	10+ years	Not specified	Interviews	Hermeneutic Phenomenology
(Pakgohar et al., 2015)	Iran	'To explore older women's experiences of management strategies in dealing with UI' (p. 2)	8	60-70	Female	Not specified	Not specified	10-23 years	Not specified	Interviews	Hermeneutic Phenomenology
(Róin and Nord, 2015)	Faroe Islands	'To explore how meaning of UI was discursively constructed and negotiated by women bothered with long-term UI' (p. 625)	7	60-65	Female	Not specified	Not specified	Not specified	Not specified	Interviews	Discourse Analysis
(Siddiqui et al., 2016)	USA	'To qualitatively assess the themes surrounding treatment seeking behaviors in White, Black, and Latina women' (p. 341)	113	48.1 ± 16.9 (white) 47.12 ± 9.9 (black) 38.4 ± 14.4 (Latina)	Female	• White • Black • Latina	Frequent or infrequent UI	Not specified	Women 'not already presenting for treatment' but no details about previous treatments (p. 347)	Focus Groups	Thematic Analysis

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Takahashi et al., 2016)	Japan	'To describe how older adults with incontinence could be resilient and actively participate in social activities' (p. 1167)	11 9 (F) 2 (M)	70-90	Mixed	Asian	Not specified	Not specified	Not specified	Interviews	Thematic Analysis
(Vethanayagam et al., 2017)	UK	'To explore the views of older people with UI on the process of seeking help' (p. 1061)	50 43 (F) 7 (M)	70.06 (9.69) Service A 68.36 (7.44) Service B 63.70 (10.07) Service C	Mixed	• White British • White Asian	Not specified	Not specified	Not specified	Interviews	Thematic Content Analysis

Table 5: Summary of Study Characteristics (Qualitative and Quantitative)

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Lagro-Janssen et al., 1992)	Netherlands	'To assess the extent to which urinary incontinence in women affects their daily lives' (p. 211)	110	20-65	Female	Not specified	Stress, urge, mixed	<2 year - > 5 years	<ul style="list-style-type: none"> • Women had not received an operation • All sought help from GP • No details about treatments 	Questionnaires (with qualitative elements)	Responses 'categorized by the GP researcher' (no further details)
(Brown et al., 1998)	USA	'To identify specific aspects of functioning and well-being affected by urge incontinence or mixed incontinence with a primary urge component' (p. 1263)	65	37-86	Female	<ul style="list-style-type: none"> • White • African-American • Latina • Asian • Other 	Urge (or mixed with urge)	11 years + average	12% of the women had never sought treatment	Focus Groups & Questionnaires	Frequency Analysis (QSR NUD*IST)
(Fitzgerald et al., 2000)	USA	To assess 'the impact of UI on working life and the strategies women use to manage incontinence' (p. 113)	1, 113	18-73	Female	<ul style="list-style-type: none"> • Black • White • Asian/ Native American/ Other 	Not specified	Not specified	46% sought help from healthcare provider	Questionnaires (with qualitative elements)	Statistical Analysis+ direct responses reported from open-ended questions
(Roe, 2000)	UK	'To identify the impact of incontinence on individuals and to explore the impact of effective and ineffective management on individuals' (p. 678)	27 19 (F) 9 (M)	28-98	Mixed	Not specified	Not specified	5 months - 46 years	All recruited through health authorities offering incontinence services but not specified	Interviews & Questionnaires	Constant Comparative Approach

Study	Setting	Aim	Sample Size	Age	Gender	Ethnicity/ Religion/ Culture	UI Type	UI Duration	UI Help/ Treatment	Data Collection Method	Analysis Approach
(Fitzgerald et al., 2002)	USA	'To identify the impact of self-reported UI on working women, to describe urine loss symptoms, strategies used to control urine loss, and help-seeking behavior among full-time women working in a rural production facility' (p. 1)	265	16-69	Female	<ul style="list-style-type: none"> • African American • Caucasian • Asian/ Native American/ Other 	Stress, urge, mixed	Not specified	Most women did not report their UI to healthcare providers' (no further details)	Questionnaires (with qualitative elements)	Statistical Analysis+ direct responses reported from open-ended questions
(Shapiro et al., 2003)	Australia	'To identify and explore OWN [Older Women's Network] members' attitudes toward and experiences of urinary incontinence' (p. 24)	38 (interviews /FGD) 336 (questionnaire)	Not specified (but at least one woman aged 55+)	Female	Anglo-Australian	Not specified	Not specified	Not specified	Interviews, Focus Groups & Questionnaires	Thematic Analysis
(Diokno et al., 2006)	USA	'To evaluate women's perceptions about bladder control problems' (p. 568)	757 (survey) 180 (FGD)	40-70 (survey) 40-65 (FGD)	Female	<ul style="list-style-type: none"> • Caucasian • African-American • Hispanic/ Latina (survey) • Not specified (FGD) 	Stress, nocturia, urge, urgency	At least 1 year	Not specified	Questionnaires & Focus Groups	Statistical Analysis No formal analysis of FGD results
(Teunissen et al., 2006)	Netherlands	'To determine the impact of urinary incontinence (UI) on the quality of life of the elderly in the general population and to identify factors with the greatest effect' (p. 166)	370 314 (F) 56 (M)	Mean: 71.1 (female) 70.9 (male)	Mixed	Not specified	Stress, urge, mixed	6 months - 5+ years	Not specified	Questionnaires & Interviews	Statistical Analysis & Grounded Theory
(Srikrishna et al., 2009)	UK	'To explore expectations and goals of women undergoing continence surgery using a combined quantitative and qualitative approach' (p. 859)	29	39-83	Female	<ul style="list-style-type: none"> • Caucasian • Afro-Caribbean • Asian 	Not specified	Not specified	All women were about to receive treatment	Questionnaires & Interviews	Grounded Theory
(Bradway et al., 2010)	USA	'To elicit salient features of a cultural model for long-term (>5 years) female UI' (p. 1533)	25 (free-list) 13 (pile-sort)	25-89	Female	<ul style="list-style-type: none"> • White • African-American 	Not specified	> 4 years	Some women (n=25) had past or current UI treatments	Free-list exercise & Pile-sort exercise	Saliency Index Analysis

3.3.3 Step Three: Reading the Studies

Step three concerns familiarisation with the literature. Noblit and Hare (1988, p. 28) argue that this phase should involve reading the literature several times and recording 'interpretive metaphors'. The term 'metaphors' refers to themes or concepts discovered in the studies (Noblit and Hare, 1988, p. 14). In this phase, each study was read several times to ensure familiarisation. During this process, emerging metaphors were recorded and confirmed on re-reading the studies. Initial metaphors were recorded as summarised terms (appendix F) as it would be too time consuming to record verbatim quotes due to the large number of studies (n=45) (Atkins et al., 2008).

3.3.4 Step Four: Determining Related Studies

Step four involves uncovering how each of the selected studies is related (Noblit and Hare, 1988). During this stage, the emergent metaphors from step three (appendix F) were compared to identify related concepts (table 6). To do this, the metaphors were organised in Microsoft excel and grouped according to the potential relationships between them. The concepts were then discussed with a PhD supervisor to confirm that the relationships between the metaphors had been appropriately identified. This stage is concerned with sorting the metaphors to identify relationships, rather than interrogating the concepts.

Table 6: Related Concepts

Concepts	Metaphors	Related Studies
Embarrassment	Accidents, embarrassment, humiliation, unpredictability, odour, shame, taboo, hygiene, visible wetness, fear, stigma, secrecy, sympathy, pride, bodily functions, dignity, privacy, disguise, context of leakage, weakness, visibility	(Dowd, 1991; Lagro-Janssen et al., 1992; Bjurbrant Birgersson et al., 1993; Eisenhandler, 1993; Brown et al., 1998; DuBeau et al., 1998; Chaliha and Stanton, 1999; Fitzgerald et al., 2000; Peake and Manderson, 2003; Shapiro et al., 2003; Bradway, 2004; Horrocks et al., 2004; Diokno et al., 2006; Komorowski and Chen, 2006; Teunissen et al., 2006; van den Muijsenbergh and Lagro-Janssen, 2006; Doshani et al., 2007; Li et al., 2007; MacDonald and Butler, 2007; Andersson et al., 2008; Sange et al., 2008; Andersson et al., 2009; Srikrishna et al., 2009; Zeznock et al., 2009; Bradway et al., 2010; Elstad et al., 2010; Wang et al., 2011; Hayder, 2012; Siu and Lopez, 2012; Delarmelindo et al., 2013; Gjerde et al., 2013; Hamid et al., 2015; Pakgohar et al., 2015; Róin and Nord, 2015; Siddiqui et al., 2016; Takahashi et al., 2016; Vethanayagam et al., 2017)
Self-Image	Threat, control, blame, guilt, misery, self-perception, anxiety, vulnerability, intrinsic value, autonomy, threat to adulthood, body, adult status, gender, unattractive, resentment, self-image, integrity, female body, 'leaky' bodies, identity, femininity	(Dowd, 1991; Bjurbrant Birgersson et al., 1993; Eisenhandler, 1993; Brown et al., 1998; DuBeau et al., 1998; Robinson, 2000; Creech, 2002; Peake and Manderson, 2003; Teunissen et al., 2006; Li et al., 2007; MacDonald and Butler, 2007; Andersson et al., 2008; Srikrishna et al., 2009; Hayder and Schnepf, 2010; Hayder, 2012; Siu and Lopez, 2012; Delarmelindo et al., 2013; Gjerde et al., 2013; Hamid et al., 2015; Róin and Nord, 2015)
Self-Management	Protection, security, preparation, confidence, management, coping, limiting fluid intake, pads, schedule, control, routine, clothing choices, pelvic floor muscle exercises, medication, toilet mapping, prevention, vigilance, improvising, learning, monitoring, adapting, humour, reliance, resilience, motivation, limited access to supplies	(Dowd, 1991; Lagro-Janssen et al., 1992; Bjurbrant Birgersson et al., 1993; Eisenhandler, 1993; Brown et al., 1998; DuBeau et al., 1998; Fitzgerald et al., 2000; Robinson, 2000; Roe, 2000; Creech, 2002; Fitzgerald et al., 2002; Peake and Manderson, 2003; Bradway, 2004; Horrocks et al., 2004; Teunissen et al., 2006; Doshani et al., 2007; MacDonald and Butler, 2007; Andersson et al., 2008; Andersson et al., 2009; Bradway et al., 2010; Hayder and Schnepf, 2010; Anger et al., 2011; Wang et al., 2011; Avery et al., 2015; Pakgohar et al., 2015; Róin and Nord, 2015; Takahashi et al., 2016; Vethanayagam et al., 2017)
Relationships (social & sexual)	Unacceptability, participation, social interaction, sexual relationships restricted, dependency, social relationships, isolation,	(Dowd, 1991; Lagro-Janssen et al., 1992; Bjurbrant Birgersson et al., 1993; Eisenhandler, 1993; Brown et al., 1998; DuBeau et al., 1998; Chaliha and Stanton, 1999; Roe, 2000; Creech, 2002; Peake and Manderson, 2003; Shapiro et al., 2003; Bradway, 2004; Diokno et al., 2006; Komorowski and Chen, 2006; Teunissen et al., 2006; van den Muijsenbergh and Lagro-Janssen, 2006; MacDonald and Butler, 2007;

	communication with partners, lack of intimacy, social interruption	Andersson et al., 2008; Sange et al., 2008; Andersson et al., 2009; Srikrishna et al., 2009; Zeznock et al., 2009; Elstad et al., 2010; Hayder and Schnepp, 2010; Hayder, 2012; Siu and Lopez, 2012; Delarmelindo et al., 2013; Avery et al., 2015; Hamid et al., 2015; Róin and Nord, 2015; Siddiqui et al., 2016; Takahashi et al., 2016)
Employment	Time consuming, jobs, recreation, inconvenience, inaccessible toilets, restriction, despair, disturbed sleep, employment restrictions, burden, annoyance, work permissions	(Brown et al., 1998; DuBeau et al., 1998; Fitzgerald et al., 2000; Fitzgerald et al., 2002; Diokno et al., 2006; Komorowski and Chen, 2006; Srikrishna et al., 2009; Bradway et al., 2010; Anger et al., 2011; Siu and Lopez, 2012)
Ageing	Normalising, inevitability, importance, ageing, fear of ageing, perceptions of old age, low expectations, generational attitudes, perceptions of seriousness, ageism, institutionalised elderly	(Dowd, 1991; Bjurbrant Birgersson et al., 1993; Eisenhandler, 1993; DuBeau et al., 1998; Chaliha and Stanton, 1999; Robinson, 2000; Creech, 2002; Peake and Manderson, 2003; Horrocks et al., 2004; Diokno et al., 2006; Komorowski and Chen, 2006; Doshani et al., 2007; MacDonald and Butler, 2007; Andersson et al., 2008; Bradway et al., 2010; Smith et al., 2011; Siu and Lopez, 2012; Avery et al., 2015; Róin and Nord, 2015; Vethanayagam et al., 2017)
Help seeking	Preference for female doctors, lack of knowledge, preference for older doctors, awareness of treatments, dissatisfaction with services, attitude of healthcare professionals, neglect, perceptions of seriousness, communicating symptoms, misinformation, desire for treatment, unhelpful advice, embarrassment of GP, ethnicity of GP, other illnesses, access, fear, religion of doctor, positive encounters, expectations, interaction with carers, empathy, attitude of carers, well-known carers, disagreement, respect, preference, communication, support, lack of choice	(Bjurbrant Birgersson et al., 1993; DuBeau et al., 1998; Chaliha and Stanton, 1999; Fitzgerald et al., 2000; Robinson, 2000; Creech, 2002; Shapiro et al., 2003; Bradway, 2004; Horrocks et al., 2004; Diokno et al., 2006; Komorowski and Chen, 2006; van den Muijsenbergh and Lagro-Janssen, 2006; Doshani et al., 2007; MacDonald and Butler, 2007; Andersson et al., 2008; Sange et al., 2008; Andersson et al., 2009; Zeznock et al., 2009; Anger et al., 2011; Smith et al., 2011; Wang et al., 2011; Hayder, 2012; Delarmelindo et al., 2013; Róin and Nord, 2015; Siddiqui et al., 2016; Vethanayagam et al., 2017)
Religion	Religious restrictions, faith, prayer, ritual, cleanliness, religious beliefs, cultural rituals, punishment	(Bjurbrant Birgersson et al., 1993; Chaliha and Stanton, 1999; van den Muijsenbergh and Lagro-Janssen, 2006; Sange et al., 2008; Gjerde et al., 2013; Hamid et al., 2015)

3.3.5 Step Five: Translating the Studies

During step five, the studies are translated into one another (Noblit and Hare, 1988). To do this, the metaphors and themes developed for each study in steps three and four, are compared directly to one another. In other words, the metaphors and themes of one study are examined as whole, before interpreting these concepts in relation to the next study. Similarities between the themes across the studies were identified, in line with the 'reciprocal translation' discussed by Noblit and Hare (1988, p. 38). To ensure trustworthiness and minimise bias, the results from this stage of the synthesis were discussed with a supervisor. Furthermore, example metaphors are illustrated below to demonstrate the process of translating the studies into one another. The concepts resulting from this stage of the meta-synthesis can be found in table 7.

Table 7: Translating the Studies

Emergent Themes	Related Concepts	Example Metaphors
Self-Perception	Embarrassment	Accidents, humiliation, odour, shame, taboo, wetness, stigma, pride, context of leakage, visibility
	Ageing	Normalising, inevitability, ageing, perceptions, perceptions of seriousness, threat to adulthood
	Self-Image	Gender, unattractiveness, female body, identity, femininity
Management of UI	Self-Management	Protection, preparation, coping, pads, routine, humour
	Help-Seeking	Preferred doctors, attitude of healthcare professionals, neglect, perceptions of seriousness, communication, expectations
Impact on Life	Sexual Relationships	Unacceptability, participation, sexual restriction, dependency, communication, lack of intimacy
	Social Life	Social interruption, isolation, participation, social interaction, relationships
	Employment	Inconvenience, disturbed sleep, employment restrictions, burden, work permissions, suffering
	Religion	Religious restrictions, prayer ritual, cleanliness, punishment

3.3.6 Step Six: Synthesising Translations

Step six involves developing a 'line of argument' (Noblit and Hare, 1988, p. 62), which is a summary of results from the synthesis. The line of argument for this synthesis is detailed following the discussion of emergent themes.

3.3.7 Step Seven: Expressing the Synthesis

Step seven relates to the communication of the results from the synthesis.

Noblit and Hare (1988, p. 29) argue that: 'To be effectively communicated, the synthesis must not only be in appropriate form but must also use intelligible concepts'. The results of this thesis will be reported in written form with the addition of tables to enhance the understanding and credibility of the results.

3.4 Description of the Literature

Within the literature, there are several papers that address issues surrounding older women's experiences of urinary incontinence. This review will synthesise 45 relevant studies, providing meaningful interpretations of the original data.

The earliest paper included was conducted in 1991 and the latest was

conducted in 2017. The papers were conducted in the following locations:

America (n=14), UK (n=7), Sweden (n=3), Australia (n=3), Netherlands (n=3),

Hong Kong (n=2), Iran (n=2), Germany (n=2), Ethiopia (n=1), Taiwan (n=1),

Brazil (n=1), Japan (n=1), Faeroe Islands (n=1), China (n=1) and Canada (n=1).

A further 2 papers did not specify this information. All papers either had a

qualitative or mixed method design. Of the 45 papers, 33 collected data using

interviews, 9 collected data using questionnaires, 9 collected data using focus

groups, 2 collected data using observations and 1 study used free-list and pile-

sorting exercises to collect data (some studies used more than one method). In

total, 3 studies were conducted in assisted-living care homes, 1 study was

conducted with a mixture of participants from assisted-living facilities and community-dwelling participants, and the remaining 41 studies included only community-dwelling women. Of the 45 studies, 23 did not provide information on whether the participants were currently receiving treatment for UI, had previously received treatment for UI, or had never sought help for the condition. A further 20 studies stated that their sample included some women who had previously received help for UI or were currently receiving treatment; although the reporting of information on treatments, timelines etc. was often lacking. The remaining 2 studies described the sample as not presenting for treatment.

Age is a central criterion for inclusion in this review as women aged 55+ are the focus of the review, however the reporting of age was varied across the studies. Of the 45 papers, 40 reported an age range, 3 reported a mean/standard deviation, and 2 did not specify the age of participants. In the absence of a clear age range encompassing women aged 55 or above, where possible, the mean and standard deviation were used to determine whether the age criteria had been met. The 2 papers which did not explicitly report the age of participants were included because it became clear from reading the descriptions attached to verbatim quotes that at least one woman aged 55+ was included in the study.

Using the Hawker et al. (2002) quality assessment tool, the scope of available quality scores ranged from 9 (very poor) to 36 (good). The lowest quality score of the papers included in this study was 21 and the highest score was 35, meaning that all papers were of good quality. Poor reporting of ethics and research bias were common amongst the papers, even those which scored highly on the quality assessment tool. Papers with a lower quality score often lacked sufficient details regarding sampling, which further impacted the score for 'transferability' on the assessment tool. Nonetheless, all papers included in

this review had a quality score of at least 21, which is considerably higher than the lowest possible score of 9. Each paper was reviewed thoroughly and deemed suitable for inclusion (appendix E).

3.5 Description of Themes

The emergent themes are summarised in table 7. A total of 3 themes and 9 sub-themes (concepts) were identified. The first theme related to self-perception and included sub-themes of embarrassment, ageing and self-image. The second theme concerns management of urinary incontinence, particularly related to self-management and help-seeking. The last theme is focused on the impact of urinary incontinence on women's lives and included sub-themes about sexual relationships, social life, employment and religion.

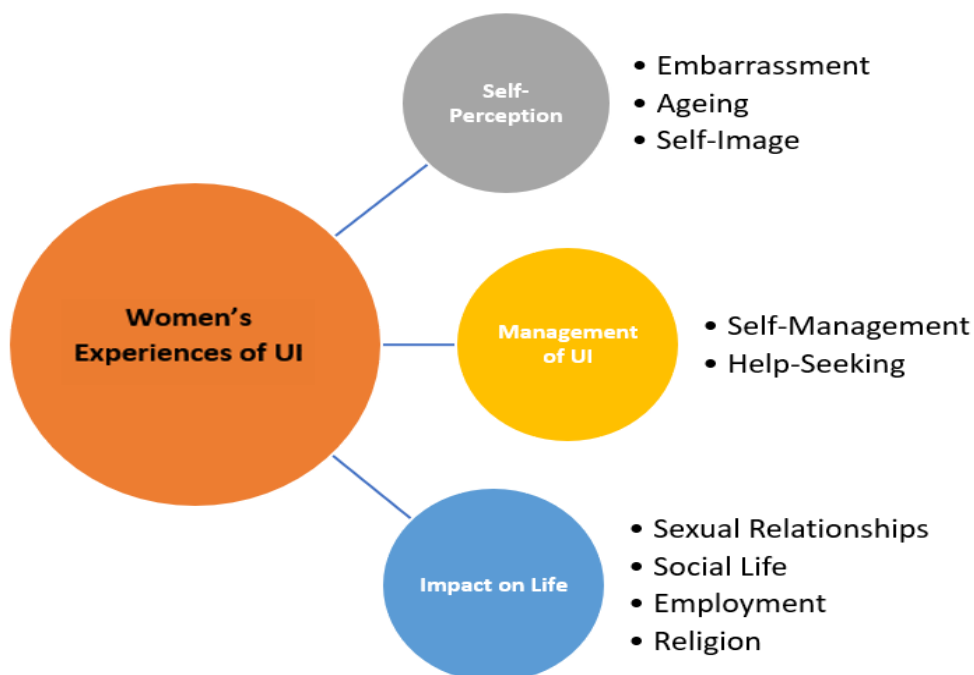


Diagram 1: Overview of Themes

3.6 Self-Perceptions

Self-perceptions surrounding urinary incontinence was a prominent theme throughout the literature. Women's self-perceptions in the context of experiencing urinary incontinence formed a significant part of women's narratives, particularly in relation to: embarrassment, ageing, and self-image.

3.6.1 Embarrassment

Embarrassment caused by urinary incontinence was a key theme throughout the literature. Despite the varying geographical contexts represented across the studies, feelings of embarrassment, shame, and fear of humiliation were frequently expressed by women. Furthermore, feelings of embarrassment and shame are present across the full date range of papers (1991-2017), indicating that there has yet to be a shift in perceptions surrounding incontinence.

"I feel embarrassed. I am ashamed, and I think everybody knows that I cannot control my urine because it leaks in front of people" [Female, Iran] (Hamid et al., 2015, p. 516)

'Odour' and 'wetness' were prominent factors raised when discussing embarrassment, as they are often viewed as signifiers for urinary incontinence. The process of concealing visible symptoms of incontinence to avoid embarrassment, is therefore jeopardised when odour or wetness are noticeable to others.

"I am sure people think I smell, I wash and wash but I know I smell, it's so embarrassing" [Female, UK] (Srikrishna et al., 2009, p. 862)

In contrast, some women expressed that leakage or 'wetness' is embarrassing only under certain situations. The context of leakage is therefore an important

factor in determining embarrassment surrounding urinary incontinence, as public versus private leakage can trigger different experiences. One woman situated this in the context of sexual intimacy:

“You can forgive anything with the passion of the moment but you can’t forgive leaking outside of passion!” [Female, Australia] (Peake and Manderson, 2003, p. 47)

The very notion of “forgiveness” highlights the stigma surrounding incontinence, which leads many women to strive for secrecy surrounding their illness. Part of this is about maintaining public perceptions of normalcy, which can be threatened by concepts of embarrassment and taboo. One woman described her effort to minimise public embarrassment by buying alternative products to disguise urinary incontinence:

“Kotex [menstrual pads] make me feel that I’m all right, that I’m normal. I’m shy about buying the others and I keep them both at the bottom of my (grocery) bag” [Female, location not specified] (Eisenhandler, 1993, p. 50)

3.6.2 Ageing

Ageing was a concept that was significant in the literature, regarding women’s self-perceptions of their illness. Beliefs about the unavoidable nature of urinary incontinence were a prominent part of the dialogue around ageing. Often women would situate their illness in the context of ‘inevitability’, whereby they would rationalise their urinary incontinence as by-product of old age (Eisenhandler, 1993; DuBeau et al., 1998; Robinson, 2000; Creech, 2002; Peake and Manderson, 2003; Siu and Lopez, 2012).

"I have always just thought that that's a part of aging and I know that I'm doing that, fast getting to that point and I just guess, just accept it as part of growing older" [Female, USA] (Creech, 2002, p. 39)

By equating incontinence with the inevitability of old age, these women are acting to normalise their condition (Doshani et al., 2007; Róin and Nord, 2015).

"I don't think it's serious at all. I mean at my age I'm lucky that I've got as few as problems that I've got" [Female, Australia] (Avery et al., 2015, p. 100)

Another emergent concept surrounding ageing is losing bodily control, leading to a child-like regression of the body (Bjurbrant Birgersson et al., 1993; Peake and Manderson, 2003; Andersson et al., 2008; Hamid et al., 2015). Some women discussed their self-perceptions of being incontinent in reference to being "a bad kid" or "a big baby" (MacDonald and Butler, 2007, p. 17). This threat to women's adult status, ultimately has a negative effect on self-esteem and confidence.

"It's difficult. Sometimes I cry, I think I have become a little child, because children can't control their urine and pee onto their diapers. I think I should use them too... I feel sad. It's a bad feeling" [Female, Iran] (Hamid et al., 2015, p. 516)

It became clear from the literature that urinary incontinence is perceived as an 'old woman's disease' (Avery et al., 2015, p. 103), thus perpetuating the supposed certainty of urinary incontinence during old age. One woman discussing her incontinence stated:

"I feel like an old woman and I'm only 55!" [Female, UK] (Srikrishna et al., 2009, p. 862)

3.6.3 Self-Image

Self-image was identified as an important part of women's experiences of urinary incontinence. Women often felt self-conscious about seeming unhygienic and neglectful of their bodies.

"It worries that me that someone might think badly of me... that I don't bathe, or that I don't change my underwear... They might think that it must be a lack of hygiene or a lack of going to the doctor to get checked" [Female, USA] (Elstad et al., 2010, p. 2466)

Feeling unattractive as a result of incontinence was another issue raised in the literature (Brown et al., 1998; Siu and Lopez, 2012).

"This just makes me feel ugly, I don't feel like a woman, certainly not an attractive one in any case" [Female, UK] (Srikrishna et al., 2009, p. 863)

Body image and unattractiveness were discussed within the context of femininity, as women often felt like their illness threatened their status as a 'feminine' woman. One woman discussed this by linking the feeling of femininity directly to the curing of urinary incontinence:

"I just want to feel feminine again" [Female, UK] (Srikrishna et al., 2009, p. 863)

3.7 Management of Urinary Incontinence

Management of urinary incontinence was a significant theme identified in the literature. Managing urinary incontinence was discussed in terms of two distinct approaches: self-management and help-seeking.

3.7.1 Self-Management

In order to manage their symptoms and help to diminish feelings of shame and preserve self-esteem, women often develop a set of routines to control or

disguise their conditions. These self-management strategies are used to minimise the outwardly visual symptoms of urinary incontinence which could threaten women's self-security. Some of the commonly mentioned self-management strategies include: limiting fluid intake, pads, protective clothing, altering medication (diuretics) and toilet mapping (Bjurbrant Birgersson et al., 1993; Eisenhandler, 1993; Fitzgerald et al., 2000; Roe, 2000; Peake and Manderson, 2003; Horrocks et al., 2004; MacDonald and Butler, 2007; Bradway et al., 2010; Hayder and Schnepf, 2010; Wang et al., 2011; Róin and Nord, 2015; Takahashi et al., 2016). Another coping strategy adopted by some women was to use humour to mask potential embarrassment about their illness (Roe, 2000; Creech, 2002; Diokno et al., 2006; Róin and Nord, 2015). One woman joked:

"It's like Niagra Falls (when I have an accident)" [Female, USA] (Diokno et al., 2006, p. 571)

Successful management strategies are developed through a process of adjustment (Andersson et al., 2008) to suit each individual woman's needs and preferences. When urinary incontinence is perceived to be self-managed successfully, women are given an element of control over their illness (Horrocks et al., 2004).

Although the use of successful self-management strategies can have a positive effect on women's experiences of urinary incontinence, it is also the case that this can sometimes come at a social and psychological cost (Horrocks et al., 2004). Furthermore, there are often monetary costs involved with self-management, e.g. purchasing pads (DuBeau et al., 1998; Peake and Manderson, 2003), which mean that optimal self-management strategies might

not be universally accessible. Environmental factors, e.g. country of residence and standards of living, must therefore be accounted for when examining experiences of urinary incontinence. Although there are common themes that transcend environmental factors, e.g. embarrassment, each individual's experience of urinary incontinence is set within the boundaries of their contextual surroundings.

"I would prefer cleaning with soap to avoid the smell, but the market is far away and we face shortage of money" [Female, Ethiopia] (Gjerde et al., 2013, p. 954)

3.7.2 Help-Seeking

Despite the impact that urinary incontinence can have on quality of life, some women suffering with urinary incontinence choose not to seek help (Horrocks et al., 2004). Self-management is often considered as a first preferred management option rather than seeking medical help (Sange et al., 2008).

Embarrassment and normalisation of symptoms due to ageing were reported in the literature as barriers to help-seeking (Chaliha and Stanton, 1999; Vethanayagam et al., 2017). Lack of awareness about potential treatments was also identified as a barrier (Chaliha and Stanton, 1999; Horrocks et al., 2004; van den Muijsenbergh and Lagro-Janssen, 2006). The studies also showed that the gender of doctors can act as a barrier to help-seeking as many women reported to prefer female doctors (Chaliha and Stanton, 1999; Horrocks et al., 2004; Doshani et al., 2007). Not being able to speak the same language as the doctor was also a hindrance to some women, and using interpreters was not always a preferred option (van den Muijsenbergh and Lagro-Janssen, 2006; Doshani et al., 2007; Andersson et al., 2009). There are also cultural and religious barriers to help-seeking amongst older women with urinary

incontinence which should be considered. Siu and Lopez (2012, p. 126), for example, argue that there is a specific 'conservative Chinese way of thinking' which impacts women's likelihood to discuss the condition.

Experiences of help-seeking were often negative. One complaint was that medical professionals do not take the issue seriously (Lagro-Janssen et al., 1992; Bradway, 2004; van den Muijsenbergh and Lagro-Janssen, 2006). One woman described her experience of this:

"He said I was going through the menopause and this was normal, he made me feel like 'what are you complaining about, woman, just get on with it'" [Female, UK] (Doshani et al., 2007, p. 588)

The attitude of medical professionals can also act as an obstacle to seeking help, as women need to feel comfortable and supported in order to openly discuss what they perceive to be an embarrassing illness. One woman described an incident where her GP displayed embarrassment at her raising the issue of urinary incontinence:

"My GP was more embarrassed than I was, probably because he is an elderly male GP and I felt I couldn't talk to him openly about the problems I had" [Female, UK] (Doshani et al., 2007, p. 588)

Although there is a lack of awareness amongst some women experiencing incontinence, there also appears to be a level of misinformation being delivered from medical professionals which could prevent women from seeking further help e.g. if the condition worsened. One woman stated:

"When I went to see the doctor he told me that no treatment existed" [Female, China] (Komorowski and Chen, 2006, p. 175)

The studies which were conducted in care homes also discussed the role of carers in managing urinary incontinence amongst female patients. Some women discussed their sympathy for the nurses due to the burden of their job, and expressed their wish not to annoy them (Bjurbrant Birgersson et al., 1993; Robinson, 2000).

“I feel sorry for those who have to do it – you feel that you are a burden to them”
[Female, Sweden] (Bjurbrant Birgersson et al., 1993, p. 167)

Due to the nature of assisted living, some women felt that there were certain restrictions placed on them which hindered successful management of urinary incontinence. One woman stated:

“You’re rationed on the number of times you can be changed” [Female, Canada] (MacDonald and Butler, 2007, p. 18)

3.8 Impact on Life

There are several ways in which being incontinent impacts daily life for those affected. The studies identified in this meta-synthesis explore some of the ways in which urinary incontinence impacts the life of older women. There were several practical restrictions imposed on women’s lifestyles, including: household chores, shopping and physical recreation (Teunissen et al., 2006; Srikrishna et al., 2009). Although negative impacts on lifestyle were reported in the literature, it was also argued that for many women, using sanitary protection enabled them to ‘live the life they wanted to live’ (Andersson et al., 2008, p. 118). The four central areas of impact include: sexual relationships, social life, employment, and religion.

3.8.1 Sexual Relationships

The impact of urinary incontinence on sexual relationships was a key factor in the literature. Women often felt restricted, dissatisfied and fearful about the restrictions that urinary incontinence placed on their sex lives (Chaliha and Stanton, 1999; Creech, 2002; van den Muijsenbergh and Lagro-Janssen, 2006; Srikrishna et al., 2009).

“We hardly do IT anymore, I’m always petrified I will leak. I don’t enjoy it as much” [Female, UK] (Srikrishna et al., 2009, p. 863)

Some women discussed the potential impact that lack of intimacy might have on their relationships:

“I never want to make love to my husband, I know it’s affecting us but I really can’t!” [Female, UK] (Srikrishna et al., 2009, p. 863)

This was also the case for women who were in new partnerships, as they expressed concerns about disclosing their condition to new potential partners (Hayder, 2012).

The impact of urinary incontinence on the spontaneity of sexual encounters was also identified in the literature, due to what were perceived to be necessary preparations e.g. ‘protecting the bed with a mattress cover’ and ‘the need to shower thoroughly immediately following intercourse’ (Hayder, 2012, p. 540).

Age was an issue reported to have an effect on the impact of urinary incontinence on women’s sex lives. Brown et al. (1998, p. 1267) highlight that the impact varied between women aged over and under 70 years old. Women aged <70 frequently discussed sexual relationships and dating, whereas this was not an issue raised by women aged >70. One woman in the <70 category stated:

"I was on a date and I couldn't get to the bathroom on time. It was terrible"

[Female, USA] (Brown et al., 1998, p. 1267)

3.8.2 Social Life

In addition to impacting intimate relationships, urinary incontinence was also reported to have a negative impact on many women's social lives. One woman discussing urinary incontinence said that the condition:

"Makes you unwilling to leave home and socialize" [Female, Australia] (Shapiro et al., 2003, p. 28)

Due to the taboo nature of urinary incontinence, women often treat their condition with a degree of secrecy, which can result in self-imposed social isolation. As one woman stated:

"Sometimes when my friends ask me to go out, I always try to make an excuse to refuse them" [Female, Hong Kong] (Siu and Lopez, 2012, p. 129)

Women with incontinence often avoid situations where they feel that their condition might be problematic. Leisure activities such as tennis, dancing or running are often avoided (Diokno et al., 2006, p. 571). Even less active social activities e.g. cinema or shopping trips, can be difficult for some women (Hayder and Schnepf, 2010, p. 485). These 'change of habits' can leave women feeling isolated from family and friends (Komorowski and Chen, 2006, p. 176), and can be a challenging adjustment. One woman articulated:

"I have to, all the time, to adapt myself to the circumstances; find a toilet, use san pads, remember clean panties in my bag, and so on" [Female, Faroe Islands] (Róin and Nord, 2015, p. 628)

3.8.3 Employment

Another area of life that is affected by urinary incontinence is employment. For some women, working environments, e.g. restricted breaks, prevent them from freely accessing toilets, therefore acting as a barrier to the successful self-management of urinary incontinence symptoms. Frequent and unexpected bathroom breaks can also negatively affect women's work life.

“Work is frequently interrupted, and sleep is always interrupted – so I don't feel rested in the morning” [Female, USA] (Fitzgerald et al., 2000, p. 115)

Women also discussed the impact of embarrassment and fear of judgement at work, as a result of incontinence (Diokno et al., 2006; Srikrishna et al., 2009; Siu and Lopez, 2012). Srikrishna et al. (2009, p. 862) state that women often experienced 'worries that their colleagues would feel they “smelt”', which was an important concern for these women. The amount of time women spent on visiting the bathroom during working hours was also an issue for some women, who felt that they were being judged for this by their colleagues (Diokno et al., 2006, p. 571).

Other concerns surrounding employment included: securing a job, performance at work and retirement (Brown et al., 1998, p. 1267).

“I retired early. This was a major factor in that” [Female, USA] (Brown et al., 1998, p. 1267)

3.8.4 Religion

Religion is another area of life that is reportedly impacted by urinary incontinence, particularly amongst Muslim women (Chaliha and Stanton, 1999;

van den Muijsenbergh and Lagro-Janssen, 2006; Sange et al., 2008; Gjerde et al., 2013; Hamid et al., 2015).

The impact of urinary incontinence was most marked in relation to the 'ritual purity' deemed necessary for prayer (van den Muijsenbergh and Lagro-Janssen, 2006, p. 948). Muslims are required to complete ablutions (washing rituals) after urine leakage in order to pray, meaning that for those affected, urinary incontinence was 'affecting their worship of the Islam faith' (van den Muijsenbergh and Lagro-Janssen, 2006, p. 946).

"It's difficult to pray. I ask God for forgiveness as I can't pray well; I am always rushed in praying because I am afraid of leaking urine" [Female, Iran] (Hamid et al., 2015, p. 517)

Additionally, some women expressed that they were unable to participate in certain religious ceremonies altogether:

"...going to the pilgrimage (Mecca) is difficult for me; also I cannot attend rituals at mosque" [Female, Iran] (Hamid et al., 2015, p. 517)

Women who have experienced long-term urinary incontinence often developed 'modified prayer routines' (Chaliha and Stanton, 1999, p. 168). These modified routines included: restricting fluids, voiding beforehand, and altering prayer position (Chaliha and Stanton, 1999, p. 168).

"I drink less before I pray, [I also] go toilet before doing Wadu" [Female, UK] (Sange et al., 2008, p. 51)

3.9 Line-of-Argument Synthesis

Older women's experiences of urinary incontinence are primarily based on the notion that the condition is stigmatised and embarrassing, meaning that women

often believe that they should hide their condition and deal with it privately. Older women's experiences are also understood in the context of ageing, which allows women to normalise the condition as an unavoidable part of growing older. The underlying perceptions of embarrassment and inevitability subsequently prevent women from help-seeking and accessing available services.

3.10 Discussion

This is the first qualitative meta-synthesis to review and synthesise existing published literature, focused specifically on the perceptions of older women (aged 55+) living with urinary incontinence. In this review, 45 studies were analysed across 15 countries (USA, UK, Sweden, Australia, Netherlands, Hong Kong, Iran, Germany, Ethiopia, Taiwan, Brazil, Japan, Faeroe Islands, China and Canada). The key finding of this meta-synthesis is that older women's experiences of living with urinary incontinence are underlined by stigma and embarrassment; which negatively impacts women's lives and influences their help-seeking behaviours. For older women, urinary incontinence is also understood in the context of ageing, thus facilitating normalisation of the condition.

The papers included in this meta-synthesis (n=45) were each interpreted thoroughly and a systematic translation across the studies was completed. Whilst including a large number of studies in the meta-synthesis allowed for a comprehensive interpretation of relevant data, the amount of papers included may have impacted on the depth of analysis (Campbell et al., 2011; Ring et al., 2011). Campbell et al. (2011, p. iv) argue that '... > ~40 papers would result in a trade-off between the breadth of included papers and the depth of scrutiny'.

Furthermore, to translate the studies into one another whilst maintaining the integrity of the original study, as advocated by Noblit and Hare (1988), it is important to understand the context in which the studies were conducted. Due to 'varied reporting styles' (Bondas and Hall, 2007, p. 117) and lack of reported information this was sometimes challenging, as key contextual facts e.g. study setting, age or treatment history of participants were frequently missing.

As with all interpretive qualitative research, there is an element of subjectivity regarding interpretations. As Noblit and Hare (1988, p. 14) argue, '... any interpretation, metaphor, or translation is only one possible reading of that studied'. However, tables of original metaphors and interpretations have been included in this synthesis for transparency.

One of the exclusion criteria for this synthesis was papers focused on the experiences of women with complicated urinary incontinence e.g. incontinence as a result of neurological conditions or other serious conditions such as pelvic prolapse. This was decided because the experiences of complicated urinary incontinence would be multifaceted and possibly incomparable with the experiences of women with uncomplicated urinary incontinence. Although the views of women with such conditions could have added to the dialogue around experiences of urinary incontinence, this would have been at the cost of increased volume and complexity of analysis.

Whilst there is existing research in the area of women's experiences of urinary incontinence, further work is needed to expand knowledge in this field. In particular, further research is needed to explore the lived experiences of older women living with urinary incontinence in the UK. In total, there were 7 studies included in this review that were conducted in the UK (Chaliha and Stanton,

1999; Roe, 2000; Horrocks et al., 2004; Doshani et al., 2007; Sange et al., 2008; Srikrishna et al., 2009; Vethanayagam et al., 2017); none of which focused specifically on the lived experiences of older women (55+). Additionally, this literature review has highlighted a dearth of research focused on the experiences of incontinent women who have either never sought professional help or have previously engaged with medical services but have since disengaged. None of the UK-based papers (n=7) focused on the experiences of these women. Furthermore, only 4 of the 45 studies included in the review used a phenomenological approach. These studies were conducted in China (n=1), Sweden (n=1) and Iran (n=2).

This meta-synthesis has identified significant gaps in the literature, which confirms that the focus of the current study is worthwhile. This study aims to contribute to knowledge in this area by addressing these gaps in the literature, through accessing women who have disengaged with medical services, and conducting an in-depth phenomenological examination of their lived experiences of urinary incontinence. Though the findings from the meta-synthesis provided context to the current study and illuminated key gaps in the literature, in keeping with the principles of IPA, data collection remained respondent-led and was therefore not directed by the meta-synthesis findings. Findings from this study will enhance understandings of how older women experience urinary incontinence and how they interact with related services; which could lead to recommendations for service improvement going forward.

3.11 Conclusion

This chapter presents a detailed account of current qualitative literature surrounding the experiences of older women with urinary incontinence. The

literature illustrates the negative impact that urinary incontinence has on women's overall quality of life including their self-perception, self-image and feelings of embarrassment. The literature also highlighted women's experiences of self-management routines and help-seeking behaviours. This review also discussed the impact of urinary incontinence on women's lives, particularly concerning sexual relationships, social life, employment and religion. This chapter concludes by considering how the aims of the current study are situated within the context of existing literature.

3.12 Summary

- This is the first qualitative meta-synthesis to review and synthesise existing published literature, focused on the perceptions of older women (aged 55+) living with UI.
- In total, 45 studies were analysed across 15 countries (USA, UK, Sweden, Australia, Netherlands, Hong Kong, Iran, Germany, Ethiopia, Taiwan, Brazil, Japan, Faeroe Islands, China and Canada).
- Overall, 3 themes and 9 sub-themes were identified:
 - The first theme relates to **self-perception** and includes sub-themes of *embarrassment*, *ageing* and *self-image*.
 - The second theme concerns **management of UI**, relating to *self-management* and *help-seeking*.
 - The third theme focused on the **impact of UI** on women's lives and includes sub-themes about *sexual relationships*, *social life*, *employment* and *religion*.
- The **key finding** is that older women's experiences of UI are underlined by stigma and embarrassment; which negatively impacts women's lives and influences help-seeking behaviours. For older women, UI is also recognised in the context of ageing, which can facilitate the normalisation of UI.
- Only a small number of studies (n=7) explored the experiences of UI in a UK context, none of which focused specifically on the lived experiences of older women (55+).
- Additionally, none of the UK-based papers (n=7) focused on the experiences of women who have either never sought professional help or have previously engaged with medical services but have since disengaged.
- The current study aims to address the dearth of research in these areas, by accessing older women (55+) in the UK who have disengaged with medical services, to explore their lived experiences of urinary incontinence.

Chapter 4: Phase 1 Research Methods

4.1 Introduction

This chapter will provide a detailed discussion of the research methods used for phase one of this study. Firstly, the aims of the research will be outlined. Details of the data collection methods will then be discussed. Following this, data analysis methods will be described.

4.2 Research Aim

The aim of this phase of the study was to explore older women's perceptions of living with urinary incontinence. To achieve this research aim, the following objectives were developed: (1) identify existing qualitative literature focused on older women's experiences of living with urinary incontinence; (2) explore the experiences and perceptions of older women aged 55+ with urinary incontinence. The broad research question that phase one of this study intends to address is: *What are older women's lived experiences of urinary incontinence?* The research question is intentionally broad in accordance with the interpretive nature of the study.

4.3 Data Collection

4.3.1 Rationale

Data were collected for this phase of the study through one-to-one, in-depth interviews with older women experiencing urinary incontinence. After reviewing the qualitative literature surrounding female urinary incontinence (chapter 3), it became apparent that the most frequently used method of data collection was interviews. Other methods of data collection included focus groups, questionnaires with qualitative elements, and observation. I decided that focus

groups would not be a suitable alternative for facilitating open dialogue in this instance. Although some studies identified in the literature did use focus groups to discuss urinary incontinence, this was often using a grounded theory approach which usually requires a larger sample size, in comparison to IPA, to create overarching theories. This study utilised an IPA approach where rich, in-depth explorations of the specific, lived experiences of incontinence would be conducted. Although focus groups can be beneficial in situations where participants are already part of an existing group within which they feel comfortable (Lewis and McNaughton Nicholls, 2014), this would not be the case for the participants included in this study. Therefore, due to the sensitive nature of the topic, I decided that focus groups would not be a suitable alternative for facilitating open dialogue. One-to-one interviews, however, provided a confidential setting, where participants were offered the opportunity to discuss their own personal experiences privately. Some studies used questionnaires with qualitative, open-ended questions to explore female urinary incontinence; however, this approach is better suited to large scale studies. Instead, my aim was to explore a small number of cases in-depth, meaning that questionnaires were not an appropriate method. Furthermore, although observations are a useful method for examining participants' social settings (Bryman, 2008), this would not have been appropriate given the subject matter. The studies that were identified in the literature as having used observation techniques were conducted in a nursing home setting (Bjurbrant Birgersson et al., 1993; Robinson, 2000). Whilst useful insights could be gained from observing experiences of UI within certain social settings like care homes; after careful consideration, I decided that interviews were the most well-suited data collection method for this phase of the study, as the focus is on older women

living independently in the community. Interviews are particularly compatible with IPA research which seeks to elicit rich, in-depth data related to a particular phenomenon (Smith et al., 2009).

The purpose of a research interview is to understand the 'life-world' of the participants '...with respect to interpretation of the meaning of the described phenomena' (Kvale, 1983, p. 174). Interviews ultimately provide a means for participants to voice their experiences first-hand through open dialogue with an interviewer. Interviews have been, somewhat simplistically, described as 'conversations with a purpose' (Burgess, 1984, p. 102); however, I recognised the potential challenges faced when conducting unstructured, in-depth interviews. Researchers are required to practice 'active listening' during interviews (Seidman, 2006, p. 79), whereby interview responses are followed-up considerably, whilst also remaining aware of the phenomenon as the focal point and evaluating the progress of the interview. This is particularly pertinent to in-depth, exploratory interviews like those undertaken in IPA studies. As Englander (2012, p. 26) argues, phenomenological interviewing requires: '*...shifting between the subject-subject relation (following the responses in the interview) and the subject-phenomenon relation (that is, the questions should be geared towards the research phenomenon)*'. Although this was initially a daunting task, my previous interview training and experiences meant that I was equipped with the skills and knowledge required to conduct effective in-depth interviews.

Traditionally, interviews were considered somewhat deductive in the sense that specific questions were often constructed around presumptive prior knowledge (Fontana, 2001). However, there has since been a shift towards so called 'postmodern trends in interviewing' (Fontana, 2001, p. 161). This postmodern

interview trend advocates for more of a shared-discussion format of interviewing, rather than the traditional 'hierarchical' interviewer-led process of questioning (Fontana and Frey, 1994, p. 369). The relationship between interviewer and interviewee is now less clear-cut and there is often a degree of collaboration between both parties when interpreting the participant's narrative (Fontana, 2001). The notion of the 'detached interviewer' has now been challenged, and researchers are encouraged to be reflexive in understanding their role in the interview process as 'active agents' (Fontana, 2001, p. 165). Seidman (2006, p. 84) argues that 'The interview can become too easily a vehicle for the interviewer's agenda rather than an exploration of the participant's experience'. I was therefore conscious of the potential pitfalls of such inadvertent bias and consequently endeavoured to assume a reflexive position throughout the research process.

4.3.2 Sampling

Sampling Strategy:

This project was prioritised and funded by the Leeds Benevolent Society for Single Ladies (LBSSL). The study therefore took place in Leeds as this is the area served by the charity. A purposive sampling strategy was used to recruit participants who would be able to 'illuminate the questions under study' (Patton, 1990, p. 169). Purposive sampling is a non-random approach to sampling, whereby participants are selected based on their appropriateness to provide information relevant to the research question. This approach is well suited to IPA, as purposive sampling provides the opportunity to encounter the experiences of participants who offer an accurate representation of the phenomenon under investigation. To identify a relevant sample, inclusion and exclusion criteria were created. Setting these criteria resulted in a demographic,

geographic and physically homogenous sample; however, such homogeneity is favoured for IPA studies (Smith et al., 2009). As Robinson (2014, p. 27) states: *'By maintaining a measure of sample homogeneity, IPA studies remain contextualised within a defined setting, and any generalisation from the study is made cautiously to that localised sample universe'*. Whilst it could be beneficial to understand the experiences of a more diverse sample of women with urinary incontinence, attempting to understand the lived experiences of a vastly heterogeneous sample could impact the depth and richness of analysis which is central to IPA research.

Participants were required to meet all of the eligibility requirements listed below to be considered for participation in phase one of the study:

- Female
- Aged 55+
- Currently have urinary incontinence (not specific to any type e.g. stress UI)
- Currently living in the Leeds area
- Not currently receiving medical help from a GP or other specialist concerning urinary incontinence symptoms

The exclusion criteria were:

- Non-English speakers
- Women currently seeking medical help for urinary incontinence

Non-English speakers were excluded from this study due to the lack of resources for translation services. Additionally, as this study sought to understand the views of women who had never, or were not currently seeking

medical help for urinary incontinence; women currently seeking medical help were excluded from this study.

Sample Size:

IPA research favours relatively small samples (Smith et al., 2009), however as per the principles of phenomenology, sample size was predominantly based on whether or not a comprehensive interpretation of the phenomenon had been achieved (Creswell, 1998). It was initially estimated that at least 3-5 women would be invited to take part in in-depth interviews. It was also anticipated that a likely maximum number of participants, from reading the accounts of previous studies in related areas (Hägglund and Ahlström, 2007; De Witt et al., 2010; Hamid et al., 2015), would be 15. As a guide, Smith et al. (2009) recommend a sample size of between 3-6 participants for IPA studies. In total, 3 women were interviewed for this study. This relatively small sample size aligns with the idiographic principles underling IPA research. The sample size was sufficient for depicting a thorough interpretation of the lived experiences of women with UI aged 55+; yet also allowed for rigorous analysis. Another benefit of having a small sample size was that participants had a 'locatable voice' in the study (Robinson, 2014, p. 29), meaning that each woman's story played a crucial role in the subsequent analysis of findings.

4.3.3 Recruitment

The chosen recruitment strategy for phase one of this study was to recruit participants through local charitable organisations. The aim was to explore the experiences of women not currently engaged with health services related to urinary incontinence; so, it was expected that recruitment through relevant charities would provide the opportunity to reach these women. Additionally, as

this study is part of a wider project concerned with urinary incontinence (LOUISA), it was anticipated that there would be opportunities to draw on existing relationships with charitable organisations. Two charities were targeted for recruitment in the first instance. These charities were Older People's Action in the Locality (OPAL) and Caring Together. These charities are both focussed on supporting the well-being of older people living in Leeds. Additional recruitment was targeted through Leeds Older People Forum (LOPF).

Initially, I approached the key workers for the charities to discuss in principle whether they would permit recruitment via their organisations. Once permission was granted by the charities, a flyer (appendix H) containing key details about the study was distributed through the charities to raise awareness of the study. My contact details were provided on the recruitment flyer and potential participants were encouraged to contact me, either via phone or email, to express their interest. Two of the three charities contacted, agreed to distribute the recruitment flyer; these were Caring Together and OPAL. However, despite permission being granted to recruit via these charities, no participants contacted me to express an interest.

The recruitment strategy was therefore amended, to include snowball recruitment. This decision was made as snowball sampling is often beneficial when recruiting for studies which cover potentially sensitive or stigmatised topics (Robinson, 2014). It was also anticipated that there might be the opportunity to make use of pre-existing relationships with potential participants involved in the LOUISA study. This change to recruitment was amended through the School of Healthcare ethics board at the University of Leeds. Potential participants were not directly contacted by myself to request participation. Instead, women who were part of the social networks residing in

the community, who I already knew, were asked to distribute recruitment flyers and the researcher's contact details to relevant participants. Participants were then able to contact me directly if they wished to participate. Relevant women involved in the LOUISA study were also contacted by the principle investigator (lead supervisor) to inform them about the potential opportunity to participate in this study. Participants who contacted me were given more information about the study, and if they expressed an interest in participating, they were sent a participant information sheet (appendix I) and a consent form (appendix J), either via post or email. Potential participants were given at least 24 hours to consider the study and read the information before consent was requested. All 3 participants for phase one of this study were recruited through this snowball sampling technique. No other women came forward to express an interest in participating in the study. Consent forms were collected on the day of data collection, prior to interview.

4.3.4 Interviews

In total, I conducted 3 in-depth interviews with older women who suffered with urinary incontinence. As per my ethics approval, participants were offered the choice to be interviewed at the University of Leeds, their home, or their place of work. Once the women had confirmed their wish to participate in the study, arrangements were then made to interview them at their preferred time and location. Two of the interviews were conducted at the University in a private meeting room and 1 interview was conducted in the participant's home.

Interestingly, there did not appear to be a difference in the openness of dialogue with the participants based on the interview location; possibly because the location was chosen by the participants.

The same meeting room was used for the 2 interviews conducted at the university. Before the interviews, I went to the meeting room to check that the room booking was listed and to ensure that the room was set up appropriately. For the first interview, I met with the participant at another location within the university which she was familiar with. We then walked across to the meeting room together. The second interviewee, however, was already familiar with the building where the interview was to be conducted. I therefore arranged to meet this participant at the entrance to the building. On arrival, refreshments were offered to participants prior to the interview commencing. The last interview was conducted at the participant's home. I ensured that I arrived on time at the location and on arrival the participant suggested that we could sit in the kitchen/dining room area to conduct the interview. This was an ideal interview setting as the room was a comfortable size and had a table which we could sit at during the interview.

All 3 interviews were conducted within the same week, which meant that I was able to self-reflect before each subsequent interview. I did, however, ensure that only 1 interview was conducted per day. This allowed me to prepare appropriately for each interview whilst also ensuring that I was fully attentive during each interview (Perry, 2000). This was especially pertinent as I also had to travel from my home in Liverpool to Leeds prior to each interview, which can be time-consuming. I also discussed each interview with the lead supervisor prior to conducting the next interview. This allowed me the opportunity to discuss the interview process, explore how the conversation progressed and raise any concerns that I had going forward. Whilst these discussions did not result in any changes to my interview schedule or approach towards the following interview; it was a valuable reflective practice which allowed me to

examine each interview experience before continuing with the next. Each interview lasted approximately 45 mins-1 hour.

Prior to conducting the interviews, I developed a topic guide (appendix K), guided by the synthesis of existing literature on urinary incontinence. The research supervisory team also reviewed the topic guide before use. A broad open-ended question was asked initially in the interviews to encourage open dialogue: *Please can you describe, in as much detail as possible, how urinary incontinence has affected your life?* As Giorgi (2009, p. 122) states, 'What one seeks from a research interview in phenomenological research is as complete a description as possible of the experience that a participant has lived through'. Beginning each interview with a broad overarching question about the impact of urinary incontinence was used as a springboard for further discussion. The subsequent questions were then formed in response to this overarching question. Possible prompts were noted before the data was collected, such as: *Please can you describe a situation where you experienced urine leakage?* Interviews were respondent-led, which resonates with the exploratory approach of phenomenology (Smith et al., 2009); however, prompts were used as a way to encourage open dialogue without steering the direction of the conversation. When I sensed that a participant had something further to add to a particular topic, I used probes (Gillham, 2005), e.g. *could you tell me more about that?* in an attempt to comprehensively explore the matter.

During the interviews I noted any significant non-verbal cues, such as body language, as they are often an important part of the 'interactional interview' process (Fontana and Frey, 1994, p. 371). Additionally, immediately after each interview, I recorded hand-written field notes to reflect on the interview process; for example, thoughts on whether the interview was successful or whether

rapport was built with the participant. After one interview I wrote: 'It was difficult at times to remain on topic whilst also allowing the participant to talk freely, but I think rapport was built throughout the interview'. Field notes were a useful way for me to reflect on the interview process before continuing data collection, and it was anticipated that these notes would be useful for contextualisation during subsequent analysis (Smith et al., 2009).

All interviews were audio-recorded and transcribed. Verbatim transcripts are an essential component for IPA research, therefore immediately following each interview, I began to transcribe them verbatim. Transcribing the interviews allowed me to become fully immersed in the data, and listening back to the recordings enhanced my familiarisation with the data. Although there are professional transcription companies who specialise in transcribing research interviews, I felt that transcribing the interviews was an important stage of the research process which required my engagement as a researcher. There is also an argument that transcribing interviews is an initial stage in the analysis process (Bailey, 2008), therefore despite the time-consuming nature of the task, I decided that I would transcribe each interview myself. Beginning the transcription of interviews whilst simultaneously collecting data was a pragmatic decision that I made based on my research timeline. As I was collecting data for 2 different phases of this study and transcribing all interviews myself, I decided that to make best use of my time I would transcribe interviews immediately in-between data collection. As discussed in the chapter 2, unlike transcendental phenomenology which posits that researchers should 'bracket' their prior knowledge, IPA aligns closely with hermeneutic phenomenology which rejects the notion of bracketing. As IPA research does not consider it possible to

achieve complete objectivity, transcribing the interviews simultaneously to data collection, did not impact on the rigour of subsequent data collection.

4.4 Data Analysis

Data analysis followed the stages of analysis promoted by Smith et al. (2009). Analysis was conducted in full on each case before focussing on the next case, in keeping with the idiographic principles underpinning IPA (Smith et al., 2009).

Stage 1: Reading

Data familiarisation is the focus of stage one of analysis, therefore interview transcripts were read repeatedly at this stage. As advocated by Smith et al. (2009, p. 82), the transcripts were read whilst simultaneously listening to the audio-recording of each interview at least once, as being able to consider the voice of the participant aids a 'more complete analysis'.

Stage 2: Initial Noting

The next stage involved noting anything of interest in each of the transcripts. Smith et al. (2009) argue that there are no rules concerning what the researcher should note during this stage, but instead, this stage should be exploratory. Smith et al. (2009) do however state that it is often helpful to make descriptive, linguistic and conceptual notes. These three areas were the focus of initial noting for this analysis. Each transcript was manually noted, keeping these categories in mind. For clarity and organisation, different coloured highlighters were used for each of the areas: descriptive, linguistic and conceptual. Smith et al. (2009) argue that it is important that all notes should be recorded on the same copy of the transcript so that links between them can be more easily realised. This was the strategy adopted for the initial noting of transcripts for phase one of this study.

Stage 3: Emergent Themes

The next stage of analysis involved ‘...mapping the interrelationships, connections and patterns between exploratory notes’ (Smith et al., 2009, p. 91). At this stage of analysis, the initial notes from stage two were examined individually and then patterns between the notes were explored. Practically, to do this the exploratory notes were first recorded in a Microsoft Excel spreadsheet (appendix L). Any connections between the notes, either complimentary or conflicting, were then recorded. Colour coding was used to organise the potential themes initially. Following this, the notes were reorganised into their respective themes (appendix M). Themes were then organised chronologically, in the order that they occur within the data, as advocated by Smith et al. (2009). Smith et al. (2009) also discuss the importance of preserving the original context from the interviews, whilst also utilising original interpretations when developing themes. The theme titles developed during this stage of analysis were therefore related closely to the original text; whilst also encompassing a broader, more conceptual meaning to the researcher. For example, in one of the interviews the participant stated: ‘...you lose your friends that way too’. The title of the emergent theme related to this was therefore labelled as *losing friends*. This label remains close to the original text whilst also making sense in a broader context. Although there are qualitative data management software packages such as NVivo which could potentially speed up the analysis process (Spencer et al., 2014); it has been argued that such software can result in ‘...flat and oversimplified descriptive results’ (Becker, 1993, p. 258). It was therefore decided that the data would be managed manually to encourage creativity and full immersion into the data. Findings from the emergent themes were discussed with the supervisory team

before moving to the next stage of analysis. Not only did this allow me to confirm that the themes were clear and coherent, but it also acted as a form of validation to ensure that there was no unfair researcher bias in the development of these emergent themes.

Stage 4: Searching for Connections

At this stage of the analysis, the emergent themes were then mapped out to identify potential relationships between them. The list of themes developed in the previous stage in an Excel spreadsheet were grouped together to form related themes. This was done through a process of 'abstraction', whereby similar themes were grouped and given a new name to create a 'super-ordinate' theme (Smith et al., 2009, p. 96). Once the connections had been made between the themes from all cases, they were discussed again with my supervisors to ensure that a coherent narrative was presented. An example of this process can be seen in appendix N.

Stage 5: The Next Case

At this point in the analysis, the previous four stages were repeated for the next transcript. Each transcript was treated as an individual case; therefore, I endeavoured to disregard the notes and themes from the previous case to prevent unfairly impacting on the development of the subsequent themes (Smith et al., 2009). Whilst it would be unrealistic to assume that previous knowledge from earlier transcripts could be entirely overlooked, it was important to allow the themes of each case to be developed naturally. To manage this, I endeavoured to remain as close as possible to the original transcript when developing emergent themes and connections. The analysis for each case,

from initial notes to searching for connections, was also reviewed by my supervisors to enhance validity.

Stage 6: Identifying Patterns

This stage of analysis was conducted after all transcripts had progressed through the first four stages of analysis listed above. The aim of this stage was to identify and interpret patterns across the transcripts for each case. The themes from each case were laid out next to one another in an Excel spreadsheet and potential correlations between the themes from each case were explored. Although the aim at this stage was to analyse the data at a wider collective level, all patterns identified were supported by individual examples. As Smith et al. (2009) argue:

'...even where the analysis is primarily at the group level, what makes the analysis IPA is the fact that the group level themes are still illustrated with particular examples taken from individuals' (Smith et al., 2009, p. 106).

4.5 Conclusion

This chapter presented the research methods used for phase one of this study. The research aims and objectives were clearly identified and a rationale for the chosen methods was provided. The chapter concludes by outlining the data analysis approach adopted for this phase one the study.

4.6 Summary

- **Phase one** aimed to explore older women's lived experience of UI.
- **In-depth interviews** with older women with UI were conducted.
 - This was the most frequent data collection method identified from reviewing qualitative literature on female UI (chapter 3).
 - One-to-one interviews offered a confidential setting.
- The **sample** was based in Leeds (the area served by the funders).
- Participants were recruited through a snowball technique (n=3).
- **Purposive sampling** was used to recruit relevant participants.
- **Inclusion criteria**: female, 55+, currently have UI, living in Leeds, not receiving medical help from a GP or specialist concerning UI.
- **Exclusion criteria**: non-English speakers, currently seeking medical help for UI.
- **Data analysis** followed the stages of analysis promoted by Smith et al. (2009): reading, initial noting, emergent themes, searching for connections, the next case, identifying patterns.

Chapter 5: Phase 1 Findings

5.1 Introduction

Chapter 5 will present the findings from phase 1 of this study which sought to explore older women's lived experience of urinary incontinence. This chapter will examine the factors recognised by the participants as important to understanding the phenomenon of urinary incontinence. There are a total of 8 superordinate themes: living with UI, coping strategies, attitudes towards healthcare professionals, perceived seriousness of UI, knowledge of UI, personal responsibility, childhood experiences and sharing experiences of UI. Each theme will be explored systematically and will be substantiated with extracts from the interviews. The themes identified from the analysis of phase 1 data are summarised in diagram 2.

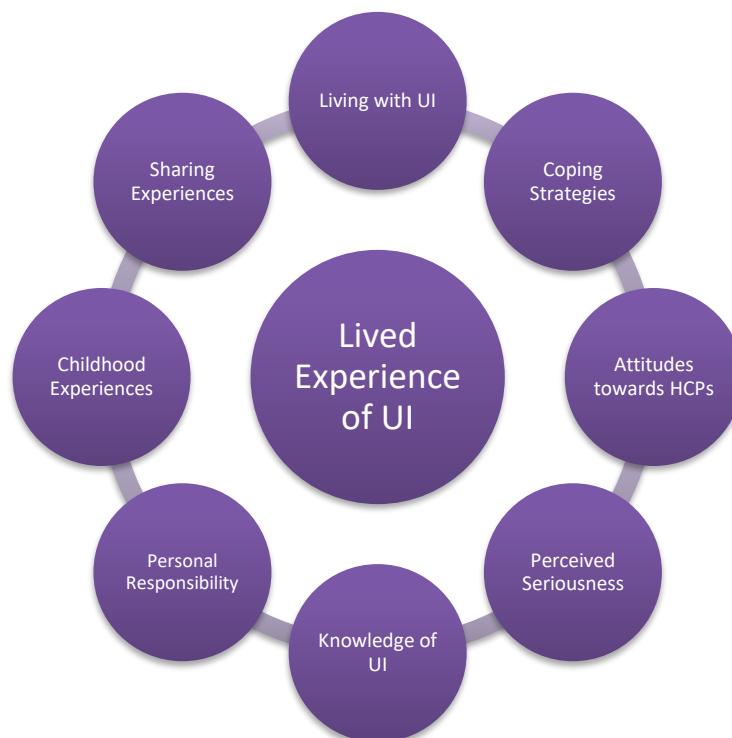


Diagram 2: Phase 1 Themes

Table 8: Participants

	SARAH	JANE	LISA
Location	Leeds	Leeds	Leeds
Age	55+	55+	55+
Family	None	<ul style="list-style-type: none"> ▪ Children ▪ Widow 	<ul style="list-style-type: none"> ▪ Children ▪ Widow
Consulted doctor for UI	Yes	No	Yes
Doctor (type)	GP	None	<ul style="list-style-type: none"> ▪ GP ▪ Specialist
Previous treatments	Oxybutynin prescription	No	2 previous surgeries: <ul style="list-style-type: none"> ▪ Tape ▪ Pessary

5.2 Living With UI

The aim of phase 1 of this study was to explore the lived experience of older women with urinary incontinence. Participants were asked at the beginning of each interview to describe in as much detail as possible, the impact that urinary incontinence has on their life. Living with UI was therefore a prominent theme throughout the interviews. During the discussions with the participants, they each described living with UI in relation their *feelings* about living with UI and the *impact* that the condition has on their lives. The superordinate theme of living with UI was therefore organised into two themes: *feelings about UI* and *impact of UI*.

5.2.1 Feelings about UI

Embarrassment

All of the participants discussed embarrassment in relation to UI, however their views around this concept differed. Sarah identified the role that embarrassment plays in her experience of UI, when discussing occasions where she had leaked urine. Sarah describes these incidents as ‘very embarrassing’. However, interestingly, Sarah later discussed an incident from her childhood where she was embarrassed due to leaking urine, suggesting that embarrassment around UI has long been a pertinent issue for her.

“You always get... you know it’s embarrassing right from a child, right onwards somehow” (Sarah: 15)

Similarly, Lisa felt that embarrassment was associated with the experience of urinary incontinence. However, Lisa attributes her feelings of embarrassment specifically to the experience of loss of control.

“... I’m not embarrassed until I’m in a situation in which I can’t control”

(Lisa: 3)

Lisa also discussed her concerns about embarrassing her children. In the following extract, Lisa discusses an upcoming holiday with her children and the precautions she was planning to put in place to avoid embarrassment.

“In fact I’m going away with two of the children to Spain in 10 days’ time and I’m thinking oh I must buy some plastic pants so if I do have an accident that I won’t be embarrassing to them and myself” (Lisa: 3)

It would appear that although loss of control was discussed as the root of embarrassment for Lisa, the visibility of such incidents seems to contribute to potential feelings of embarrassment. This is reinforced later in the conversation, where Lisa discussed how she needed to consider how she would manage the ‘padding situation’ whilst wearing less clothing on holiday.

In contrast to the views expressed by the other participants, Jane did not consider embarrassment to be a feature of her experience with urinary incontinence. However, unlike the other participants, Jane has only recently started to experience the symptoms of UI. Jane reported that UI currently has little impact on her life, which could potentially impact her feelings around embarrassment.

“I’m not embarrassed by that sort of thing. I know it happens to a lot of women... So no it wouldn’t embarrass me [to talk to friends]” (Jane: 3)

Annoyance

Annoyance was also expressed as a significant sentiment related to living with urinary incontinence. When Jane was asked how she felt when she began to

experience the symptoms of urinary incontinence, she discussed the annoyance she felt.

“P: Erm... well it was just annoying.

I: Just annoying?

P: Just annoying you know. Like oh gosh, another pair of clean knickers.”

(Jane: 8)

Similarly, Lisa discusses annoyance in reference to the experience of incidents where she has leaked outside of the home.

“...its annoying to be sort of wet but as far as I’m aware it usually

happens when I’m walking home rather than while I’m out.” (Lisa: 7)

UI was described as annoying by these participants, indicating that the persistent feeling of bother caused by UI plays a significant role in their experiences.

Gradual Worsening

The gradual worsening of symptoms was an issue that was described during the interviews. Rather than recalling a specific time where the symptoms of UI were first experienced, the participants often expressed that the symptoms had ‘crept up’ on them over time.

“Yeah it’s sort of crept up on me I suppose over the last couple of years really” (Jane: 1)

Sarah discusses how her symptoms gradually worsened over time, which eventually led her to the point where she identified her symptoms as a real problem.

“And so, it sort of creeps up on you gradually really and only when you reach a certain stage, like me waking up in the night and having to you know go that, there and then, that really brought it home to me you know, this is a real problem” (Sarah: 15)

The suggestion that the symptoms of UI ‘crept up’ on these participants, potentially delaying the realisation that UI is a real problem, could be indicative of the normalisation of early stage symptoms for urinary incontinence. The concept of normalisation of UI will be explored in more detail, later in this chapter.

Hopelessness

The notion of hopelessness was also discussed in the interviews, in relation to the prospects of alleviating the symptoms and impact of urinary incontinence. Sarah uses the word ‘hopeless’ in reference to her decision to stop going on holidays as she once had, because of the difficulty of managing her UI.

“P: ... But certainly the type of holiday I used to go on, we went all over the world and you’re sometimes on the road for hours at a time and so where do you go, so...?”

I: Yeah.

P: So it’s hopeless” (Sarah: 1)

After having two previous surgeries to treat UI, Lisa describes her current outlook on her continuing management of UI.

“I’ve learnt to live with it I think really. It’s going to be there and I think everything I’ve done is helping it to not be any worse but I think I will have it for the rest of my life” (Lisa: 2)

Rather than hoping that her condition improves, Lisa expresses her belief that she will live with UI for the rest of her life; her only hope therefore, is that her condition does not worsen.

With regards to UI treatment options, Sarah states that she has not been informed of anything 'encouraging'. Later in the discussion, when questioned about how the lack of hopeful treatments made her feel, Sarah said:

"Well you know, you learn to live with it that's all" (Sarah: 7)

Whilst the notion of learning to live with UI can be positive in terms of encouraging effective self-management to improve quality of life, it can also be understood as a lack of hope for improvement. It would appear that for some, maintaining current levels of incontinence and 'learning to live with it' is felt to be the best-case outcome.

Accidents

Feelings about experiencing accidents were also expressed by the participants. When discussing 'accidents' this was in reference to the accidental leakage of urine, usually outside of the home. The exception to this was Jane, who is in the early stages of UI and had no experience of accidents outside of the home.

Sarah describes the prospect of not making it to the toilet in time as 'disastrous' and this sense of despair can be seen in the excerpt below:

"P: Well just you know, in my experience when I have had the odd accident and really I mean it's pints, really large quantities of fluid come out and either you're sitting in this fluid wearing your pants or whatever, or you know it's all going to leak through. Oh dear, oh dear.

I: Yeah

P: It doesn't bare thinking of" (Sarah: 5)

Lisa highlighted that she would feel embarrassed if she had an accident, however this was considered in relation to whether the urine was outwardly visible. This indicates that the visibility of UI has an impact on the feelings experienced by those living with the condition.

"I: Right. And if you did have an accident while you were out and you were not on your way home how would you feel?"

P: Yes. Erm... well if I wet myself badly I'd feel very embarrassed. Yes, if it showed" (Lisa: 7)

When asked further about this, Lisa highlights the fear that she has about having accidents in public. Although Lisa has never been in such a situation, she still suffers with fear related to the possibility of this outcome.

"I: So you've never been in that situation?"

P: No I haven't, no. Whether I, I'm so afraid that it will happen so I support myself doing pelvic floor support, whereas when I get near home I think oh gosh and it just, I just lose that determination to keep the muscles supported. I don't know, but it hasn't happened [laughs]. I'm afraid it's going to happen when I'm on holiday but we shall see [laughs]"
(Lisa: 7)

5.2.2 Impact of UI

Daily Life

All of the participants discussed the impact that UI has on their lives, however, it is important to note that the severity and stage of UI differs amongst these

women. Jane reported experiencing early symptoms of UI and described that her daily life is not affected by the condition.

“I don’t honestly think about it during the day” (Jane: 8)

Sarah, on the other hand, explained that UI has a significant impact on her life, especially in relation to the activities she can do outside of her home.

“...it does effect what I can do really... out of the house anyway” (Sarah: 6)

Similarly, Lisa considered the impact of UI as partially limiting her daily life.

When asked if UI prevents her from being able to do anything, Lisa said:

“No I... don’t do anything like as much as I used to and I suppose this is partly why” (Lisa: 10)

The impact of UI varied amongst the participants. Whilst Sarah and Lisa described UI as partly limiting their daily life, predominantly outside of the home; Jane described UI as having little impact on her life at this stage. In addition to the effect that the severity of UI has on everyday life, the impact of UI is also relative to the individual daily routines and activities undertaken by the participants.

Travel Restrictions

The impact that UI has on travel was discussed by all of the participants, in relation to travel constraints, prior preparation and apprehensions about travelling. For Sarah, going on holiday was the first issue raised when asked how UI had impacted her life, which could be indicative of the importance Sarah places on this issue. Sarah discussed that she had ‘given up’ on the idea of

going on holiday like she used to (Sarah: 1), as it was too difficult to find toilets whilst on the road.

“Well yes erm... one thing actually is going away on holiday because the sort of holidays I like to go on I would be travelling around and you know, and then finding the toilets anywhere” (Sarah: 1)

Lisa stated that travelling is something that she worries about because of her UI. Lisa discussed an upcoming holiday abroad, which would be her first time travelling since her UI symptoms had worsened, meaning that prior planning was important to consider.

“... I’ll be wearing less trousers so I shall have to think about the padding situation. That’s why I’m planning to get some of those plastic pants which I hope I can get from the local ASDA to take with me then I’ll be prepared” (Lisa: 3)

Jane also discussed the practical aspects of travelling that must be considered when living with UI.

“... But I am going away in March with a friend on a coach trip so I’ll probably make her aware of it just in case I have to bang on the door in the hotel room to say can I come in its urgent, if she’s only getting washed or whatever” (Jane: 3)

Although Jane did not feel like her UI had an impact on her travel plans, the practical aspect of sharing a room with her friend on holiday was something that she was having to navigate for the first time.

Social Restrictions

Social restrictions were also discussed in the interviews, however the impact of UI on this area of life appeared to be less prominent than the impact on travel.

Sarah discussed how UI had been a contributing factor in her decision to stop attending a walking club which she had been a member of for some time.

“... but again, you lose your friends that way too. Because although we keep in touch, but we used to meet every fortnight or so and now I don’t see them more than once or twice a year or something like that” (Sarah: 2)

Sarah described her disappointment at missing out on the social activities that she had once enjoyed. Although UI was only a contributing factor to the social restrictions felt by Sarah, the discontent of the resulting social isolation was significant in this instance.

Conversely, Jane did not experience any social restrictions as a result of her UI. When asked if UI affected her social life, Jane stated:

“No because in the evenings, after this morning spell it seems to be ok then” (Jane: 2)

Again, the type and severity of UI appear to influence whether the condition had an impact on Jane’s life. Although there is an element of secrecy surrounding UI, which will be discussed later in this chapter, the social restrictions discussed by Sarah in the interview appeared to be due to practical rather than emotional reasons i.e. not having access to toilets.

5.3 Coping Strategies

Coping strategies related to managing UI were discussed by each of the participants. These coping strategies are the tactics employed by the participants to self-manage the symptoms and impact of UI. This is summarised

by one of the participants who suggests that developing coping strategies is essential to manage UI as there is a lack of help available elsewhere: “... *but I don't think there's anything much available at the moment so you have to work out your own coping strategies and hope for the best*” (Sarah: 6). The coping strategies identified from the interviews were: planning, continence products, fluid restriction, adjusting prescriptions and humour. Each of these strategies as they relate to the participants' experiences will be explored.

Planning

Forward planning was a coping strategy discussed during the interviews with the participants. Preparation for potential accidents was an important aspect of this planning.

“I suppose it has really, in as much as I... I've got to be prepared.

Whatever I'm doing, wherever I'm going, I've got to be prepared” (Lisa: 4)

One specific aspect of planning centred around being able to find toilets in public. All of the participants discussed their experiences of having to consider their access to toilets whilst out for the day. As Sarah states:

“Yes well you know, again you plan your journey really, almost around the toilets” (Sarah: 1)

Although planning was discussed as a coping strategy by two of the participants; this was not a strategy that was adopted by Jane, who was experiencing early UI symptoms, primarily in the morning. Instead, Jane considered her only coping strategy to be acting on signals immediately:

“No I think at the moment my strategy is working now. I've got one, now that I've realised that this is going to continue and I just now, I tell myself when I've got to go, I've got to go. I've not got to wait, I've not got to send

another email, I've not got to, you know, finish washing up or anything.

I've got to drop everything and go to the loo.” (Jane: 7)

Continence Products

Continence products were discussed by all of the participants. Both positive and negative views were expressed and each participant had their own individual preferences and perceptions related to continence products. Sarah, who confirmed that she uses continence pads, discussed the pads in a positive light.

“... I discovered these as I say in Aldi and they're really quite adequate and they do the job on the whole” (Sarah: 2)

The cost and availability of the products were described as a benefit for Sarah.

“Aldi are marvellous at that actually. They've started selling them and they're ever so cheap which is great [laughs]” (Sarah: 2)

On the other hand, Jane viewed the use of continence pads negatively. Despite never having used these products, Jane had a perception that the smell of urine would be an issue if she were to use continence pads.

“I: And you said that you don't really like the idea of the continence pads, why is that?

P: Well I'm just thinking that the urine smell is still there. I know they're supposed to have chemicals to kill the smell and everything but I don't think I fancy them, but I realise I might have to eventually. But I could be proved wrong, they could be wonderful I don't know [laughs]” (Jane:10)

It is possible that the potential embarrassment associated with UI could be contributing to Jane's negative views of continence pads, as the smell that she anticipates could be a noticeable signifier for the condition.

Lisa expressed that using a continence pad/‘nappy’ product was helpful for managing her UI. When asked what strategies she employs to manage UI, Lisa stated:

“Yeah I wear a pad of course. And I also, when... wear.... A sort of nappy really, a towelling pad erm... which I find more helpful because I can change that as soon as it happens” (Lisa: 4)

Despite discussing the use of pads positively, Sarah did voice her negative perceptions of continence pants.

“P: Unless of course you got into wearing you know, incontinence pads or erm what do you call them, pants you know sort of thing. That’s probably the next stage on but it’s not where I wish to be.

I: Hmm. And why is that?

P: Well I just, you know, in my experience when I have had them the odd accident and really I mean its pints, really large quantities of fluid come out and either you’re sitting in this fluid wearing your pants or whatever, or you know it’s all going to leak through. Oh dear oh dear.” (Sarah: 5)

Here, the supposed discomfort or possibility of leakage, were problematic for Sarah. Furthermore, the potential for visible leakage was a prospect that Sarah was anxious to avoid.

Fluid Restriction

Fluid restriction was another strategy actively employed by two of the participants, to manage their UI during the day. Lisa, for example, stated that if her day varied from her normal routine, then she would restrict her fluid intake as a way to manage UI symptoms.

“But if I go out of my routine then I have to remember that I mustn’t drink too much and erm I must prepare myself with a thicker pad perhaps”

(Lisa: 2)

However, for Sarah, fluid restriction appeared to be a coping strategy that is exercised daily.

“So erm, again I’ve slightly cut down on how much fluid I drink every day because I tend to like sort of things like porridge and soup and you know, and not to mention coffee of course [laughs] so I’ve tried to get that down a bit and that’s helped I think to an extent” (Sarah: 2)

Despite the fact that Sarah believes this to be an effective strategy, she is also aware of the need to avoid dehydration whilst trying to manage UI, which is an issue that could be potentially difficult to manage.

“But even then, I mean you...you shouldn’t sort of dehydrate yourself because you do need 2 and a half pints a day or something like that”

(Sarah: 2)

Adjusting Prescriptions

One of the women interviewed, revealed that she receives a recurring prescription for Oxybutynin to treat her UI. This was the only option presented to the participant by her doctor and she soon discovered that taking the medication as prescribed was not a suitable solution for her. When taking the medicine as prescribed the participant found that she became very dehydrated. Instead, the participant decided to self-adjust the prescription and only take the tablets when she felt that she most needed them.

“I: So you just have a recurring prescription?”

P: Hmm that's right yes. But again perhaps I'm naughty and don't take it as it says on the tin. But erm taking 6 a day, oh dear, just 2 like I had now and I'm desperately thirsty so I don't know what 6 would do for me [laughs]" (Sarah: 12)

Adjusting her prescription like this is a coping strategy for Sarah, as she chooses to assess her symptoms and daily schedule and decide how and when to take the medication based on this.

Humour

Humour also appeared to be a coping strategy used by some of the participants to underplay the gravity of the situation they are facing. When discussing whether she has shared her experiences with any of her friends, Sarah stated:

"Well I mean we have mentioned it, I've certainly mentioned it from time to time. As a jokey thing you know" (Sarah: 13)

The fact that Sarah felt that she should mention UI as a 'jokey thing' demonstrates that humour can sometimes be used as a way of dealing with the potential embarrassment that is often associated with UI.

Additionally, when discussing the impact that incontinence had on her life when she was younger and her symptoms were less severe, Lisa said:

"Well not really... I was younger and I'd just cross my legs and laugh about it really" (Lisa: 7)

Although the symptoms were comparatively mild when Lisa was experiencing stress incontinence at a younger age, the symptoms of UI should still be taken seriously; however Lisa appeared to use humour to mask the issue.

5.4 Attitudes Towards Help-Seeking

Attitudes towards help-seeking was another prominent theme throughout the interviews. During the conversations with the participants they expressed their feelings towards HCPs and their views on medicine and medical management, specifically in relation to their UI and also more generally. Feelings towards healthcare professionals related to: *trust in HCPs, negative experiences* and *gender of HCPs*. Views on medical management of UI related to: *ineffective treatments* and *distrust of medicine*.

5.4.1 Feelings Towards Healthcare Professionals

Trust in HCPs

Oposing views were expressed related to feelings about healthcare professionals. Whilst the predominant feeling about HCPs was positive for the participants, one of the women expressed negative views about HCPs based on prior experiences.

The following excerpt demonstrates how Sarah had a positive experience with her GP and trusted her advice:

"I: So in general how would you say... how do you feel like the GP kind of dealt with the issue when you raised it?"

P: Well I think she did her best really. I think, well she's pretty... well I admire her I think she's pretty clued up about everything and erm if there was anything else available she would offer it I'm sure" (Sarah: 5)

Lisa also described her experience with her doctor as positive, saying:

"... and erm I went to the doctor and saw, she was very helpful" (Lisa: 2)

Jane on the other hand, expressed a general lack of trust in doctors:

"I don't trust them at all. I just think... I'll go if it gets that bad, if something gets bad enough I'll go" (Jane: 6)

This lack of trust seemed to originate from negative past experiences with doctors, for issues unrelated to UI. However, these negative experiences impacted Jane's current feelings of distrust towards HCPs. This is evident when Jane states:

"... I take everything they say to me with a pinch of salt" (Jane: 6)

Negative Experiences

Negative experiences with HCPs were discussed by two of the participants. Lisa discussed her experience with a specialist doctor she was referred to for her UI symptoms.

"P: I honestly don't think the doctor was very helpful. My own doctor was much more helpful, it was a young doctor who was very helpful yes.

I: Right. And why do you think that they weren't very helpful?

P: Erm... well he was a guy, man, who sees people with much more serious problems that mine and erm... possibly had I not had information from LOUISA I would've not found what he said, apart from advising me not to drink stimulant things, no more helpful that what I already knew, you know" (Lisa: 2)

Lisa described feeling that her doctor did not appreciate the significance of her condition because he was used to seeing more serious cases. Although Lisa found this consultation to be unhelpful, her general feelings towards HCPs were not negative.

In contrast, Jane described how her previous experiences with doctors had negatively impacted her overall feelings towards HCPs. Jane depicted an incident where she was incorrectly prescribed a medicine that had an unnecessary negative impact on her health. When discussing this, Jane stated:

“And erm it was in a way it was as if this specialist was punishing me because I refused to go on Warfarin” (Jane: 6)

Jane felt that she had been personally mistreated by a previous HCP and this negative experience appeared to shape her outlook on HCPs more generally.

Jane said:

“I’ve no faith in doctors anyway I’m afraid. I’m not a doctor person” (Jane: 5)

Gender of HCPs

Despite the potential embarrassment that is often associated with UI, only one of the participants discussed the gender of HCPs in relation to this.

“It was a male doctor which didn’t matter for me, but I’ve spoken to a person who saw him and was very embarrassed about it being a... but I had no, no problems” (Lisa: 2)

Here, Lisa discusses how the gender of a doctor had caused further embarrassment to a woman that she knew who was seeking help for UI, however Lisa states that this was not the case for her. Yet later in the discussion, Lisa discussed her previous experience of having a ring pessary fitted, including how she had specifically requested a female doctor:

“Well I went because I wanted to have a pessary, a ring pessary, so I asked to see a lady doctor” (Lisa: 5)

Lisa's preference for a female doctor in this situation might suggest that there is an element of embarrassment associated with the gender of a HCP when seeking help for an intimate condition such as UI.

5.4.2 Views on Medical Management of UI

Ineffective Treatments

Both of the women who had experienced symptoms of UI for a prolonged period of time discussed the ineffective treatments they had received. Sarah was prescribed Oxybutynin by her GP, however she found that this was not sufficient to manage the symptoms of her UI.

"... you're supposed to take 6 tablets a day but I'm afraid I find that it gives me a very dry mouth and erm so I take it when I'm not sure where the next loo is coming from but even then I take 2 tablets at once and then even that lasts only 3 or 4 hours so overnight it's not much use really" (Sarah: 3)

Lisa also discussed her previous treatments, particularly the tape procedure that she underwent for UI. Lisa deliberated the possible consequences that this procedure has had on her subsequent experiences with UI.

"So whether had I not had the operations, I would have – well the consultants thought that the tape was possibly partly to blame for the incontinence now" (Lisa: 7)

Despite the ineffective treatments that Sarah has received so far, she discussed her hope that she will one day receive a successful treatment for her UI.

"P: Well I hoped, well I always hope I shall get some sort of treatment-effective treatment"

I: Yeah

P: But there doesn't seem to be anything much really that's all that effective that's available" (Sarah: 4)

Distrust of Medicine

One of the participants illustrated a distrust of medicine throughout the interview. Jane, who had negative past experiences with HCPs, also expressed that she had no confidence in the use of prescribed medicines.

"Doctors and drugs I'm not into. I think you take a drug it gives you something else. It might cure what you've got or help with what you've got, but it will definitely give you something else" (Jane: 5)

Jane discussed her concern that taking medicines could lead to further illness, which impacted her approach to potentially taking medication for UI. Jane argued that "It'd have to be bad" for her to consider taking a prescription for the symptoms. Jane reasons that:

"Your body's meant to be natural" (Jane: 5)

This underlying belief, in addition to negative past experiences with incorrectly prescribed medicines, appears to underpin Jane's approach to seeking treatment for UI.

5.5 Perceived Seriousness of UI

During the interviews there appeared to be a perceived lack of seriousness of UI amongst the participants. Discussions about declining health in old age and perceptions of ageing highlighted the normalisation of UI for the participants.

Additionally, the comparison between UI and other health conditions seemed to illustrate the perceived lack of seriousness associated with UI.

Perceptions of Ageing

Declining health in old age was a topic considered by the participants in the interviews. When discussing the potential embarrassment related to UI, one participant said:

“I mean, I’m not because I think it’s just a natural thing and you know as you get older you wear glasses, your ears go, you know you can’t, you just get older and everything wears out” (Jane: 11)

By referring to UI as “natural” and comparing the condition to relatively routine health issues e.g. wearing glasses, Jane highlights the normalisation and inevitability that she believes is associated with experiencing UI in old age.

Jane also stated that she had not researched or looked into the symptoms of UI. When asked why, she replied:

“... I just thought it was normal ageing really. I didn’t think it were important enough really” (Jane: 4)

Sarah also seemed to make light of the general decline in health that can be experienced in older age, stating:

“And as I say, by the time you get old you’ve got so many things wrong with you anyway [laughs]” (Sarah: 7)

Despite the fact that UI can have a negative impact on the lives of women living with the condition, the normalisation of UI in old age can minimise the perceived seriousness of the symptoms.

Comparison of Health Conditions

Two of the participants compared the severity of their UI with other health conditions that they had previously experienced or were currently living with. The two participants both referred to conditions related to their bowels and discussed how the symptoms were comparatively worse than those for UI.

“P: And I actually, also too, which is not the same thing- but I also now suffer from irritable bowel disease and erm again I’ve got tablets and they are very good actually. I appreciate those. Because that again – oh gosh [laughs]

I: [Laughs]

P: Possibly... possibly even worse than erm incontinence” (Sarah: 7)

Similarly, another participant discussed bowel issues that she had experienced in comparison to the issues faced with UI.

“So that was worse when my bowels were bad... because a little dribble of urine isn’t that bad if you do have an accident but opening your bowels in public is not a good thing really” (Jane: 3)

Although the participants did not state why they felt that the symptoms for bowel conditions were worse than the symptoms for UI, the fact that one of the participants discussed the public aspect of having an accident related to bowel incontinence, could suggest that embarrassment plays a role.

5.6 Knowledge of UI

Knowledge about UI was identified as an important theme from the interviews, specifically related to the participants' misinformation about UI and the sources of their knowledge.

Misinformation about UI

It was identified from the interviews that there is a certain lack of understanding about UI, with the exception of one participant who was a retired HCP. One participant said:

“Whatever causes it, it’s a sort of erm, I’m just speculating, it’s sort of a nerve awareness or something, you lose nerves in your bladder or something that would normally say to you, look come on do something”
(Sarah: 15)

Sarah reported having seen her doctor more than once about her UI symptoms, yet she did not seem to be aware of the causes of her condition.

Likewise, another participant discussed how she was not initially aware that the symptoms she was experiencing were UI related.

“Yeah I think, yeah when I did it once or twice I thought oh, oh well it must be some odd, maybe I’ve got a bladder infection or maybe it’s something sort of not quite right, but then it’s continued so I thought oh you know, you’ve got to keep going to the toilet. So yeah.” (Jane: 5)

These examples demonstrate the need for a greater awareness of the symptoms, causes and treatments for UI.

Sources of Knowledge

The sources of knowledge about UI varied amongst the participants. One of the participants had sourced information from her doctor and also through engaging with a charity called Leeds Older People Forum. Whereas, another participant discussed using various media sources, e.g. magazines and internet resources:

“Also I looked at something called saga magazine, something that was recommended on the internet, and that is very good actually. A short little talk, if I’m finding things I go back to that which helps” (Lisa: 2)

The third participant was in the early stages of UI and had therefore decided that she did not yet need to research the condition.

“But that’s all really. I never really looked into it or anything. Still haven’t looked into it or anything” (Jane: 4)

However when discussing this, Jane stated that instead of seeing a doctor she would “rather look on the internet” (Jane: 5). Personal preference is central to how and where knowledge about UI is sourced, however reliable and consistent information is essential to avoid misinformation which can lead to a lack of understanding as illustrated in the previous section.

5.7 Personal Responsibility

Feelings of personal responsibility for managing the symptoms of UI were expressed during the interviews.

“I still feel that I should be managing it. So I still think it’s down to me to say, go to the toilet you want to go, go now, don’t be doing anything else” (Jane: 8)

Here, Jane illustrates that she holds herself accountable for managing her symptoms, with no help from a doctor.

“... I’ve got to learn now that as soon as I want to go I’ve got to go”

(Jane: 1)

Personal responsibility was also linked to self-blame, especially relating to the occurrence of accidents, where some participants explained that they felt responsible for allowing the accident to happen.

“It’s just, I just feel it’s my fault at the moment if I have an accident because I could have avoided it by going when I said I wanted to go”

(Jane: 9)

Sarah also expressed self-blame related to accidents that she had when she was younger. Although she stated that she did not have UI when she was younger, Sarah did describe occasions where she had accidents. Self-blame was illustrated when Sarah refers to her actions as “stupid”.

“I: And did you have incontinence when you were younger or-

P: No, no not really no

I: Right

P: As I say you know unless I’m being stupid and going for hours and you know, really that’s ridiculous” (Sarah: 11)

Whilst self-management can play an important role in the management of UI, it is important that this does not translate to patients feeling burdened with the sole responsibility of managing the symptoms as this can lead to self-blame in the aftermath of urinary accidents.

5.8 Childhood Experiences

Childhood experiences related to UI were discussed by one of the participants.

Sarah discussed an incident when she was younger, where she had experienced UI while at a friend's house. Sarah was still able to recall this memory as it had such a lasting effect on her.

"P: Yes indeed. And I mean as a child you know it was a problem then sometimes and again I've been and had an accident then and I can remember it even still [laughs]

I: Really? And why do you think that is?

P: Well you know, because it's pretty... well a very bad experience to have really and so on the whole it's embarrassing anyway..." (Sarah: 6)

Sarah discussed this incident again later in the interview and explained how her mother had reacted following the accident.

"... oh gosh, and when I got home my mother was absolutely furious [laughs] oh dear, oh dear [laughs]" (Sarah: 11)

Sarah later elaborates on the impact that this incident had on her perceptions of UI in later life. Sarah considers how this incident confirmed to her that she should not do this again, as the embarrassment that Sarah experienced as a result of this incident was sustained throughout her life. The reaction from her mother also lead Sarah to question whether the embarrassment associated with UI is something that children learn from parents.

"P: As I say as a child it happened [laughs] and it certainly made an impression on me certainly. Do not do this again. So yes.

I: And why do you think that was? That it had such an impression?

P: Well as I say you know... well it was embarrassing for one thing. You always get... you know it's embarrassing right from a child, right onwards somehow. I don't know why but you sort of know that. And then it's something you don't discuss in public. Whether you're brought... whether your parents teach you to do that I don't know. I can't remember but um, but certainly as I say my mother was furious when I went home dripping, oh dear oh dear, it didn't go down well [laughs]" (Sarah: 15)

5.9 Sharing Experiences of UI

Sharing experiences of UI was a theme discussed during the interviews in relation to *confiding in friends* and *charity involvement*. Both of these sub-themes relate to the issues around communicating the experiences of UI.

5.9.1 Confiding in Friends

Talking to Friends

Whilst all of the participants said that they had discussed UI to some extent with their friends, their motives seemed to be based on practical reasons, rather than for emotional support. The extent of the dialogue about UI seemed to be cursory, with the participants highlighting that their discussions were not detailed. When asked if she had discussed UI with her friends, Lisa stated:

"Erm... only as much as erm... because I always when I've finished an exercise class or whatever I go to the loo. And I'm the only one in the class who does that, so they obviously notice that you know, there she goes again you know. Erm... so, but I haven't actually discussed it in detail [laughs]" (Lisa: 4)

Similarly, Sarah discussed that she had only mentioned her UI in passing with her friends:

“Only really in passing and erm as I say you know, most old people have got some kind of a problem so... so you don’t go into the details actually”

(Sarah: 5)

Jane had only discussed her UI with one of her friends because she did not consider it necessary to discuss the issue further with others. However, Jane was experiencing early symptoms of UI at the time of the interview which could explain this rationale.

“I’m not worried enough to want to discuss it with anybody really...”

(Jane: 3)

Social Conventions

When discussing whether the participants had talked to their friends about their UI, social conventions surrounding UI were also referenced.

“Yes well, I suppose because fundamentally it is a thing you don’t talk about normally...” (Sarah: 14)

As stated previously, there was a lack of detailed discussion about UI amongst the participants and their friends. When asked why she has not discussed UI in detail with her friends, Lisa states that whilst she is comfortable talking about UI, she believes that her friends are embarrassed. Lisa also believes that her friends do not feel that UI is a topic that should be discussed and this influences her willingness to discuss her situation.

“I: Ok. And why is that?”

P: Erm... because they’re a bit embarrassed really

I: They are?

P: Hmm, I think yes. I suppose, I don't mind talking about it but I think they feel that it's not a subject that one should talk about" (Lisa: 4)

Sarah recognises the need for UI to be more openly discussed, demonstrating the potential impact of social conventions surrounding UI which can often result in the issue being overlooked.

"Well again I suppose it should be more talked about really... but it's sort of swept under the carpet a bit really" (Sarah: 13)

5.9.2 Research Involvement

Sharing Experiences

Two of the participants had worked with charities on projects related to UI. During the conversation they expressed that their involvement with such projects was because of their desire to share their experiences and help other's living with UI.

"Erm... because it's not very nice to be incontinent and the fact that my knowledge perhaps I could contribute in some way" (Lisa: 5)

It also appeared that research involvement was used as an additional mode of support, whereby participants had the opportunity to increase their knowledge about UI and the potential self-management options available.

"Well I wanted to share the experience really because you know I mean obviously your department is interested in it which is great and I mean just exchanging ideas. I think if anybody can come up with good ideas I'd like to know [laughs]" (Sarah: 7)

Research Outcomes

The impact of not talking about UI was also discussed in a wider context by Sarah, who felt that the secrecy around UI could potentially impact research and funding opportunities.

“Well again, because I think really, it’s sort of erm, chicken and egg really you know because, because it’s sort of something you don’t normally talk about, and then it’s not known and not erm taken into account by the powers that be you know who fund these sort of projects...” (Sarah: 14)

Sarah elaborated on this notion by comparing the progress made in cancer research, with that of UI.

“... like cancer you know everyone knows about cancer and erm millions and trillions of pound have been thrown at it and as a result we’ve got some much better treatments than we used to have, not necessarily cured but we have got treatment for it. So again maybe we should make more of a fuss about incontinence, because really it is a real problem certainly” (Sarah: 10)

Sarah’s thoughts about the research limitations around UI, highlight the wider negative impact that could possibly be caused by the secrecy and lack of communication surrounding the impact and experiences of living with UI.

5.10 Phase 1 Findings Summary

The key findings from phase one of this study relate to the concepts of embarrassment and normalisation of UI in the context of ageing. These are the key themes that resonated across both the qualitative meta-synthesis and the

findings resulting from data collection. *Embarrassment*, shame and fear of humiliation underlined the lived experience of UI for many women, both in this study and in the wider literature. Visibility of UI symptoms was central to the concept of embarrassment, which relates to the feelings of loss of bodily control often associated with UI. Embarrassment appeared to be a major factor which influenced how women placed restrictions on their social life, for example, travel and holidays. Experiencing UI was often *normalised* by women as the symptoms were interpreted as an inevitable part of ageing. This normalisation resulted in a perceived lack of seriousness towards the symptoms of UI, which could potentially delay or prevent help-seeking. These concepts will be explored in more depth in the discussion chapter of this thesis, drawing on wider theory and existing literature.

5.11 Conclusion

This chapter has presented the themes arising from the analysis of interview data for phase 1 of this study, which focused on the lived experience of urinary incontinence for older women. Eight themes were identified: living with UI, coping strategies, attitudes towards healthcare professionals, perceived seriousness of UI, knowledge of UI, personal responsibility, childhood experiences and sharing experiences of UI. The themes illustrate the factors of living with UI that are recognised by the participants as pivotal aspects to understanding of the phenomenon of urinary incontinence.

5.12 Summary

- Phase one of this study aimed to **explore older women's perceptions of living with urinary incontinence**.
- A total of 8 superordinate themes were identified: living with UI, coping strategies, attitudes towards healthcare professionals, perceived seriousness of UI, knowledge of UI, personal responsibility, childhood experiences and sharing experiences of UI.
- **Living with UI** refers to the participants' *feelings about UI*, including embarrassment, annoyance, gradual worsening, hopelessness and accidents. This theme also reflects *the impact of UI* on the participants' lives, such as: daily life, travel restrictions and social restrictions.
- **Coping strategies** used by the participants were also identified in the literature. These included: *planning, continence products, fluid restriction, adjusting prescriptions* and *humour*.
- **Attitudes towards help-seeking** was another theme related to the lived experience of UI. *Feelings towards healthcare professionals* concerned trust in HCPs, negative experiences and gender of HCPs. *Views on medical management of UI* related to ineffective treatments and distrust of medicine.
- **Perceived seriousness of UI** as understood by the participants was identified as an important factor influencing the lived experience of UI. *Perceptions of ageing* and *comparison of health conditions* were central to this theme.
- **Knowledge of UI** was another theme identified, which includes issues around *misinformation* and *sources of knowledge about UI*.
- **Personal responsibility** related to UI highlights the self-blame around UI accidents and the perceived personal responsibility around managing the symptoms of UI.
- **Childhood experiences** was another finding from the data, concerning UI related accidents experienced during childhood.
- **Sharing experiences of UI** played an important role in the lived experience of this condition. *Confiding in friends* and *research involvement* were discussed by the participants in this context.

PHASE 2: CO-PRODUCTION

Chapter 6: Phase 2 Scoping Review

6.1 Introduction

Phase 2 of this study aims to examine the principles of co-production within the context of an ongoing research project focussed on UI. A scoping review was therefore conducted as part of phase 2, to examine the existing literature surrounding co-production in healthcare research. This chapter will firstly describe the methods used for this literature review. Following this, findings from the scoping review will be discussed.

6.2 Review Method

There are two aims of the current review. The first aim is to map the literature on co-production in healthcare research. The second aim is to characterise the experience of using co-production in the literature. A scoping review, therefore aligns with these aims. Unlike systematic and rapid reviews, which often have highly focused research questions; scoping reviews facilitate the exploration of broader themes (Arksey and O'Malley, 2005) which is a more suitable approach to address the aims of this review. Furthermore, whilst a narrative review seeks to summarise and critique exiting literature, often this is not done in a systematic way which offers explicit methodological details (Collins and Fauser, 2005), which can affect the transparency and reproducibility of the findings. Unlike the aforementioned approaches, a scoping review provides a broad approach to systematically chart the current body of research in a given area. Scoping reviews can provide an overview of the range of existing research on a given topic (Arksey and O'Malley, 2005; Levac et al., 2010; Armstrong et al., 2011; Pham et al., 2014); and can be used to map current literature. Scoping

reviews are a fairly recent method for reviewing literature and the process of conducting this type of review is often not well defined (Pham et al., 2014). Whilst a scoping review can be done as a first step in reviewing the literature prior to a systematic review, it can also be conducted as a stand-alone assessment of the literature (Arksey and O'Malley, 2005, p. 22). A scoping review is a suitable approach for mapping literature on a given topic as the method allows for the inclusion of papers with varying study designs (Arksey and O'Malley, 2005); allowing researchers to provide a comprehensive picture of the current body of research. As the aim of this review was to map the literature on co-production in healthcare literature, a scoping review was conducted, as this approach was a best fit for facilitating this aim.

6.3 Scoping Review Approach

Arksey and O'Malley (2005) developed a methodological framework for conducting a scoping review, which offers a structured 5 stage approach (table 9). Each stage will be described in this chapter.

Table 9: Arksey & O'Malley Methodological Framework

Stage One:	Identifying the research question
Stage Two:	Identifying the relevant studies
Stage Three:	Study Selection
Stage Four:	Charting the data
Stage Five:	Collating, summarizing and reporting the results

(Arksey and O'Malley, 2005, p. 22)

6.3.1 Stage One: Identifying the Research Question

The first stage in the Arksey and O'Malley (2005) framework is focused around identifying the research question. Arksey and O'Malley (2005, p. 23) suggest that a broad approach should be adopted during this stage to ensure that an extensive range of literature is obtained. The overarching research question for this scoping review is: What are the key components and experiences of co-production research within healthcare research?

The aims of the review are:

- To map the literature on co-production in healthcare literature
- Characterise the experience of using co-production in the literature

6.3.2 Stage Two: Identifying Relevant Studies

To identify relevant studies related to the research question and aims of the review, a search strategy was developed. A list of keywords was established and a search strategy using truncations, MeSH headings, and Boolean searching was developed (appendix G). The search strategy was applied to the following academic databases: MEDLINE, PsycINFO, Embase, CINAHL, ASSIA and Sociological Abstracts. Grey literature was also searched on the following databases: Social Care Online (SCIE) and OpenGrey. Targeted hand-searching of the INVOLVE library was also conducted as the INVOLVE national advisory group is dedicated to public involvement in research. No date limits were placed on the search strategy, to ensure that a comprehensive range of studies were identified. The last date searched was June 15th 2018.

6.3.3 Stage Three: Study Selection

A series of inclusion and exclusion criteria were developed to screen the literature:

Inclusion Criteria

- Papers directly related to co-production concerning adults living with non-life-threatening long-term conditions (LTCs)
- Papers describing key principles of co-production derived from experience, that have direct relevance to the development of a framework for people with long-term conditions
- Research conducted in a setting with a similar healthcare context to the UK
- Papers in English language
- Primary research papers, secondary research papers, charitable organisation reports

Exclusion Criteria

- Non-English language papers (due to lack of translation resources)
- Commentary or opinion papers
- Papers related to children or adolescents
- Papers focussed exclusively on mental health
- Papers with a focus on population or community level healthcare initiatives

The search strategy returned a total of 899 studies; 741 from academic databases and 158 from grey literature databases. No studies were selected from the hand-searching of the INVOLVE library. All references were imported

into EndNote (v.8), where duplicates were removed. After duplicates were identified and removed, the total number of studies was 740; 582 from academic databases and 158 from grey literature databases.

The title and abstract of each paper were screened using the inclusion and exclusion criteria. This screening was done in collaboration with the lead supervisor of this PhD. Following initial screening, a total of 15 papers remained. The full-text of the remaining 15 papers were obtained, and these papers were then assessed for eligibility against the inclusion and exclusion criteria. Any papers which were difficult to categorise were discussed with a member of the PhD supervisory team before making the decision to include or exclude the paper. A total of 5 papers were included in the study. There were a high number of excluded records (figure 4) predominantly because they were not related to healthcare research, which is possibly due to the broad search terms used for this scoping review (appendix G).

Table 10: Reasons for Exclusion of Papers

Reason for exclusion	Number of papers
Not healthcare focused	4
Life-threatening illness	2
Not about experiences of co-production	3
Unsuitable study setting	1
Total excluded	10

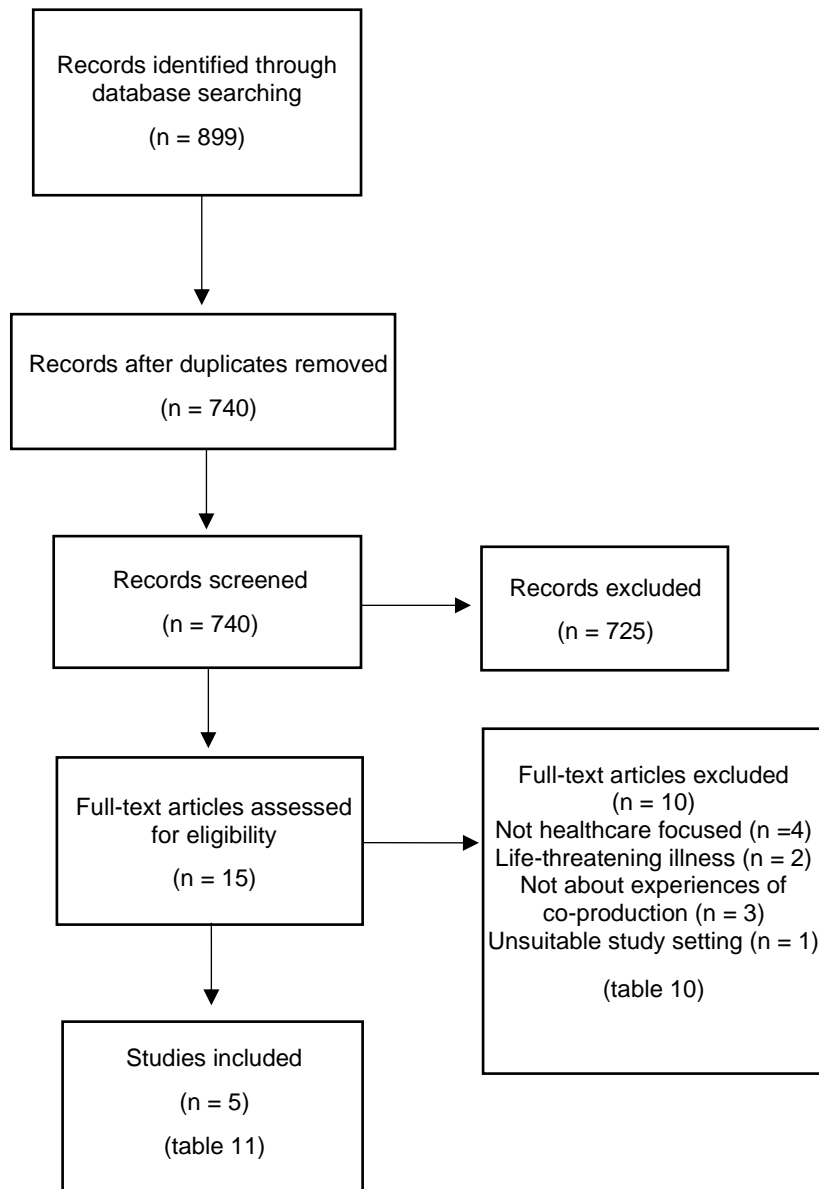


Figure 4: PRISMA Flowchart

6.3.4 Stage Four: Charting the Data

Stage four involves 'charting' the data to extract key information (Arksey and O'Malley, 2005, p. 26). A data charting table was developed specifically to record data relevant to the aims of this study (tables 11 and 12). This included information about: study setting, aim(s), design, sample, health condition, data collection method(s), findings, co-production principles and author comments.

6.3.5 Stage Five: Collating, Summarizing and Reporting

According to Arksey and O'Malley (2005), this stage of the scoping review framework involves, '...collating, summarizing and reporting the results' (2005, p. 27). Unlike other types of literature review, e.g. systematic reviews or qualitative meta-synthesis, the focus of a scoping review is not cross-interpretation or synthesis of results, but rather to provide a 'narrative account' of the literature (Arksey and O'Malley, 2005, p. 27). This 'narrative account' was created by thematically organising the data extracted for stage four of this methodological approach ('charting the data'), to depict an accurate explanation of the existing literature. To do this, data were input in Microsoft excel and organised into relevant themes to describe the literature. The themes identified were benefits, challenges and lessons learnt from using a co-production research approach.

Quality assessment of included studies is not an essential component of a scoping review as the aim is to map all relevant existing literature, regardless of quality (Arksey and O'Malley, 2005; Levac et al., 2010; Armstrong et al., 2011; Pham et al., 2014). However, some researchers argue that quality assessment of studies in a scoping review is crucial, to ensure that findings can contribute to practice or policy (Daudt et al., 2013, p. 5). Assessing the quality of papers in a

scoping review is often difficult due to the varied range of study types included (Levac et al., 2010, p. 8). Furthermore, as the current review was focused on the co-production elements of the included studies, rather than the actual study findings, conducting a quality assessment would be problematic. It was therefore decided in agreement with supervisors, that studies would not undergo a quality assessment.

Table 11: Charting the Data (Summary)

Authors	Title	Setting	Aim	Design + Data Collection	Sample	Health Condition
(Batalden et al., 2015)	Coproduction of healthcare service	<p>UK: NHS England & Scotland</p> <p>USA: Massachusetts Clinic + 71 site USA network of patients, professionals, families & researchers</p>	<ul style="list-style-type: none"> - To present a co-production model for healthcare - To explore the model in relation to healthcare service case studies 	<p>Qualitative study design</p> <p>Case study 1: UK</p> <ul style="list-style-type: none"> - NHS setting - The Health Foundation's Co-Creating Health Initiative - Patients & health care professionals in England and Scotland trained to support patients to self-manage their conditions <p>Case Study 2: USA</p> <ul style="list-style-type: none"> - Shared medical appointments - Diabetes patients <p>Case Study 3: USA</p> <ul style="list-style-type: none"> - <i>ImproveCareNow</i> network - Concerns children with inflammatory bowel disease 	<ul style="list-style-type: none"> - Patients & clinicians involved in <i>The Health Foundation's Co-Creating Health Initiative</i> (UK) - More than 600 patients and 900 professionals (one Scottish site) - No further details about sample size 	<ul style="list-style-type: none"> - Chronic pain - Diabetes - Depression - Chronic obstructive pulmonary disease

Authors	Title	Setting	Aim	Design + Data Collection	Sample	Health Condition
(Clayson et al., 2018)	When two worlds collide: critical reflection on co-production	UK: - 'Recovery voice in action project' - Focused specifically on a dry bar called <i>The Brink</i> (Liverpool) which is managed by a national drug/ alcohol treatment service (p. 51)	To 'identify thematic features of the co-productive experiences from different positions and through the process of adaptation to a co-productive relationship' (p. 51)	- Qualitative study design - Individual and group reflection: diaries, film, presentations and audio recordings - Continuously collected throughout project	- Community researchers - Academic researchers - Community intermediary - No specific details about sample size	Drug & alcohol recovery
(Ottmann et al., 2011)	Coproduction in Practice: Participatory Action Research to Develop a Model of Community Aged Care	Australia (Melbourne): <i>People at Centre Stage</i> (PACS), a 'self-directed aged care service model' (p. 416)	To 'describe and critically reflect on key events that shaped a 12 month-long action research inspired 'coproduction' process which involved older people with complex care needs, carers, government and industry stakeholders' (p. 416)	- Qualitative study design - Focus groups - Group meetings - Document analysis	- Older people - Service providers - Government representatives - Carers - Sample size: focus group (n=62), UCG (n=8), PG (n=10), AG (n=14)	'members reported a plethora of serious illnesses and/or disabilities stroke, cancer, arthritis, mild cognitive impairments' (p. 420)

Authors	Title	Setting	Aim	Design + Data Collection	Sample	Health Condition
(Sadler et al., 2017)	Shaping innovations in long-term care for stroke survivors with multimorbidity through stakeholder engagement	UK: Stroke Research Patients and Family Group (SRPFG) at Kings College London	'to develop a process of engaging stakeholders in the use of clinical and research data to coproduce potential solutions, informed by a LHS [Learning Health System], to improve long-term care for stroke survivors with multimorbidity' (p. 1)	<ul style="list-style-type: none"> - Qualitative study design - Focus groups - Interviews - Stakeholder meetings - Nominal group techniques 	<ul style="list-style-type: none"> - Service users - Carers - GPs - Health care professionals - Social workers - Service managers - Policy makers - Researchers - Overall sample (n=37) 	Stroke
(Thomas et al., 2016)	The Experience of Older People in the Shared Decision-Making Process in Advanced Kidney Care	UK: Two hospitals (1x large inner-city teaching hospital + 1x smaller hospital)	To explore 'the experiences of older people (>70 years) in the shared decision-making process in advanced kidney care' (p. 2)	<ul style="list-style-type: none"> - Qualitative study design - Patient and Carer Group (PCG) involved at every stage of the research process (e.g. developing interview questions and conducting interviews) - Interviews with patients about dialysis decisions (main study) - Focus group discussion (FGD) with members of PCG about co-producing the research (facilitated by a renal counsellor) 	<ul style="list-style-type: none"> - Patients & carers - 29 people included in main study - No details on sample size or characteristics of PCG members 	Renal failure

Table 12: Charting the Data (Results)

Study	Title	Aim	Results + Key Co-Production Principles	Researcher Comments
(Batalden et al., 2015)	Coproducton of healthcare service	<ul style="list-style-type: none"> - To present a co-production model for healthcare - To explore the model in relation to healthcare service case studies 	<ul style="list-style-type: none"> - Authors developed a conceptual model of co-production related to healthcare services: co-production contributes to 'good health for all', structure of healthcare system supports & constrains partnerships, patients and professionals have 'agency to shape the system', co-production 'blurs roles', basic co-production requires 'respectful interaction and effective communication', shared planning requires understanding of peoples expertise, shared execution 'demands deeper trust, more cultivation of shared goals and more mutuality in responsibility and accountability' (p. 3) - Limitations and challenges of the conceptual model illustrated from the case studies: <ul style="list-style-type: none"> - Not all patients are able to/want to participate - Difficulty around mutual accountability - Potential to diminish professional expertise - Co-production challenges standardisation - 'Resistant healthcare culture' (pp. 6-7) - Example of Scottish workshops called <i>Moving on Together</i> (patients) and <i>Working in Partnership</i> (Professionals) - All sessions were co-delivered (patients & professionals) - Curriculum included: 'communication skills, strategies for negotiating visit agendas and for articulating goals and monitoring progress, collaborative problem solving and action planning' - Participants reflected (professional): the process helped them to understand that consultations need to allow patients to express their experiences, hopes and concerns rather than professionals 'imposing' ideas (p. 4) 	<ul style="list-style-type: none"> - Only extracted data from the UK case study as the other case studies were set in USA - No specific sample size detailed but one Scottish site had 600 patients and 900 professionals included so the overall sample size would be significant - The model was not specific to any country or setting so is applicable - Reflections from the case studies identified similar issues reflected in the themes

Study	Title	Aim	Results + Key Co-Production Principles	Researcher Comments
(Clayson et al., 2018)	When two worlds collide: critical reflection on co-production	To 'identify thematic features of the co-productive experiences from different positions and through the process of adaptation to a co-productive relationship' (p. 51)	<ol style="list-style-type: none"> 1. Reach – different channels of communication because of diverse stakeholders 2. Reason – reasons for participation varied e.g. to help others, produce research for career 3. Reciprocity – community researchers not as comfortable sharing knowledge as academics 4. Recovery – being involved in co-production research helped recovery (self-learning, self-esteem) 5. Relationship – relationships formed based on shared experiences 6. Reward – varied rewards (combating stigma, helping, using voice) 7. Risk – both academic and community researchers felt out of their comfort zones 8. Robustness – balance between creating robust research but maintaining authenticity 9. Rub – disagreements between researchers led to discussion and debate in a positive way 	<p>Reflections on the process of co-production research (rather than focus of drug/alcohol recovery) which is relevant to the aims of the scoping review</p> <p>Challenges of university setting: 'Overall, the sense was that the challenges and implications of co-production were poorly accommodated by the university's institutional processes' (p. 55)</p> <p>'Rub' caused by differences between conventional and co-production research processes</p>

<p>(Ottmann et al., 2011)</p>	<p>Coproduction in Practice: Participatory Action Research to Develop a Model of Community Aged Care</p>	<p>To 'describe and critically reflect on key events that shaped a 12 month-long action research inspired 'coproduction' process which involved older people with complex care needs, carers, government and industry stakeholders' (p. 416)</p>	<p>1. When co-producing with frail older people it is important to: a. Build trust. It may take time for older people to feel secure enough to speak their minds; b. Make appropriate arrangements so that frail older people can participate in meetings and discussions; c. Clearly and repeatedly outline the context of a discussion (e.g. explain how this discussion feeds directly into the project decision-making process); d. Fill knowledge gaps; e. Use practical examples when explaining concepts and processes; f. Test out whether 'role playing' exercises are acceptable to participants; g. Provide advocacy support 2. When co-producing with service providers it is important to: a. Carefully select group participants in order to avoid overly competitive behaviour and mutual 'policing'. This may involve the i. Splitting of the supply chain into discrete logistic units; ii. Avoid representatives from agencies who predominately represent the interests of legislators b. Employ an experienced group mediator with substantial knowledge of the sector 3. When co-producing with government stakeholders it is important to: a. Establish whether government partners endorse and share the principles of co-production; b. Ascertain whether the project has attracted decision makers who are relevant to the project and have the authority to make decisions; c. Confirm that stakeholders have the necessary time at their disposal to participate in lengthy negotiations and discussions 4. When co-producing with agencies that are to implement a project it is important to:</p>	<p>Although the setting is not UK, in Australia the government finances home-based care for older people</p> <p>'It [co-production] is an epistemological device that, if charged with moral and political authority can unite actors with competing agendas to bring about systemic change' (p. 424)</p> <p>Lessons learnt are relevant to the LOUISA project as participants are 'older' and co-production includes service providers</p>
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Study	Title	Aim	Results + Key Co-Production Principles	Researcher Comments
			a. To develop risk analysis-based contingency plans accepted by all major stakeholders that outline how the project is to progress when a major obstacle is faced b. Ensure senior executives and/or board members are aware of the project's requirements to guard against disruption if the manager supporting the project leaves c. Delineate a clear change management strategy' (p. 419)	
(Sadler et al., 2017)	Shaping innovations in long-term care for stroke survivors with multimorbidity through stakeholder engagement	'to develop a process of engaging stakeholders in the use of clinical and research data to coproduce potential solutions, informed by a LHS [Learning Health System], to improve long-term care for stroke survivors with multimorbidity' (p. 1)	<ul style="list-style-type: none"> - Tension between 'the philosophy of co-production and applying this approach in practice in an applied health research context' - Stakeholders engaged in a 'flexible manner' - Difficulty recruiting GPs and clinicians - Difficulty translating complex concepts (pp. 12-13) 	<p>Although main study not directly relevant, the paper reflects on the benefits and challenges of co-producing healthcare research</p> <p>Authors recommend that further research is needed to clarify what co-production is and what methods to use</p>

Study	Title	Aim	Results + Key Co-Production Principles	Researcher Comments
(Thomas et al., 2016)	The Experience of Older People in the Shared Decision-Making Process in Advanced Kidney Care	To explore 'the experiences of older people (>70 years) in the shared decision-making process in advanced kidney care' (p. 2)	<p>Results from FGD about co-production process with PCG members:</p> <ul style="list-style-type: none"> - Experience of interviewing was challenging for members - Personal gain through shared stories was expressed by participants who enjoyed the process and felt inspired by others - Feeling valued was a positive effect of the process as members felt like their opinions matter - 'Camaraderie between interviewer and interviewee' meant that interviewees were more forthcoming (p. 6) 	<p>Older people are the focus of this study (relevant to LOUISA/PhD)</p> <p>Diverse population covered by including two hospitals in different locations</p> <p>Members were reimbursed for their involvement & held volunteers' contracts ('which included a confidentiality agreement' (p. 2))</p> <p>Training was given to participants – important if participants are collecting data</p> <p>Only results from the FGD with members involved in the research extracted as study results on kidney failure are not relevant</p>

6.4 Description of the Literature

This scoping review included a total of 5 papers (Ottmann et al., 2011; Batalden et al., 2015; Thomas et al., 2016; Sadler et al., 2017; Clayson et al., 2018). The earliest paper was conducted in 2011 and the latest was conducted in 2018.

Three papers were conducted in the UK, one paper was conducted in Australia, and one paper was conducted in both the UK and USA. All 5 papers had a qualitative study design.

One study used a case study design to create and examine a co-production model for healthcare, using a sample of patients and clinicians involved in the *Health Foundation's Co-Creating Health Initiative* (UK); which is a programme aimed to include self-management within the context of mainstream health services (Batalden et al., 2015). Another study utilised several methods of individual and group reflection for people recovering from drug and alcohol addiction, including: diaries, film, presentations and audio recordings (Clayson et al., 2018). Alternatively, one study described and critically reflected on a co-produced project with older people with 'complex care needs' using focus groups, group meetings and document analysis (Ottmann et al., 2011, p. 416). Another paper reported the findings of a study which aimed to develop a process to co-produce possible solutions to long-term care for people who have survived stroke (Sadler et al., 2017); using interviews, focus groups and nominal group techniques. The final study reported on the experiences of older people who were involved in the decision-making process regarding their advanced kidney care (Thomas et al., 2016), where focus group discussions were used to explore participants' experiences.

All of the studies included service users and a combination of healthcare professionals, academics, stakeholders, or government representatives. Each study included in this scoping review used a co-production research approach. Whilst each study reported on findings related to their initial aim e.g. advanced kidney care, they also reported experiences of working within a co-production framework. The focus of this review will be on the reported experiences of using a co-production approach in real world research in a variety of settings.

6.5 Description of Themes

Several important themes were identified from this scoping review, related to co-production of research within a healthcare setting. The first theme relates to the benefits of using a co-production approach and includes sub-themes of personal and research benefits. The second theme concerns the challenges experienced when adopting a co-production research approach, and includes sub-themes of practical and theoretical challenges. The third theme focuses on the lessons learnt from researchers using co-production research methods.

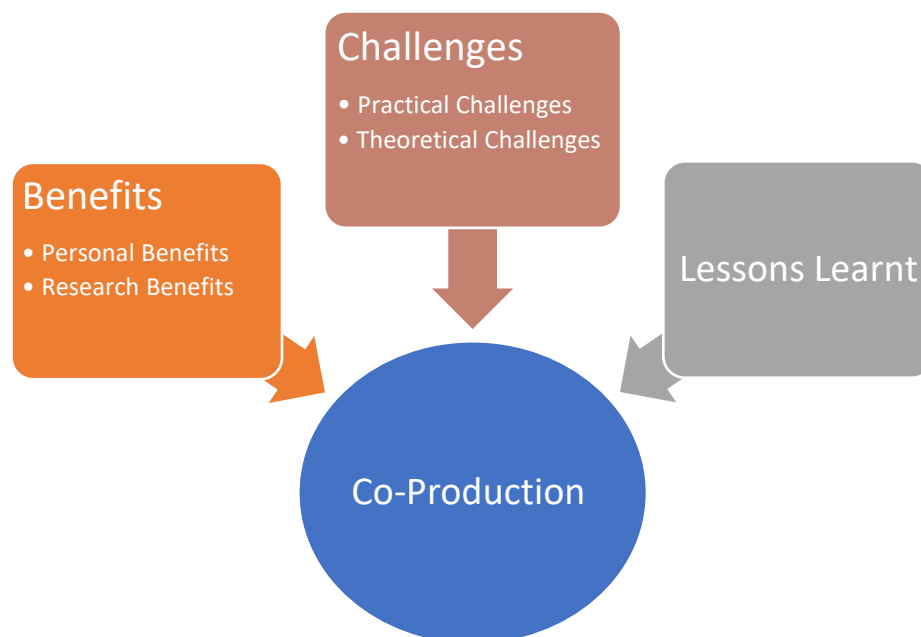


Diagram 3: Co-Production Themes

6.6 Benefits

Benefits to using a co-production research approach were discussed in the studies included in this review. Both personal benefits and research benefits were reflected upon in the research.

6.6.1 Personal Benefits

“I thoroughly enjoyed it and glad I’ve been involved and hopefully the patients will have got something out of it, I certainly have and if nothing else met other people” [Patients and Carer Group Member]

(Thomas et al., 2016, p. 6)

One of the findings of this scoping review relates to the personal benefits of participating in a co-produced research project. The personal rewards experienced by participants are likely to be dependent on their initial reason for participating in the study, however some of the reported benefits include: helping people, combating stigma, building relationships and feeling valued (Thomas et al., 2016; Clayson et al., 2018). Feeling valued was a particularly prominent benefit reported in the studies. Participants described how they felt respected as a result of being listened to by professionals during their involvement in co-producing research (Thomas et al., 2016). This was also echoed in a study conducted by Clayson et al. (2018, p. 56) where ‘having a voice’ was reported as one of the personal benefits of involvement in co-producing research. One nurse described how the process of being trained and involved in a co-produced project changed their personal approach to patient consultations in a positive way: *“Before...I thought it was more of me, imposing my ideas on the patient, but [after training], it’s more allowing the patient[s] to tell me what they want or what they expect, what they are hoping to achieve, if*

they are concerned with a problem” (Batalden et al., 2015, p. 4). This shift in approach contributes to patients’ sense of feeling valued and understood. The personal rewards associated with involvement in co-produced research is a huge benefit for this approach.

6.6.2 Research Benefits

“As the community researchers (people with lived experience) were actively involved in the research process, they had a stake in the research and understood it” (Clayson et al., 2018, p. 54)

In addition to the personal benefits experienced by members participating in co-produced research, the researchers in the included studies also discussed the benefits to the quality of research that can be gained from using this approach. Clayson et al. (2018, p. 55) identified that the ‘reach’ of their co-produced research was significantly impacted by ‘community researchers extending the methods and routes of dissemination’. Whilst traditional methods of dissemination, such as publishing in academic journals or presenting at conferences, are effective methods for distributing findings within the academic community; there is often a lack of focus on circulating findings within the wider community. This is a component of the research process that can be strengthened through co-producing research with patients and members of the public, by utilising their connections within the relevant communities.

In the study conducted by Thomas et al. (2016, p. 6), members of the patient and carer group (PCG) were involved in interviewing participants. The authors reflected on this and discussed the ‘camaraderie between interviewer and interviewee’. One PCG member said: *“It helped because they felt that you understood what they were telling you, there’s almost that immediate bond”*

(Thomas et al., 2016, p. 6). This 'bond' between group members and participants created an atmosphere that encouraged open dialogue, in a way that traditional researcher/participant relationships might be unable to. By removing the power relationships usually exhibited, even if unintentionally, during traditional interviewer/interviewee interactions, co-production research offers an opportunity to explore participants' stories in a potentially more meaningful and relatable manner.

6.7 Challenges

Challenges to using a co-production research approach within a healthcare setting were reported frequently in the literature. Researchers reflected on a variety of both practical and theoretical challenges to using this approach within their studies.

6.7.1 Practical Challenges

6.7.1.1 Unwillingness to Participate

"Not all participants have the desire or capacity to be active participants in coproducing their healthcare service" (Batalden et al., 2015, p. 6)

Through reviewing relevant case studies, Batalden et al. (2015) identified that patients are often unwilling to participate in the research process. Some patients would rather relinquish the appropriate decision-making abilities to health professionals so that they can 'relieve the burden' for the participants (Batalden et al., 2015, p. 6). This would be particularly pertinent in the context of emergency illnesses where it is essential that the responsibility of care lies with the relevant healthcare provider. However, even in a context where co-

production with service users would be appropriate, such as managing long term conditions (LTCs), it should not be assumed that patients will automatically want to be included in the process. Participants should be given the option to participate without pressure from researchers or healthcare professionals. The potential unwillingness of service users to participate should be factored into the research planning process for studies using a co-production approach.

6.7.1.2 Lack of Research Experience

“I’d interviewed all my career, but this is a completely different type of interview” [Patient and Carer Group Member] (Thomas et al., 2016, p. 5)

In the study conducted by Thomas et al. (2016) on older people’s involvement in decision-making regarding advanced kidney care, they found that many of the participants had never been involved in a co-produced research project previously. Participants in this study were involved in collecting data via interviews, therefore training was given prior to collecting data. Training content included: *‘What makes a good interviewer’, ‘Peer review of interview skills’, ‘Practicalities of interviewing’ and ‘Preparation for interviews’* (Thomas et al., 2016). In this study, the participants reported that they felt prepared for collecting data and expressed that they had *‘learnt a lot about themselves’* (Thomas et al., 2016, p. 6). This example highlights the importance of understanding each participants’ level of research knowledge and providing skills training where appropriate. One of the defining features of co-production research centres around encouraging participants to be involved at all stages of the research process. For this approach to produce robust and ethically sound research, participants must be supported to develop the relevant skills

necessarily. This support not only increases the reliability of the research but could also encourage more people to participate in such studies.

6.7.1.3 Reluctance to Share Experiences

“Community researchers appeared less comfortable with sharing knowledge than academic researchers” (Clayson et al., 2018, p. 55)

Clayson et al. (2018) reflected that in their study about recovery from alcohol and drug addiction, service users often felt uncomfortable sharing their experiences. This is an issue that is particularly relevant for service users who are experiencing an illness that is associated with negative stigmatisation (Clayson et al., 2018). This is a challenge that should be addressed sensitively when researching stigmatising conditions, e.g. urinary incontinence, by creating a comfortable and safe environment. In this study it was reported that as the co-production process progressed, the participants felt more comfortable in sharing their experiences as they came to realise the power and value of their knowledge within the research group (Clayson et al., 2018, p. 55). It is therefore important to emphasise the importance of participants' views, experiences and knowledge to cultivate an atmosphere which encourages openness and involvement. Furthermore, the length of time invested in developing the confidence and trust of all stakeholders is important for nurturing good working relationships, and should be considered as a central principle for any co-produced project.

6.7.1.4 Communicating Concepts

“I used to switch off when they started talking about data this and data that” [Community Researcher] (Clayson et al., 2018, p. 56)

Due to the diversity of group members involved in co-produced research projects, communicating technical concepts can sometimes be challenging. The use of academic language can act as a barrier to communication so it is important to use language that encourages a shared understanding. Sadler et al. (2017) discuss the challenges of translating complex concepts to stakeholders. In their study on long-term care for people who have survived stroke, Sadler et al. (2017) reflected that difficulties in developing a shared understanding of key issues led to a lack of engagement from stakeholders in subsequent meetings. Clayson et al. (2018) reported similar issues regarding language and communication, however they stated that as the project progressed, the use of language became conducive to shared understandings of complex concepts (2018, p. 56). Communication should be a key consideration for researchers conducting co-produced research, as a shared understanding should be achieved from the beginning, as a foundation on which to build the project.

6.7.2 Theoretical Challenges

6.7.2.1 Healthcare Culture

“Like any paradigm, the construct of co-produced healthcare service is imperfect and contains its own pragmatic challenges and moral hazards...” (Batalden et al., 2015, p. 7)

The healthcare settings within which co-produced research is often conducted, can present challenges to the approach. As Batalden et al. (2015, p. 7) argue, often with the burden of increased workload, healthcare professionals return to ‘professional-centric priorities’. In the example of the *Health Foundation’s Co-Creating Health Initiative* in Scotland, Batalden et al. (2015) identified that

despite receiving training relevant to co-production, service users and healthcare professionals failed to consistently apply their skills on-the-job. Inconsistencies in the application of skills related to co-production, e.g. encouraging shared decision making, could undermine the confidence and belief in the core principles of co-production.

Furthermore, issues around accountability can be challenging within current healthcare culture. Whilst it is important to value all members of a co-produced project equally, it is not always appropriate to assign mutual accountability to all parties. As Batalden et al. (2015, p. 6) argue, ‘...the health care service system must continue to function as a safety net’ in situations where detrimental choices might be made by patients. Batalden et al. (2015, p. 6) describe this prospective distribution of responsibility as ‘letting the pendulum swing too far’, and highlight the potential for professional knowledge and skills to be devalued.

Additionally, current healthcare systems have successfully implemented the standardisation of healthcare services, which has positively impacted on the safety and quality of service delivery (Batalden et al., 2015, p. 6). This context of standardisation is a potential challenge to co-production, which essentially encourages the development of more individualised interventions and services to best suit service users. These challenges relating to current healthcare systems must be considered when creating a research project with a co-production approach.

6.7.2.2 Academic Research Culture

“I noticed that I got panicky thinking that we had to be doing this and this otherwise the funders get upset and the Dean gets upset”

[Academic Researcher] (Clayson et al., 2018, p. 56)

There currently exists a discord between the values underpinning co-production and the realities of using this approach within healthcare research (Sadler et al., 2017). Researchers often need to maintain a balance between creating robust research whilst remaining true to the principles of co-production. As Clayson et al. (2018, p. 56) illustrate, for academic researchers, relinquishing power over the direction of the study was viewed as a risk associated with co-producing research. Often, especially within an academic setting, research projects are confined within certain boundaries and targets set by funders or university structures. However, as co-production is such a collaborative effort, there is an element of unpredictability associated with the approach, as a diversity of opinions must be considered. Despite this, in their study, Clayson et al. (2018, p. 55) indicated that, 'Where funding was secured, traditional research outcomes (practice recommendations, reporting, dissemination) continued to be used as benchmarks for success'. Maintaining the balance between producing research which is deemed to fulfil university or funder requirements, whilst also encouraging genuine input from participants, is a challenge to co-producing research that requires further reflection.

6.8 Lessons Learnt

In the study conducted by Ottmann et al. (2011), the authors reflected on a series of 'lessons learnt' from their co-produced project involving older people with 'complex care needs' (Ottmann et al., 2011, p. 416). When discussing co-producing research with older people, Ottmann et al. (2011) outline several key practices that should be considered, including: building trust to encourage open discussion, organising practical arrangements e.g. venue to make participation as easy as possible, and communicating clearly using practical examples (Ottmann et al., 2011, p. 419). Sadler et al. (2017) also discuss how involving

stakeholders in a flexible way encouraged greater engagement in their study. The option to participate in as little or as much of the research process should therefore be made clear to all potential group members to further encourage participation. This scoping review identified that one of the challenges to co-producing research is that patients or members of the public may be unwilling to participate or share their experiences; however, these practical 'lessons learnt' could contribute to overcoming this challenge.

In relation to co-producing with service providers, Ottmann et al. (2011) recommend that members are selected carefully to avoid 'overly competitive behaviours and mutual 'policing'' (Ottmann et al., 2011, p. 419). The researchers also advise that an experienced 'mediator' should be present to oversee group discussions (Ottmann et al., 2011, p. 419). Clashes or disagreements between group members was one of the issues reported in the studies included in this review. Although Clayson et al. (2018, p. 56) argue that disagreements were a 'valued' aspect of the research, this may not always be the case, as disruptive conflicts could hinder the research progress, especially if they are not handled effectively by a moderator. Implementing the recommendations of Ottmann et al. (2011) could help to prevent any disruptive clashes by managing group dynamics effectively.

The 'lessons learnt' outlined by Ottmann et al. (2011) are useful for informing researchers conducting similar studies, however further reflection from researchers co-producing studies are needed to contribute to this growing area of examination.

6.9 Discussion

There is a rapidly growing interest in the co-production of research in health management (Realpe and Wallace, 2010), demonstrating the importance of this topic. There appears to be a strong emphasis on co-production within the field of mental health, however seemingly little co-production research focusing on long-term physical health conditions. This scoping review sought to focus on literature concerning adults living with non-life-threatening LTCs in a setting with a similar healthcare context to the UK. Furthermore, whilst often papers on co-production in healthcare related exclusively to mental health, it was decided for this review, that studies solely exploring co-production in a mental health setting would be excluded. This decision was based on the fact that the specific circumstances surrounding mental health would not directly translate to long-term physical conditions, which is the focus of the current study. Additionally, papers describing key principles of co-production derived from experience, that have direct relevance to the development of a framework for people with LTCs were considered for inclusion.

The aims of this review were to: map the literature on co-production in healthcare and characterise the experience of using co-production. The scoping review identified 5 papers directly related to these inclusion criteria. Whilst this is a relatively small number of papers, the included studies offered valuable and rich data related to co-production. This scoping review identified a series of benefits, challenges and lessons learnt, based on the experiences of co-production reported in the studies. The benefits associated with co-producing research concerned both personal rewards (e.g. feeling valued) and research benefits (e.g. further dissemination). The challenges related to co-producing research, concerned both practical and theoretical issues. The practical

challenges identified included: unwillingness to participate, lack of research experience, reluctance to share experiences, managing relationships and communicating concepts. The theoretical challenges included issues related to healthcare culture (e.g. accountability), and those related to academic research culture (e.g. robustness). Lastly, the review identifies some of the 'lessons learnt' related to co-producing healthcare research.

One issue that must be considered in relation to research on co-production, is the lack of standardisation of this approach. There is no universally agreed upon definition of co-production; instead, this approach is 'continually reimagined in order to meet the beliefs, needs and wants of those involved in the research projects' (Thomas-Hughes, 2018, p. 232). As such, it is therefore difficult to provide clear recommendations for adopting this approach.

Specifically, within healthcare research, co-production is often a collaboration with patients experiencing a specific condition, therefore the exact approaches and experiences will be individual to that group. The findings related to the experiences of co-production research in this review are therefore not generalisable to all healthcare research. However, the findings reported can inform current understandings of co-production research and aid the development of this approach. Furthermore, these findings could guide researchers in the planning and conducting of co-produced research of a similar nature.

Due to the fluidity of co-production, tensions can occur between the philosophical and theoretical concepts of co-production and the practicalities of co-producing research in a real-life research context (Sadler et al., 2017).

Power relationships are a key consideration in relation to such tensions, as co-production seeks to share power and decision making equally amongst

stakeholders (Clayson et al., 2018). Whilst theoretically this concept is clear, the practicalities of this shift in dynamics need to be considered by researchers planning to conduct co-produced research. Batalden et al. (2015, p. 6) also argue that within healthcare service delivery 'It is neither possible nor desirable to share power and responsibility equitably between patients and professionals'; which raises questions as to whether true equality of power can be achieved through the co-production of research. Farr (2018) suggests that constant reflection is important to understand how power dynamics are established within co-produced research. This reflexive process should be considered a crucial part of co-production and should be approached sincerely by researchers adopting such an approach.

Related to the tensions between the theoretical and practical components of co-production is the consideration of research quality and ethics. As Thomas et al. (2016) illustrate, training is important if participants are involved in aspects of the research project which they are not familiar with, e.g. data collection.

Thomas et al. (2016) reported that participants felt more confident following training; however, as Batalden et al. (2015) state, often the skills learnt are not applied consistently following training. This raises questions concerning research rigour and ethical soundness and is an issue that researchers must be aware of before conducting co-produced research. Although the concept of co-production centres on shared decision making, ethical accountability is still essential. For an academic research project, for example, it might be necessary for an experienced researcher to verify that correct data collection procedures are followed. The Centre for Social Justice and Community Action, Durham University and the National Coordinating Centre for Public Engagement, developed guidelines for ethical issues in community-based participatory

research. These guidelines suggest that ethical agreements should be approved by all participants and could include protocols on: safety, communication and managing conflict (Centre for Social Justice and Community Action, 2012 , p. 9). The additional time required to identify training needs, conduct training and establish agreed upon ethical protocols, is therefore a practical consideration that could conflict with the philosophical belief that participants should be involved in all stages of a research project.

The dates of publication for the included studies ranged from 2011-2018, which demonstrates that the topic of co-production is relatively new within the field of healthcare research. This could be one of the reasons why only a small number of relevant studies were identified for this review. However, whilst there are many papers reporting on projects that have used a co-production approach, only a small subsection of those papers reflect on the experiences of using the approach. This scoping review identified that there is a lack of research exploring the realities of using a co-production approach to healthcare research. Identifying these gaps in the literature confirmed the importance of further research on co-production and substantiated the focus of phase 2 of this study; which aims to explore the realities of co-production, within the context of a project focused on developing a self-management intervention for older women with urinary incontinence. This is an area of research that will be explored throughout the current study, in relation to a project focused on developing a self-management intervention for older women with urinary incontinence.

6.10 Conclusion

The aim of this chapter was to present the results of a scoping review on the concept of co-production in healthcare research. Several key themes were identified from this scoping review related to; benefits of using a co-production approach, challenges experienced when adopting a co-production research approach, and lessons learnt from using co-production research methods.

These findings have the potential to guide researchers planning to conduct co-produced research of a similar nature.

6.11 Summary

- This scoping review mapped the literature on co-production in healthcare and characterised the experience of using co-production.
- This scoping review sought to focus on literature concerning adults living with non-life threatening LTCs in a setting with a similar healthcare context to the UK.
- A total of 5 papers were identified as relevant for inclusion in the scoping review.
- Three overarching themes were identified from the literature:
 - The first theme relates to the **benefits** of using a co-production approach, including sub-themes of *personal benefits* (e.g. feeling valued) and *research benefits* (e.g. wider dissemination).
 - The second theme concerns the **challenges** experienced when adopting a co-production research approach and includes sub-themes of *practical challenges* (e.g. lack of research experience) and *theoretical challenges* (e.g. accountability).
 - The third theme focuses on the **lessons learnt** from researchers using co-production research methods.
- There appears to be a strong emphasis on co-production within the field of mental health, however seemingly little co-production research focusing on long-term physical health conditions.
- It can be difficult to provide recommendations for adopting a co-production approach to research as there appears to be a lack of standardisation related to the approach. Additionally, as co-production is a collaboration between relevant parties, the experiences may be specific to those groups.
- However, the findings from this scoping review can inform current understandings of co-production research and support the advancement of this approach.

Chapter 7: Phase 2 Research Methods

7.1 Introduction

This chapter will provide a detailed discussion of the research methods used for phase two of this study. Firstly, the aims of the research will be outlined. Details of the data collection methods will then be discussed. Following this, data analysis methods will be described.

7.2 Research Aim

The aim of this phase was to examine the principles of co-production within the context of an ongoing research project focussed on urinary incontinence. To achieve this research aim, the following objectives were developed: (1) examine existing literature focussed on co-production within healthcare research; (2) explore the experiences of key stakeholders currently engaged with the co-production research approach used in the LOUISA project; (3) present meaningful recommendations for researchers conducting co-produced research. Phase two of the study sought to explore the question: What are stakeholders' views and experiences of co-producing research?

7.3 Data Collection: Observation

7.3.1 Rationale

Observations were conducted during phase 2 of this study, to examine the interactions between stakeholders at LOUISA advisory group meetings. Data were collected through observation, as this is a useful approach when researching 'complex interactions or processes which it would be difficult to describe accurately or fully' (McNaughton Nicholls et al., 2014, p. 245). Furthermore, it was intended that observational data would be used to

supplement the data gained from interviewing LOUISA stakeholders. As Bryman (2008, p. 269) highlights, observation methods are often of 'greater utility' when accompanied by other methods of data collection. Although other data collection methods, such as diary research, are useful for supplementing interview data and examining experiences '...in their natural, spontaneous context' (Bolger et al., 2003, p. 580); this approach would not offer any independent insight into the interactions and relationships between members of the research group. Group observation on the other hand, provides an opportunity to view these interactions and relationships directly. As McNaughton Nicholls et al. (2014, p. 245) state, observations offer insight that '...goes beyond the understanding conveyed in verbal accounts'.

Advisory group meetings for the LOUISA project were the focus of observation. An advisory group is a collection of people who provide recommendations to an organisation, based on their expertise in the area. Advisory groups often consist of experts and specialists in the field, along with relevant members of the public. Advisory groups can also be established to advise on research projects, e.g. research design plans or intervention development. The role of an advisory group is to support and offer guidance; therefore, organisations are not required to act on recommendations made. An advisory group was set up for the LOUISA study, to advise on the development of a self-management intervention for urinary incontinence. Observing advisory group meetings held as part of the LOUISA study allowed the practicalities of a co-production research project to be observed first-hand. The current study was uniquely positioned to observe the co-production research process in action throughout the LOUISA project. Despite the criticism that observation is unlikely to uncover the intentions behind any observed actions (Bryman, 2008), utilising this research method enabled

me to access the social setting of the LOUISA group meetings (Kawulich, 2012), which helped to establish context for the subsequent interviews. I therefore decided that observation would be the most appropriate method of data collection to supplement data collected through interviews about the co-production research process.

Researchers working within an interpretivist paradigm such as that adopted in this study, recognise that observation ‘...is always subject to interpretation and constructed to some extent via the research process’ (McNaughton Nicholls et al., 2014, p. 246). However, to acknowledge this subjectivity, researchers must first decide which observation approach to adopt. Gold (1958) outlines the various approaches that a researcher can assume during observation. Firstly, a complete participant approach to observation can be adopted, whereby the researcher attempts to interact ‘naturally’ with the people under observation, without revealing their identity as a researcher (Gold, 1958, p. 219). Participant-as-observer is similar to a complete participant approach in that the researcher seeks to engage closely with the person or group of people in a natural setting, however the fact that this is a ‘field relationship’ is known to both parties (Gold, 1958, p. 220). Observer-as-participant is the third approach outlined by Gold (1958), which advocates a more ‘formal’ approach to observation, where the researcher reveals their identity but remains relatively uninvolved in the actions under observation (Gold, 1958, p. 221). Lastly, the role of complete observer requires no social interaction with those being observed. Instead, the researcher remains detached from the informants who are not aware of the presence of a researcher. For the observational component of this study, my role as a researcher aligns most closely with the observer-as-participant approach. McNaughton Nicholls et al. (2014, p. 247) highlight that this approach

entails ‘...observing as unobtrusively as possible, engaging in the setting to some extent but usually only for short periods of time or perhaps just once’. This approach supports the aim of the observation for this study, which is to observe LOUISA advisory group meetings to examine the interactions between stakeholders.

There are various approaches to capturing data through observation (McNaughton Nicholls et al., 2014). Spradley (1980) outlines the different processes that can form the focus of observations as: descriptive observation, focused observation and selective observation. My intention was therefore to shift the focus from descriptive observations to selective observations as the data collection progressed. It was expected that firstly, a descriptive observation method would be utilised to ‘grasp the complexity of the field’ (McNaughton Nicholls et al., 2014, p. 248). During this stage, I hoped to broadly observe the meeting to become familiar with the field and to note any initial ideas. Following this, I intended to narrow the focus of observation down to relate more specifically to the research questions under investigation. Lastly, I planned to conduct selective observation to identify additional data to supplement findings from the second observation stage (Spradley, 1980; McNaughton Nicholls et al., 2014). I hoped that this would allow me to ensure that findings from earlier observations were validated and supported by substantial data.

7.3.2 Sampling

Sampling Strategy:

A purposive sampling strategy was adopted to recruit participants for the observation, as the aim was to observe members attending LOUISA advisory group meetings. The only necessary inclusion criterion was that participants needed to be current members of the LOUISA advisory group, to be included in

this stage of the research. No exclusion criteria were set for this stage of the research.

Sample Size:

The sample size for the observational component of this phase, was determined by the number of attendees at the LOUISA advisory group meeting. It was initially estimated that approximately 8-16 participants would be observed during this phase of data collection. In total, 8 advisory group members were observed. The sample size was sufficient to ensure that a thorough observation of the group interactions could be conducted.

7.3.3 Recruitment

As the recruitment for this stage of the study is focused on LOUISA advisory group members, potential participants were contacted directly by the principal investigator of the LOUISA team (Professor McGowan), via email, to explain the purpose of the study. My contact details were also provided so that participants were able to make further contact to express their interest in participation.

Whilst this study is linked to the LOUISA study, advisory group members were assured that participation in my PhD research was entirely voluntary, and refusal to participate would not affect their position within the LOUISA study advisory group. Participants who contacted me to express an interest in participation were sent a participant information sheet (appendix O) and a consent form (appendix P), either via post or email. Participant information sheets contained all relevant details of the study, such as: purpose of the study, why they have been invited to participate, time requirements, data collection methods, details of how data will be disseminated, funder details, and researcher contact details. Participants were asked on the consent form, to confirm that they had read and understood the participant information sheet and

to confirm that they understood that participation in the study was voluntary. At least 24 hours were given between participants receiving their information sheets and seeking written consent. Participants were given a maximum time of 2 weeks to confirm their wish to participate in the study. Signed consent forms were collected from participants on the day of data collection, prior to the beginning of the advisory group meeting.

No pressure was placed on participants to agree to participate. Participants were informed that although the format of data collection was group observation, they were still able to refuse participation without explanation. Prior to data collection, I had informally discussed the possibility of observations with the group, and this suggestion was received enthusiastically by all members. It was therefore not expected that participation would be refused by any of the advisory group members, however I was prepared for this eventuality. After discussing this possibility with my supervisors, a decision was made that I would continue with partial observation in the event that one or more of the participants refused consent. By partial observation, I mean that although the group would be observed as a whole, no data would be collected related to any specific interactions e.g. conversations, that involved a participant who refused participation. This decision was based on the fact that participants might have felt pressured to agree if the research was dependent on gaining the consent of every participant. Although it would be challenging to exclude individual advisory group members from the observations, the desire to avoid placing inadvertent pressure on potential participants merited this decision. Despite this plan being put in place, all group members agreed to participate in the observation. However, one additional group member arrived considerably late to the meeting and I was therefore not able to secure the consent of this

participant. I consequently did not collect any data related to this group member.

7.3.4 Observation

The LOUISA advisory group was expected to meet every 6 months and it was expected that a total of 3 advisory group meetings would be observed. It was therefore anticipated that the different phases of observation outlined by Spradley (1980) would be adopted progressively throughout these meetings. Despite this initial plan however, it was unfortunately only possible to observe 1 LOUISA advisory group meeting. Although 3 observations were planned, I was unable to attend the second meeting due to illness, and the third meeting was cancelled due to a power outage at the university. I was therefore only able to complete the first 'descriptive' phase of observation (Spradley, 1980).

During descriptive observation, Spradley (1980, p. 73) advocates that researchers should conduct the observation with a general approach, by asking: 'What is going on here?'. I therefore strove to note initial ideas and become familiar with the setting. As the aim of descriptive observation is to note anything of interest to the general topic there is a risk that the resulting field notes '...may bog down in irrelevant minutiae' (Werner and Schoepfle, 1987, p. 263). I therefore used an observation guide during the observation, which I used to collect fieldnotes by hand. Observation guides are useful for ensuring that important features of the observed interactions are recorded (Nicolls et al. 2014). I followed Spradley's (1980) 9 dimensions of descriptive observation to guide me to record data on: space, actors, activities, objects, actions, events, time, goals and feelings (Spradley, 1980, p. 78). To guide data collection, I printed out a copy of table 13 to bring to the observation, which summarises the 9 dimensions advocated by Spradley (1980). Similar recommendations for

observations have been created, for example, Merriam (1998, p. 97) offers a checklist including: physical setting, participants, activities, conversation, subtle factors and own behaviour. As this was my first time conducting an observation, I decided that following Spradley's (1980) 9 dimensions of descriptive observation would be the most helpful approach. This guidance gave me general points of focus e.g. space, whilst also providing flexibility to record any relevant notes of importance. Furthermore, following a structured guide for recording fieldnotes, reduced the risk of subjective recording of data. Some authors argue that using fieldnotes, instead of video or audio recordings, can lead to selective and subjective data, as researchers may be more likely to '...reflect their own experience of what they are observing' (McNaughton Nicholls et al., 2014, p. 246). However, I believed that using video or audio recording equipment could cause disruption to the advisory group meetings and might therefore have affected the natural flow of discussion.

Table 13: Spradley's 9 Dimensions of Descriptive Observation

1	SPACE	Layout of setting e.g. room surroundings
2	ACTORS	Study participants (advisory group) e.g. users or funders
3	ACTIVITIES	Activities undertaken by participants
4	OBJECTS	Objects in the meeting e.g. furniture or equipment
5	ACTIONS	Single actions of participants
6	EVENTS	Key points in the meeting e.g. presentation
7	TIME	Sequence of events during the meeting
8	GOALS	How advisory members contribute
9	FEELINGS	Participant emotions (verbal or non-verbal cues)

(Spradley, 1980, p. 78)

The observation took place in a meeting room in the University of Leeds. As the principle investigator (PI) for the LOUISA group was unable to attend the meeting in person, the meeting was therefore led by Professor Andrea Nelson. Professor Nelson has been involved with the project from the beginning so was well-known to the advisory group members. In total, there were 8 advisory group members who attended the meeting: 2 academics, 3 funders, 2 healthcare professionals and 1 service user. The meeting room was large enough to facilitate the meeting and also had the necessary facilities required for the PI to join the meeting remotely via conference call. Myself and Professor Nelson arrived at the meeting room early to set up the presentation and prepare the refreshments. Prior to the start of the meeting, Professor Nelson reminded the group that I would be observing the meeting as previously discussed. Participants were given the opportunity to ask any questions about the observation, however no questions were asked. I then had time to collect consent from the members. All 8 members gave consent. In total, the observation lasted for 3 hours. The meeting was broken into 3 sections led by Professor Nelson: overview of the progress of the LOUISA project and associated PhD, focused group discussion on developing the intervention and general group discussion about the LOUISA project.

During the meeting, whilst the group sat together around a table (as seen in appendix Q), I sat to the side of this to limit the intrusiveness of my presence. As I was not participating in the meeting, the sole focus was on collecting data from observations; meaning that I was more alert to relevant observational notes worth documenting. Using this approach also allowed me to observe the dialogue and interactions between the group as they occur, without inadvertently influencing the direction of discussion. That being said, it is

important to recognise the potential 'reactive effect' which questions whether participants alter their behaviour when they know they are under observation (Bryman, 2008, p. 265). However, I had already met most of the advisory group members as I had attended the previous advisory group meeting, which may have alleviated some of the possible tensions about being observed. As this was a brief meeting, I had no preconceptions about the participants before conducting my first observation. To validate my observational data, I sent my fieldnotes to my lead supervisor, who is also the PI for the LOUISA group, following data collection. Although my supervisor attended the meeting remotely, our accounts of the discussions and interactions between the group were consistent.

7.4 Data Analysis: Observation

Data for phase 2 were analysed thematically, led by the 6-step thematic analysis phases (table 14) outlined by Braun and Clarke (2006). Firstly, the fieldnotes were read several times to ensure familiarisation. Initial ideas were noted during this stage. Following data collection, I typed up the hand-written notes electronically which made noting the data easier and allowed me to share the field notes with my supervisors. Following this, preliminary codes were developed systematically and recorded in an excel spreadsheet. Once initial codes were developed, they were organised and grouped into relevant themes. Themes were then reviewed to ensure validity. Following this, themes were named and further refined. Lastly, the relationships between the themes were examined in relation to the research questions of the study.

Table 14: Braun & Clarke Thematic Analysis

Phase 1	Familiarising yourself with your data
Phase 2	Generating initial codes
Phase 3	Searching for themes
Phase 4	Reviewing themes
Phase 5	Defining and naming themes
Phase 6	Producing the report

(Braun and Clarke, 2006)

7.5 Data Collection: Interviews

Phase 2 of this study also included interviews with key stakeholders involved in the LOUISA study. The interviews explored the stakeholders' experiences of being part of a co-produced research project.

7.5.1 Rationale

Semi-structured interviews were used to collect data for phase 2 of the study.

The aim of phase 2 was to examine the experiences of key stakeholders in the LOUISA project and explore their reflections on being part of the research process. The semi-structured approach allowed pre-specified topics to be discussed; however, there was also flexibility to explore emerging themes.

Topics covered included: views of co-production research, general experiences of co-production research, specific experiences of co-production research related to the LOUISA project, views surrounding user involvement and general comments. However, due to the semi-structured nature of the interviews, there was leeway to cover further topics raised naturally during the interview.

Another method of data collection considered for this phase was focus groups, which can work well for participants included in a pre-existing group (Lewis and McNaughton Nicholls, 2014). However, because the aim was to understand the

participants' personal experiences of working within this group, I decided that a more confidential setting was important. I wanted the participants to be able to discuss their views openly and I felt that this might not have been the case if the discussion were to be held in front of the other team members. Interviews offer participants a chance to express their thoughts and experiences through open dialogue with an interviewer in a private setting, which is why I decided that this would be the most relevant method of data collection.

7.5.2 Sampling

Sampling Strategy:

A purposive sampling strategy was adopted to recruit interview participants for phase two of the study, as this provided the opportunity to explore the experiences and perspectives of key stakeholders in the LOUISA project. The aim of purposive sampling is to select participants based on their ability to accurately inform on the research topic (Patton, 1990); therefore, I decided, with input from my supervisors, to invite specific stakeholders to be interviewed based on their appropriateness to contribute to the research topic.

No exclusion criteria were set for this stage of the research; however, participants were required to meet at least one of the eligibility requirements listed below to be considered for interview in phase 2 of this study:

- Service user involved in the LOUISA study
- Funder of LOUISA study (i.e. member of the LBSSL committee)
- Academic involved in LOUISA study based at the University of Leeds
- Healthcare professional involved in the LOUISA study

Sample Size:

The total number of participants interviewed for phase 2 of this study was 4. To ensure that all viewpoints were represented, 1 participant was interviewed from each of the eligibility criteria listed above. This sample size enabled an in-depth exploration of the phenomenon under investigation, whilst remaining manageable within the structure of this PhD.

7.5.3 Recruitment

As the recruitment for this stage of the study is focussed on LOUISA advisory group members, potential participants were contacted directly by the principle investigator of the LOUISA team, via email, to explain the purpose of the study. My contact details were also provided so that participants were able to make further contact to express their interest in participation. Whilst this could have potentially posed a risk of coercion to participate, Professor McGowan was the only researcher with access and permission to contact the group. Furthermore, although this study is linked to the LOUISA study, advisory group members were assured that participation in my PhD research was voluntary, and refusal to participate would not affect their position within the LOUISA study. No pressure was placed on participants to agree to participate.

Participants who contacted me to express an interest in participation were sent a participant information sheet (appendix R) and a consent form (appendix S), either via post or email. Participant information sheets contained all relevant details of the study, such as: purpose of the study, why they have been invited to participate, time requirements, data collection methods, details of how data will be disseminated, funder details, and researcher contact details. Participants were asked on the consent form, to confirm that they had read and understood the participant information sheet and to confirm that they understood that

participation in the study was voluntary. Participants were also asked whether they were willing to grant permission for interviews to be audio-recorded and for the use of direct quotations from interviews, on the understanding that they will be fully anonymised. At least 24 hours were given between participants receiving their information sheets and seeking written consent. Participants were given a maximum time of 2 weeks to confirm their wish to participate in the study. Signed consent forms were collected from participants on the day of data collection, prior to interview. I took spare consent forms with me in case participants forgot to bring their signed consent, however no pressure was ever placed on participants to sign a consent form and complete the interview.

7.5.4 Interview

In total, I conducted 4 interviews with key stakeholders from the LOUISA advisory group. As per my ethics approval, participants were offered the choice to be interviewed at the University of Leeds, their home, or their place of work. Once the participants had confirmed their wish to participate in the study, arrangements were then made to interview them at their preferred time and location. Two interviews were conducted at the participants' homes and 2 interviews were conducted at the participants' place of work (one of which was based at the University of Leeds). These interviews were conducted over a period of 3 months due to the availability of the participants. Although ideally, I would have liked to complete the data collection over a shorter time period so that I could more easily recall any relevant details between interviews; collecting the data over a longer timeframe allowed me to self-reflect and transcribe each interview before the next.

Prior to conducting the interviews, I developed a topic guide (appendix T), guided by the existing literature on co-production and my experience of

observing the group. As the purpose of the interviews was to explore the views and experiences of stakeholders in relation to co-production, the interview schedule was intentionally broad; this was to prevent narrowing the focus too much and to allow an open dialogue. For example, one question I asked the participants was: *What are your views on co-produced research?* The subsequent questions were then formed in response to this broad question. Prompts were only used if needed as a way to encourage a more open dialogue without steering the direction of the conversation. Participants were also encouraged to express their views and experiences from different times in the process e.g. expectations at the beginning. This allowed for a broader perception of experiences with co-produced research to be explored across the timeline of the project. The interviews lasted approximately 45 mins-1 hour.

All significant non-verbal cues were noted during the interview e.g. body language, as these notes can be important for contextualising the data. I also recorded field notes immediately after each interview, which also helped to contextualise the data and allowed me to reflect on the interview process. This was particularly important as my relationship with the interview participants was unique, in that I was informally involved with the work of the LOUISA group as my PhD is embedded in the larger study. I felt that it was important to reflect on the interview process, especially in instances where there was a potential power imbalance, e.g. when interviewing a representative of the charity funding my PhD. However, that being said, I do not think that these interviews presented additional challenges based on these pre-existing relationships; possibly because the topic was focussed on their personal experiences of the LOUISA project rather than my PhD, meaning that there was a degree of detachment. Furthermore, whilst I did know the participants prior to data collection, I was not

completely familiar with the group. I had built a rapport with the participants, but this prior association was not extensive and therefore did not affect my approach to data collection.

7.6 Data Analysis: Interviews

Thematic analysis was also used to analyse the interview data for phase 2 of this study. This mode of analysis seeks to explore patterns in qualitative data (Bryman, 2008) and can be used on data collected using different methods (Clarke and Braun, 2013). As with the phase 2 data collected through observation, the analysis of interview data was also guided by the 6-step thematic analysis phases (table 14) outlined by Braun and Clarke (2006). Each of the 6 steps of the analysis framework were followed for each interview transcript in full, before progressing to the next set of data. This allowed me to analyse and interpret the data from each participant fully, before developing broader themes across the data. As with the phase 1 interviews I decided that to make best use of my time I would transcribe interviews immediately in-between data collection, however, I made a conscious effort not to allow this to influence the subsequent interviews. Following the independent data analysis of each stage of data from phase 2 (interviews and observation), the data were examined collectively (appendix U). During this final stage of analysis, the interrelationships, similarities, and differences between the data were examined. Exploring the interview and observational data together provided a more comprehensive depiction of co-production research within the context of the LOUISA study.

7.7 Conclusion

This chapter presented the research methods used for phase two of this study. The research aims and objectives were clearly identified and a rationale for the chosen methods was provided. The chapter concludes by detailing the data analysis approach adopted for this phase of the study.

7.8 Summary

- **Phase two** aimed to examine the principles of co-production within the context of a live ongoing research project focussed on UI.
- Data collection included **observations** and **semi-structured interviews**.
- **Observations** of advisory group meetings were conducted to examine the interactions between LOUISA stakeholders (n=1).
 - Observations were intended to supplement interview data.
 - Spradley's 9 dimensions of descriptive observation (1980) was followed.
- **Semi-structured interviews** were conducted with key stakeholders.
 - Interviews explored the stakeholders' experiences of being part of a co-produced research project (n=4).
- No **exclusion criteria** were set, however, participants were required to meet at least one of the following **inclusion criteria**: service user, funder, academic, or healthcare professional involved in LOUISA.
- A **purposive sampling** strategy was used to explore the experiences of key stakeholders in the LOUISA project.
- **Data analysis** followed the thematic analysis process outlined by Braun and Clarke (2006): data familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report.

Chapter 8: Phase 2 Findings

8.1 Introduction

This chapter will present the findings from phase 2 of this study, which aimed to examine the principles of co-production within the context of an ongoing research project focussed on urinary incontinence. First, the background of the LOUISA study will be presented for context. Next, the themes identified will be explored. Lastly, recommendations will be made for researchers related to using a co-production approach for research.

8.2 Background

The findings for phase 2 of this study are based on data collected from observing and interviewing stakeholders involved in the Leeds Older women Urinary Incontinence Self-mAnagement study (LOUISA). The LOUISA study was established to develop a self-management package for older women with urinary incontinence. The study is funded by the Leeds Benevolent Society for Single Ladies (LBSSL), a charity that was founded to assist elderly single women living in Leeds. Initially, the charity contacted the University of Leeds with a proposal for collaborating on a research project. The charity were then connected with members of the School of Healthcare to develop a research project focussed on a specific health condition concerning older women. As a co-production model of research was adopted for the study, the specific research topic of urinary incontinence was decided in a series of priority setting meetings with members of LBSSL and the academics working on the project.

The LOUISA advisory group consists of academics, funders, service users and healthcare professionals. Stakeholders were initially approached by the principle investigator in consultation with the funders and were asked if they

would like to be a member of the LOUISA advisory group. It was anticipated that including members with a range of different experiences would enhance discussions and work in accordance with co-production. The advisory group were informed that they would meet at regular intervals throughout the progress of the project, which would give them an opportunity to share their experiences and make recommendations for the project.

The three-year LOUISA study launched in May 2016 and aims to develop and test a self-management package for older women living with urinary incontinence. However, due to unforeseen circumstances related to staff absences amongst the academic team, the project was delayed by 6 months. The project is therefore ongoing at the time of writing this thesis.

8.3 Description of Themes

The themes identified from the analysis of phase 2 data related to the facilitators and barriers to using a co-production model of research, as identified from the LOUISA study. In total 4 themes were identified: group roles, competing motivations, funder involvement and communication (diagram 4). Each of these themes were identified as having components that both facilitated and acted a barrier throughout the project. In the subsequent sections of this chapter, each theme will be explored from these differing perspectives. A summary of these themes as they relate to these facilitators and barriers can be seen in table 15.

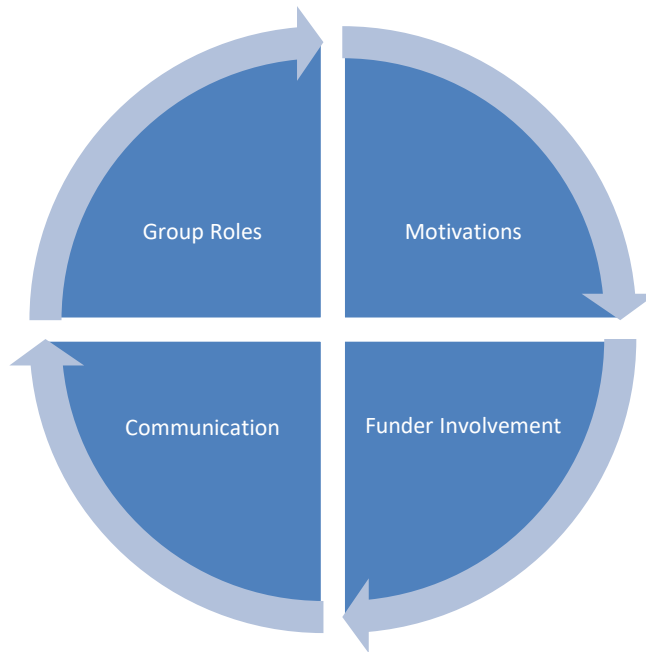


Diagram 4: Phase 2 Themes

Table 15: Phase 2 Summary of Themes

FACILITATORS		BARRIERS	
GROUP ROLES			
Diversity of members		Unclear expectations/roles	
Group dynamic managed well		Doubts about value of contributions	
		Lack of involvement	
COMPETING MOTIVATIONS			
Working towards common goal		Desired outputs	
		Financial motivations	
FUNDER INVOLVEMENT			
Engagement with funders		Power relationships	
		Impact on principles of co-production	
COMMUNICATION			
Communication during meetings		Communication between meetings	
Communicating issues		Communicating research processes	

8.4 Group Roles

The roles of the group involved in the LOUISA project were identified in the findings as both a facilitator and a barrier to the success of the co-produced project. The members chosen as stakeholders and the effective ways in which the group dynamic was managed, were acknowledged as having a positive influence on the project. However, lack of clarity concerning the roles and expectations of the members were recognised as barriers to the project. Some members were also uncertain about the added value that they offered to the project. Additionally, the lack of involvement of some stakeholders presented challenges to the project.

8.4.1 Group Roles: Facilitators

Diversity of members:

The members chosen as stakeholders for the LOUISA group were identified as a facilitator for the effective partnerships developed during the project. One service user involved in the project stated:

“Erm the makeup of the group, you know, it just seems to be so well balanced... you know, it seems to have somebody from all the important areas” (service user, interview 1, p.16)

An important principle of co-production is the equal inclusion and representation of all relevant stakeholders. This collaboration between traditional experts (e.g. healthcare professionals) and experts by experience (e.g. service users) is crucial for co-produced research. The importance of this engagement was reiterated by the service user, who discussed the personal benefit she experienced from participating in this study:

“I’ve found it really interesting though getting all the different viewpoints because obviously I’ve only seen it from my side” (service user, interview 1, p. 2)

The positive group dynamic of the stakeholders involved in the LOUISA project also influenced the expectations of future projects for some of the participants. When discussing possible future projects undertaken by the charity, one funder stated:

“And so, I would hope that if we moved forward it would be with similar types of people” (funder, interview 1, p.13)

Similarly, when asked whether the experience of being involved in the LOUISA study would impact her willingness to participate in similar studies, one stakeholder said:

“If there were such great people involved in it – yes [laughs]” (service user, interview 1, p. 12)

Management of group dynamic:

Co-produced research emphasises shared decision making, therefore when dealing with such a diverse group of people in this context, it is important for the group dynamic to be managed effectively.

One of the academics involved in the study discussed instances where certain stakeholders dominated the conversation and used “different language” related to practice. On these occasions, the academic expressed that her role was to “...make sure everyone has a voice”, particularly the women included as service users (academic, interview 4, p. 9):

“I always went back to them and said do you have any comments based on your experiences in clinic or based on your stories, or how

do you feel about this condition, or do you feel like what they said reflects what you are experiencing” (academic, interview 4, p. 9)

This was also reiterated by other stakeholders, who conveyed that the group sessions were managed well. One healthcare provider stated:

“They’re supportive and respectful and I think it was very well chaired which is important” (healthcare professional, interview 3, p. 5)

The effective management of the group dynamic was also captured in the data collected from the observation of one of the stakeholder meetings. Although the session was primarily led by one of the academic stakeholders as the meeting was focussed on the progress of the project, all members were actively encouraged to share their views, experiences and suggestions for improvement.

8.4.2 Group Roles: Barriers

Unclear expectations/roles:

Within the sample of stakeholders interviewed for phase 2 of this study, only the healthcare professional had experience of working on a co-produced project of this sort. Setting clear expectations was therefore essential prior to the start of the project. However, the participants explained that they were unclear as to what to expect from participating in this project. One stakeholder stated:

“P: In a way I didn’t have an expectation, that was what worried me

I: Right

P: Because I didn’t know what...what was wanted of me”

(service user, interview 1, p. 6)

Similarly, one of the funders of the project expressed her concerns about the unfamiliarity of this new project:

“Erm... well we were apprehensive because it was the unknown”

(funder, interview 2, p. 6)

Although prior briefing was given for this project, it appears that the concerns around expectations were not always alleviated for the stakeholders. An additional, more comprehensive briefing and setting of expectations might have helped to clarify the position of the stakeholders.

There was also uncertainty related to the roles and responsibilities during the project. One stakeholder said:

“I suppose at times I’ve not quite known what my role was to be

honest” (healthcare professional, interview 3, p. 1)

Furthermore, the expectations about which parts of the research process the stakeholders would be involved in were at times ambiguous. One stakeholder had hoped to contribute to the research publications but discussed how this prospect was not discussed as openly as it could have been:

“I hope that I get to participate in the writing of the literature and the publication and I suppose I’d be a bit disappointed if I didn’t”

(healthcare professional, interview 3, p. 2)

It appears that management of expectations and clarification of roles were needed in some cases, to prevent unclear responsibilities from acting as a barrier to the co-production of the project.

Value of contributions:

The service user interviewed for phase 2 of this study, expressed concerns about where her value lay within the project team. She stated:

“... I could see the reason why the other people would be involved, erm, you know because they’re at the coal face, they’re dealing with people who have the problem, erm, but I wasn’t sure because she’d got interviews, I wasn’t sure what else I could contribute really”
(service users, interview 1, p. 6)

This concern about personal contributions was also echoed when she said:

“I don’t mind giving my opinion but I’m not... I’ve never done it in a formal way. That’s a bit more formal than I have ever done. So I was a bit worried that I wouldn’t be able to contribute enough” (service users, interview 1, p. 6)

One of the key advantages of conducting co-produced research is the significance of shared experiences from diverse participants. In the LOUISA study, the knowledge that service users were able to share, added a valuable dimension to understanding the experience of urinary incontinence; however, the importance of this unique perspective does not appear to have been considered by the service user. This could have acted as a potential barrier to the project, as it may have influenced the level of involvement that the participant felt was warranted.

Lack of involvement:

Although most of the stakeholders engaged with the project regularly, there were some issues related to the lack of involvement of some members of the funding charity. This often led the key contact from the charity to feel like she

was *“in-between everybody”* (interview 2, p. 6) and responsible to act as a mediator between the charity and the academic team. When discussing this role she said:

“But you have to be quite erm... what’s the word I’m trying to think of... you have to be kind of a bit political when you’re chairing the committee and keeping everybody happy” (funder, interview 3, p. 6)

Despite being invited to the LOUISA meetings, the majority of the funding committee did not attend. The funder interviewed, reflected that she had hoped that the rest of the committee would take a more active role in the project:

“I would have liked some of them to have been more involved with the meeting stages” (funder, interview 2, p. 3)

If the wider committee had taken a more active role in the project, they would have been better informed about the progress of the study and would have been given more opportunities to share their opinions or ideas, which would have benefitted the project. Furthermore, the burden of relaying information between parties would have been alleviated for the committee chair.

8.5 Motivations

The motivations for becoming involved in the LOUISA project acted as both a facilitator and a barrier to the success of the project. Whilst the fact that the stakeholders all shared the common motive of wanting to help women with urinary incontinence; there were also barriers related to project outputs and incentives.

8.5.1 Motivations: Facilitators

Working towards a common goal:

The reasons for participation in this project were varied, including factors such as personal experiences or professional development. However the overriding motivation was to help women suffering with urinary incontinence. This common goal was identified in the data as a facilitator for the effective working relationships in the group.

When discussing the motivations for wanting to conduct this project with one of the funders, it was clear that the motivation was to help women. When discussing how the decision was made to finance the project, the funder recalled that the committee discussed ways they could help and ultimately asked themselves:

“What do we put our money towards which would help elderly women?” (funder, interview 2, p. 1)

Another stakeholder discussed how her interest in urinary incontinence was initiated when she had acted as a carer for her mother who was suffering with the condition. At the time there was no helpful information on self-management so the condition had a negative impact on her mother’s life. When discussing her involvement with the LOUISA study, she said:

“I’d like to think that I’m maybe contributing something that will help future women or women, you know, now” (service user, interview 1, p. 2)

Similarly, the healthcare professional interviewed, stated that her motivations for participating in the project were due to personal interest and a desire to help a worthy cause:

“I just thought it was a really interesting and valuable project because it addresses the needs of a lot of women I think. A lot more women than I think we realise” (healthcare professional, interview 3, p. 1)

When discussing motivations for the project with one of the academics working on the project, the use of a co-production approach was linked to the motivation of creating a useful and acceptable package to help women:

“... if we could capture their views and have them involved at an early stage when we’re designing the intervention, while I can’t say that will guarantee it, but you know it’s highly likely that we will produce something highly relevant and useful for them [women] to use” (academic, interview 4, p. 2)

The fact that the motivations for participation were centred around the same goal of helping women, was recognised and appreciated by members of the group:

“Everybody’s genuinely interested and genuinely cares and genuinely wants to make it better” (service user, interview 1, p. 11)

8.5.2 Motivations: Barriers

Whilst sharing a common goal towards helping women with UI was a facilitator for the project, there were also some practical issues surrounding motivations that acted as a barrier at times.

Desired outputs:

One issue identified from the data was the desired output of the project. When discussing this, one funder stated:

“I think one of the primary erm... arguments amongst ourselves was erm that it had to be not like a university paper” (funder, interview 2, p. 4)

Although she did later acknowledge that academic work plays an important role in the project, for the funders this was not their priority. Whereas, for academics working within a university setting, the publication of papers is crucial for academic development.

“So yeah it’s certainly a barrier if the people don’t know, you know, what the research really involves in making sure we deliver a high quality rigorous study” (academic, interview 4, p. 8)

Whilst it is possible to produce several outputs from a project, this is an issue that needs prior clarification through clear communication, which is a theme that will be discussed further in section 8.7.

Financial motivations:

Another potential barrier identified was the lack of financial motivation for participation in this group. One academic expressed the importance of recognising the input of stakeholders with financial payment:

“I mean, unfortunately, we should, we couldn’t afford to give them any sort of payment or anything, but I think it’s important to you know recognise the time, the input, the responsibilities and the data that they contribute. I think it’s important to value that by some sort of payment or financial support” (academic, interview 4, p. 10)

This lack of financial support could have impacted the amount of time that stakeholders were willing or able to contribute to the project. However, it could also be argued that offering financial incentives could influence the motivation of stakeholders, who might not otherwise choose to participate in such a study.

8.6 Funder Involvement

The involvement of the funders in this co-produced study was a divisive issue within the project. On the one hand, the project benefitted from the sincere interest and input from the funders; however, at times the participants expressed potential barriers presented by the role that the funders played in the project.

8.6.1 Funder Involvement: Facilitators

Engagement with funders:

The funders of this project are a local charity dedicated to supporting older women in the Leeds community. For that reason, the relationship between the academics and funders was more involved than might usually be expected of a standard funder-academic relationship. Added to that was the fact that this project adopted a co-production approach which called for greater collaboration and shared-decision making than other approaches. This critical involvement

was advocated by one of the funders of the project when discussing her hope that more members of the charity would participate in the group meetings:

“It’s, it’s if you’re having research and people are involved in funding...because they’re all very kind of “oh well you know we’re paying for this” well that’s all very well and... but you can’t just pay for something, you have to involve, you have to know what you’re paying for” (funder, interview 2, p. 9)

The benefit of this involvement is that the charity members are embedded in the community and have knowledge and experiences that are unique from other stakeholders. This genuine interest and passion shown by the funders of this project was an important element for some stakeholders:

“...obviously they clearly have a deep interest in the subject. It’s not just here we’ll dole out the money and then oh we couldn’t care less once we’ve done our bit. You feel that they’re committed and they think it’s an important project” (service user, interview 1, p. 11)

This stakeholder also raised a further point related to the funders:

“I was just going to say that there’s just one thing that I like as well, is the fact that it’s not financed by any of the erm, you know the Lily Whites or whoever makes pads or something” (service user, interview 1, p. 17)

The fact that the project was funded by a local charity focused on improving the lives of elderly women, rather than a corporation seeking to make profit, was seen as a benefit in this case.

8.6.2 Funder Involvement: Barriers

Power relationships:

One of the barriers to the project related to the involvement of the funders, was the power relationship between the funders and the rest of the group. The funder perspective of the relationship with the academics is illustrated in the extract below:

“I: And do you feel like if you’ve ever raised any concerns that they’ve been taken on board and actions been taken?”

P: Yes. Well yes because you see we hold the purse strings so really they have to listen to us” (funder, interview 2, p. 3)

Despite the fact that co-production is about shared-decision making, it would appear here that the funders believe that their suggestions must be listened to based on the perceived power of financial support, rather than because of the principles of equal participation advocated by the project.

Additionally, the negative influence of power relationships were also recognised within the wider group setting:

“... if they just sat there I’m sure that would have a huge impact on everyone else in that room... you can tell from their body language because they’re sitting like that [leans forward], and showing people that I am the funder of this research study” (academic, interview 4, p. 9)

This power-relationship was not something that was noted during the observation undertaken of one of the stakeholder meetings, however this is possibly because the meeting observed was relatively early on in the overall project lifespan.

Impact on principles of co-production:

Another issue raised, concerned whether the inclusion of the funders affects the validity of the co-production approach. One stakeholder stated:

“I suppose its had an added complication because the people who are co-producing it are also the funders. So how, so technically is it co-production? Or actually is it the funder overseeing the delivery of the project?” (healthcare professional, interview 3, p. 4)

Although the project was initially co-produced exclusively with the charity during the inception of the project, since the formation of the advisory group the shared-decision making process involved all participants. However, the potential dominance of the funders, both in terms of number of members and assumed power, could have biased the collective nature of the project at times.

An added complication is that it was unclear amongst the group whether the members of the charity were sharing opinions based on personal experiences.

As one stakeholder discussed:

“Yeah because it’s never been clear whether those people contributing to the meetings, whether they experienced urinary incontinence or whether they were doing it on behalf of their group” (healthcare professional, interview 3, p. 4)

Clarifying the role of the funders within the group could have alleviated some of these issues and encouraged a more open dialogue amongst the stakeholders about the direction of the project.

8.7 Communication

Communication was also viewed as both a facilitator and barrier by the participants in the LOUISA study. Communication at meetings and communicating issues were both perceived to be positive by the stakeholders. However, communication between meetings and communicating research processes, presented challenges in this study.

8.7.1 Communication: Facilitators

Communication at meetings:

Communication at the group meetings was highly praised by the participants. Stakeholders reported that they were consulted regularly and felt like they were listened to as a valued member of the group. One stakeholder said:

“Because they’re consulting all the time and coming back and saying is that ok? Do you think that’s good? Can you see any other way of doing it? Or an improvement? They’re going to end up with something that should be very, very helpful to people” (service user, interview 1, p. 7)

One of the stakeholders discussed how she felt that her experiences had been listened to and valued following a discussion with one of the academics:

“And it was a little thing, and I noticed [researcher name] had put it in the brochure and I thought “oh she’s taken notice of that” (funder, interview 2, p. 10)

Good communication is essential for the progression of any project, especially a project using a co-production approach where all opinions should be equally

valued. The positive open communication at the group meetings were therefore identified as a facilitator to this project.

Communicating issues:

Another facilitator to the project was the impact that good communication had on the way that issues were resolved within the team. The excerpt below demonstrates this:

“P: Because it’s not, you know it has to be a group decision and I’ve asked for example, [researcher name] something or [researcher name] something, there has been a reaction.

I: Yeah?

P: Yes. There’s not been a time when where I’ve wrote to [researcher name] and said this is wrong and... she would definitely write back and say “oh well we’ll get onto it”

I: Yeah.

P: I’ve never felt that we’ve been ignored at all”

(funder, interview 2, p. 7)

Communicating and resolving issues within a group co-producing research is essential for the progression of the study. It appears from the data that establishing good relationships with the stakeholders and prioritising open communication helped to advance the LOUISA study.

8.7.2 Communication: Barriers

Communication between meetings:

Whilst the stakeholders felt that there was good communication at the team meetings, the most common barrier reported by the participants was lack of communication between meetings. One participant stated:

“Yeah they could do with erm being erm less time in between. Because you tend to lose the flow of it as though sometimes what you... at the beginning of the meeting you’re just kind of refreshing your memory’ (service user, interview 1, p. 10)

This was reiterated by another participant who said:

“Erm so I think maybe a bit more of a reminder in-between the meetings about where we’re up to would have been helpful” (healthcare professional, interview 3, p. 3)

When asked about lessons learnt from the LOUISA study which could be carried forward to potential future projects, one stakeholder expressed that greater communication would be expected:

“I would erm... well again I would be probably looking for more communication” (funder, interview 2, p. 11)

Although communication was good in some areas, predominately meetings, the participants reflected that more frequent communication throughout the project as a whole would have been appreciated.

Another time when greater communication was expected by the stakeholders, was during a time when both academics working on the project were unexpectedly off-work for a prolonged period of time. One of the funders

discussed the lack of communication around this time, specifically regarding the recruitment of a temporary staff member to cover the staff absences:

“We were told it was being done by somebody who we never met. I don’t know who she was. But that was a period of a few months where I was getting a little bit, from my point of view, concerned”
(funder, interview 2, p. 12)

Communicating research processes:

For some of the stakeholders, the LOUISA project was their first experience of being involved in academic research in this format; therefore, there was a general lack of knowledge about research processes for some of the participants. Communicating these research processes was a barrier that had to be addressed by the academic team. As one academic stated:

“And erm, yeah I mean, and also we didn’t expect that you know, just getting them to understand the research process is so difficult although we have tried” (academic, interview 4, p. 6)

At times it was difficult to manage expectations for timelines which were dominated by lengthy research processes, e.g. conducting a systematic review, as there was a lack of knowledge around these processes.

“... but I don’t think they have much research experience and they couldn’t see why we have to wait for so long to get something done”
(academic, interview 4, p. 3)

To alleviate some of these concerns and communicate the relevant academic processes to the stakeholders, sessions were held at the university to clarify these issues. For example, a session was held on the stages involved in conducting a systematic review. However, not all members attended this

session and the communication of these methods remained unclear to some of the stakeholders.

“So yeah, the other issue I would say is the effective communication.

So if you can't have everyone on board, you know say the

experience with us, we can't deliver that workshop with everyone

inside so erm they didn't really understand” (academic, interview 4, p.

7)

Although attempts were made to communicate the necessary research processes, lack of attendance at these meetings prevented this from being effective. Further modes of communication e.g. written, could have been a useful addition in such circumstances.

8.8 Recommendations

A set of recommendations have been developed from the findings of phase 2 of this study, related to co-producing research. Although the expected research outcome for this study was to develop a framework for conducting co-production research, the data generated from this research was more suitable for producing broader recommendations. These recommendations will not be applicable to all studies using co-production due to the individualised nature of this approach. Instead, these recommendations are intended to provide general guidance for researchers planning to conduct co-produced research in similar areas related to stigmatised, physical LTCs.

Table 16: Phase 2 Recommendations

CO-PRODUCTION RECOMMENDATIONS	
BEFORE PROJECT:	
(1) Managing Expectations	
<ul style="list-style-type: none"> • Full briefing to the group (either individually or as a group) 	
<ul style="list-style-type: none"> • Expectations of involvement (e.g. time commitment expected) 	
<ul style="list-style-type: none"> • Format of involvement (e.g. group meetings) 	
<ul style="list-style-type: none"> • Value of contributions to be made clear (e.g. experts by experience) 	
<ul style="list-style-type: none"> • Ensure the role of funders is made clear (if involved) 	
(2) Group Diversity	
<ul style="list-style-type: none"> • Important to include group members with diverse experiences 	
<ul style="list-style-type: none"> • Understand and acknowledge potential competing motivations 	
<ul style="list-style-type: none"> • Ensure experienced or well-trained facilitators manage group dynamics 	
DURING PROJECT:	
(1) Communication	
<ul style="list-style-type: none"> • Open communication at all research stages is essential 	
<ul style="list-style-type: none"> • Regular communication in between face-to-face meetings 	
<ul style="list-style-type: none"> • Explain research processes to all members (regardless of experience) 	
(2) Involvement of Group Members	
<ul style="list-style-type: none"> • Encourage involvement from all members throughout project 	

Before Project:

The findings from this study identified that there are several steps that can be taken at the beginning of a co-produced study to aid the success of the project.

The recommendations made from these findings relate to management of expectations and group diversity.

Managing expectations is a crucial first-step when developing a project using a co-production model. It became clear from the interviews conducted with members of the LOUISA study, that participants were not always clear about

their role within the group. Although members had been briefed prior to the start of the project, the individual roles and responsibilities of the members were not clear. A recommendation for similar projects would be to ensure that these expectations are managed from the beginning. A comprehensive briefing should be conducted with group members to clarify the aims, expectations, and formats of involvement for the project. This could be conducted as a group or individually, depending on the suitability for the project. Additionally, the value brought to the project from the input and experiences of each participant should be made clear, to encourage personal confidence in contributing to the project. For example, if a participant has no clinical experience, but has first-hand experience of an illness either as a patient or carer, then the importance of these experiences should be made clear to the participant. Lastly, whilst the level of involvement of the funders in the LOUISA study was unique, lessons can still be learnt for projects with similar arrangements. If funders are actively involved in co-producing research with a wider group, the boundaries for involvement must be explained upfront. This is to clarify that co-production advocates for equal participation and shared-decision making, and therefore no preference will be given to the requests of any specific stakeholders.

Group diversity was seen as a benefit to the stakeholders in the LOUISA study, as the varied experiences and perspectives could be shared amongst the group. This varied representation is important to consider when approaching potential stakeholders for a co-produced project. With varied representation there is, however, the potential for participants to have varied motivations for participation, such as personal interest, publications or career development. It is important to understand and acknowledge any potential competing motivations upfront. Whilst it is possible to produce several outputs from a project, which

may accommodate the individual needs of the participants, these practical issues need prior clarification. Another recommendation related to group diversity, is the inclusion of an experienced or well-trained facilitator. Despite the benefits of a diverse group, practically managing the discussions between such a varied group can be challenging due to clashing personalities and points of view. In the LOUISA study, the stakeholders reported that the group was managed well which facilitated open discussions where participants felt listened to within the group setting. To offset any potential clashes between the group, experienced facilitators are necessary.

During Project:

Further recommendations from this study related to actions that can be taken throughout the project. These recommendations concerned communication and involvement of group members.

Communication is key for all research, particularly research involving a variety of stakeholders working in a shared-decision making format such as co-production. Communication during stakeholder meetings was regarded positively by the participants of the LOUISA study as they felt that they were consulted throughout. However, there was a lack of communication between meetings, which was recognised by the stakeholders as a barrier to the project. A future recommendation would therefore be to ensure that regular communication in between face-to-face meetings is upheld throughout the research process. Another recommendation related to communication, is that time should be taken to explain the research process to all stakeholders, especially as some members might not have experienced research in an academic setting. This was a challenging part of the LOUISA study, as some of the participants had a lack of prior knowledge about research processes, which

meant that communicating lengthy research processes e.g. systematic reviews was difficult. However, communicating these methods is essential for participants to be able to understand and fully-participate in all stages of the research process.

Involvement of group members is another important issue to consider throughout the duration of the project. Lack of ongoing involvement and attendance at meetings was identified as a barrier in the LOUISA project, as sharing information became difficult and led to certain stakeholders having to relay information between parties. Although it might not be feasible for all stakeholders to attend every meeting across a 3-year project, there should be continued engagement. If full attendance at meetings is not occurring then further attempts could be made to encourage active involvement. Additional modes of communication e.g. written, could also be used to prevent barriers to effective communication and contribution of stakeholders.

8.9 Phase 2 Findings Summary

A key finding from phase two of this study relates to *power differentials* within the context of a co-produced project, where shared decision-making is prioritised. This was a theme that was identified in both the scoping review and the findings from data collection. One of the theoretical challenges identified from the scoping review, concerned issues of power relationships whilst conducting co-produced research within an academic research culture. The potential challenges that could be faced by academics required to relinquish power e.g. difficulties upholding university requirements, was an issue that was raised in relation to co-producing research. From the data collected during

phase two of this study, issues concerning power relationships were also highlighted, however, in a different context. The role of the funder in the co-production process for the LOUISA study was identified as challenging, due to the power imbalance perceived by the group. As co-production adopts a unique format for conducting research, it is important to understand the different ways in which power imbalances can be managed within the research structure. The concept of power differentials will be explored in more depth in the discussion chapter of this thesis, within the context of wider theory and existing literature.

8.10 Conclusion

This chapter describes the findings from phase 2 of this study, which focused on the realities of co-production within the context of a live research project. Four themes were identified: group roles, motivations, funder involvement and communication. Each theme encompassed components that both facilitated and acted a barrier to the project. Recommendations were made as a result of these findings, relating to: managing expectations, group diversity, communication and involvement of group members. It is anticipated that researchers conducting similar research on LTCs may find these recommendations useful.

8.11 Summary

- Phase two **examined co-production within the context of the LOUISA study**. Themes identified were: group roles, competing motivations, funder involvement and communication. Each theme included facilitators and barriers.
- **Group roles (facilitators):**
- Successful partnerships encouraged through diversity of members.
- Effective management of group dynamics facilitated co-production.
- **Group roles (barriers):**
- Some participants had unclear expectations about their roles.
- Some participants worried about the value of their contributions.
- Lack of involvement of some members was identified as a barrier.
- **Competing motivations (facilitators):**
- Working towards a common goal to help women with UI.
- **Competing motivation (barriers):**
- Conflicting desired outputs were a potential barrier.
- Lack of financial motivation could impact contributions.
- **Funder involvement (facilitators):**
- The interest and passion shown by the funders was viewed positively.
- **Funder involvement (barriers):**
- Power relationships related to the funders acted as a barrier.
- Funder involvement could impact on the shared principles of co-production.
- **Communication (facilitators):**
- Good communication at meetings meant that members felt valued.
- Communicating issues was a positive experience as issues were always resolved effectively.
- **Communication (barriers):**
- Lack of communication between meetings was a prevalent barrier.
- Some stakeholders had never participated in academic research, meaning that communicating research processes was a barrier that needed to be overcome.
- **Recommendations** were made as a result of these findings, relating to managing expectations, group diversity, communication and involvement of group members (table 16).

Chapter 9: Ethical Considerations & Research Quality

9.1 Introduction

This chapter will present a discussion of the ethical considerations and research quality issues for both phases of this study. Firstly, ethical considerations will be detailed, including informed consent, confidentiality and anonymity, and risk assessment. Next, research quality will be discussed in relation to eight core components of quality: worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence.

9.2 Ethical Considerations

9.2.1 Informed Consent

Prior to recruitment and data collection, full ethical approval was granted from the School of Healthcare Research Ethics Committee (SHREC) at the University of Leeds. At least 24 hours were given between participants receiving their information sheets and seeking written consent, to give participants time to consider. Individual written consent was sought from all participants prior to inclusion in the study. Signed consent forms were collected from participants on the day of data collection, prior to interview or observation. All recruitment materials were written in a clear and understandable manner to ensure accessible and transparent communication with participants. No pressure was placed on participants to agree to partake in the study. Additionally, for phase 2, participants were assured that refusal to participate would not affect their position within the LOUISA study. No deception of any kind was used to recruit participants. Participants were informed that there may not be any direct

personal benefits from participating in the study e.g. financial incentives.

Participants were informed of their right to withdraw from the study in the participant information sheet and consent forms.

9.2.2 Confidentiality & Anonymity

To maintain participant confidentiality and anonymity, pseudonyms were used throughout the research. Personal details obtained through data collection, such as participant names, were stored separately from the corresponding data associated with the participant to ensure full anonymity. Participants were given anonymised ID numbers which were used for reporting during dissemination.

Only myself, and PhD supervisors, had access to this identifiable information.

Maintaining anonymity was more challenging for phase 2 of this study, where LOUISA stakeholders were interviewed and observed, due to the small number of potential participants. Throughout this thesis and future related publications, the use of direct quotes in addition to descriptive information provided, could make the participants potentially identifiable within the group. However, the data for phase 2 is not particularly sensitive and each participant gave full consent to participate in the study. That being said, to manage confidentiality, any feedback on findings given to the group will be summarised, with no identifiable information provided e.g. quotes. Furthermore, if a participant disclosed that they were unhappy with certain aspects of the study, then this information would be anonymously raised with the PhD supervisors. However, if a participant disclosed that they were unhappy with the performance of the academics involved in the study, guidance would be sought from another supervisor who is not involved in the project, who would be able to provide impartial advice.

Following data collection, data were managed and stored securely. Electronic data, such as audio recordings and interview transcripts were encrypted and

stored on a password protected computer. Data recorded in paper form were stored in securely locked drawers in the lead supervisor's office within the University. On completion of the study, paper documentation will be scanned and stored on a password protected computer. Paper documentation will then be shredded.

9.2.3 Risk Assessment

Participants were not deemed to be at risk from participating in this study.

Although the interview topics were not expected to cause upset to participants, a distress policy was put in place in case of such instances (appendix V). Lone working was a risk associated with the research, as one-to-one interviews were conducted. As interviews were conducted either in the University or at a participant's home, the University of Leeds Lone Worker policy was adhered to at all times. A risk assessment was conducted prior to fieldwork, supervisors were informed of the times and locations of data collection, and I carried a mobile phone in case of emergency. I also regularly de-briefed with PhD supervisors to ensure that any issues or concerns were addressed. This was particularly important following the phase 1 interviews where women were discussing their experiences of UI, as there was the possibility that these participants could become distressed during the interviews. A check-in schedule was developed prior to data collection, where I sent an email or text to one of my supervisors as I arrived at the location of data collection, and then immediately after I left the location. When interviews were conducted away from the university e.g. at a participant's house, the contact details and address of the participant were sent in a password-protected Word document to my supervisor. The password was then sent in a separate email. These documents were deleted following data collection.

9.3 Research Quality

Qualitative research has been criticised for lack of rigour, often relating to problems of subjectivity, generalisation, difficulty of replication and lack of transparency (Bryman, 2008). In an attempt to dispel such criticisms, numerous evaluative criteria have been developed over the years for qualitative research (Lincoln and Guba, 1985; Yardley, 2000). However, as Tracy (2010, p. 832) highlights, having varying quality criteria can often 'bewilder' researchers in the field. Traditional positivist criteria used for assessing quantitative research, such as replication, are not well-suited to qualitative research (Bryman, 2008). Instead, more applicable criteria must be utilised to assess the quality of qualitative research. Tracy (2010) provides a comprehensive guideline for assessing such research, by addressing eight core components of quality. These criteria are: worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence (Tracy, 2010, p. 837). The criteria set out by Tracy (2010) guided the quality of this research study as outlined below.

9.3.1 Worthy Topic

Phase 1 of this study focusses on the topic of urinary incontinence, specifically related to the lived experiences of women aged 55+. Urinary incontinence is commonly viewed as a stigmatised illness (Elstad et al., 2010) and is often not openly discussed with healthcare providers (Hägglund and Wadensten, 2007). Conducting research in this area is therefore crucial to unearth some of the key issues faced by incontinent women. Phase 2 of this study focusses on co-production research. Co-production is a relatively new method of research, therefore exploring the practicalities of this approach is a worthy topic which has the potential to offer recommendations to other researchers.

9.3.2 Rich Rigour

Tracy (2010) argues that rich rigour can be achieved by: ensuring that there is sufficient data to support findings, enough time is spent gathering interesting data, the sample is appropriate, and research procedures are suitable (e.g. field notes, interview techniques and analysis procedures). Although the sample sizes for each phase of this study were relatively small, the in-depth, interpretive nature of the data collection meant that sufficient data was collected.

Furthermore, the chosen methods of data collection were appropriate given the topic and the research aims and ensured that rich data was collected. Depth of analysis is also important to consider when discussing how much data to collect. As Tracy (2010, p. 841) argues, 'Close line-by-line data analysis can be rigorous even when using just several lines of transcription'. Data were analysed in-depth using the IPA guidelines advocated by Smith et al. (2009) (phase 1) and thematic analysis advocated by Braun and Clarke (2006) (phase 2). The data collected for this study was therefore substantial enough to adequately answer the research questions and contribute to knowledge around these topics, due to the depth of analysis and interpretation. Additionally, each interview was transcribed verbatim to ensure that the analysis remained as close to the original context as possible. Furthermore, the sample was appropriate for addressing the research aim and participants met the inclusion criteria outlined in earlier in the thesis. To further aid rigour, the data analysis processes used have been described fully and tables have been included in the results chapters to show the journey of analysis from raw data to relevant themes.

9.3.3 Sincerity

Sincerity refers to the authenticity of the research, specifically in relation to self-reflexivity and transparency (Tracy, 2010). Prior to collecting data for this study, I underwent a process of self-reflection by attempting to recognise my personal feelings in relation to the study. Although I do not believe that true objectivity can be achieved through “bracketing” (Creswell, 2007), I hoped that this self-examination would allow me to consider my thoughts and aid sincerity in the research process. Through this exercise I identified that the key points of relevance were my prior knowledge and my involvement in the LOUISA project. Before embarking on this PhD research journey, I had no prior knowledge of the topics of urinary incontinence or co-production. Although it was challenging at first to become familiar with the literature surrounding these topics, ultimately, I think that this was a positive factor as I had no pre-conceptions prior to developing the research design or collecting data. Additionally, my involvement in the LOUISA project was an issue that I reflected on throughout the research process. As my PhD is embedded in the LOUISA study, I had a degree of familiarity with the progression of the project prior to collecting data from stakeholders. To prevent this knowledge from unfairly influencing the research, I ensured that the interviews were respondent-led and I consciously reflected to confirm that I was not asking leading questions. Transparency is also an important factor to consider when maintaining research sincerity. Research transparency represents ‘honesty about the research process’ (Tracy, 2010, p. 842). To aid transparency, a reflexive research journal, field notes and an audit trail were kept throughout the research process. Additionally, I have also made it explicit that this study is funded by LBSSL.

9.3.4 Credibility

One of the key components of credibility is 'thick description' of the data, meaning that enough details are provided so that 'readers may come to their own conclusion about the scene' (Tracy, 2010, p. 843). Due to the idiographic nature of IPA research, remaining true to the specific context of the individual case is crucial. In-depth descriptions of the data are therefore provided throughout this research. Tracy (2010, p. 843) also highlights the importance of 'tacit knowledge' such as silence and humour (Altheide and Johnson, 2011). The acknowledgements of 'what is not said' is also important to aid the illustration of context to the data. This is something that I strove to document and record throughout the research process; for example, given the sensitive nature of incontinence, humour and laughter often featured in the interviews. Although the fieldnotes were brief jottings rather than formalised notes, they provided context to the subsequent analysis and reporting of findings.

Triangulation is another component that contributes to the credibility of a study (Tracy, 2010). Triangulation is often used to seek a greater understanding of a phenomenon, and can be achieved by using multiple: methods, sources, researchers or theoretical perspectives (Patton, 1999). For phase 1 of this study only 1 method of data collection was used. However, for phase 2, both interviews and observations were conducted to obtain a more comprehensive understanding of the co-production research process. Although originally several observations were planned, it was only possible to conduct 1 observation due to unforeseen issues. Nonetheless, observing one of the stakeholder meetings allowed me to contextualise the subsequent interviews with stakeholders and facilitated a deeper understanding of the issues raised

during the data collection. Furthermore, as the meeting was 3 hours long, I was able to collect sufficient in-depth data.

Member reflections are also key for maintaining credibility and should be viewed as 'an opportunity for collaboration and reflexive elaboration' rather than a test of the data (Tracy, 2010, p. 844). I decided not to send interview transcripts to the participants for review as I wanted to avoid any undue revisions that could potentially alter the accuracy of the conversations held (Hagens et al., 2009). I did however, ensure that I gave participants a chance to reflect on their experiences throughout the interview by recapping. This allowed me to verify whether I had understood the meanings conveyed by the participants, and provided an opportunity for them to clarify or elaborate on their experiences. As Gillham (2005, p. 33) argues, 'People often think they are being clear when they are not'. Recapping during the interview therefore acted as a form of validation.

9.3.5 Resonance

Resonance relates to whether the research meaningfully affects the audience. Firstly, resonance can be achieved through 'aesthetic merit' which emphasises the importance of the presentation of the content (Tracy, 2010, p. 845).

Although the structure of this PhD is multifaceted in that there are two phases with separate aims and data collection methods; I have endeavoured to present the research in a clear and compelling manner throughout. Secondly, resonance develops through transferability and naturalistic generalisations, both of which are 'processes that are performed by the readers of the research' (Tracy, 2010, p. 845). These processes refer to the practice whereby the reader transfers the knowledge or experiences gained from the research to their own situation, allowing resonance across contexts. One of the aims of this research is to understand how better to co-produce research with people suffering with

long-term conditions. Although this study is specifically focussed on urinary incontinence, it is anticipated that knowledge gathered from this research could be applicable to other similar long-term health conditions.

9.3.6 Significant Contribution

Another marker of research quality is whether a significant contribution has been made to the field. As identified in the qualitative meta-synthesis (chapter 3), very little research has been conducted focusing specifically on the experiences of older women with urinary incontinence living in the UK. Furthermore, there is a dearth of research focussed on the experiences of women who have either never, or are not currently seeking medical treatments or interventions for the condition. Therefore, this study offers a unique perspective on the topic of urinary incontinence; as it is the first study to explore UI from the perspective of older women in the UK who have never, or are not currently seeking medical interventions. Additionally, phase 2 explores the practicalities of conducting co-produced research in a real-world setting. Furthermore, whilst most research focused on co-production is conducted retrospectively, the data for phase 2 of this study were collected whilst the project was in-progress; meaning that the views expressed were not affected by recall bias. Recommendations made from this research will contribute knowledge to this relatively new method of conducting research. Furthermore, this research is 'heuristically significant' due to the fact that suggestions for further research have been developed from the research findings of this study (Tracy, 2010, p. 846).

9.3.7 Ethics

Ethical considerations are crucial for all research studies and should be reflected upon throughout the research process (Webster et al., 2014). Tracy

(2010) highlights a variety of ethical practices that should be addressed:

procedural ethics, situational ethics, relational ethics and exiting ethics.

Procedural ethics refers to 'ethical actions dictated as universally necessary by larger organizations, institutions or governing bodies' (Tracy, 2010, p. 847), e.g.

informed consent. These procedural ethical considerations were upheld

throughout the study and ethical approval was obtained from the University of

Leeds prior to data collection. The full details of these procedural ethical

processes have been described fully in the previous section of this chapter.

Situational ethics focusses on the notion that 'ethical decisions should be based on the particulars of a scene' (Tracy, 2010, p. 847). Situational ethics

emphasises the need for researchers to constantly reflect on their ethical

decisions throughout the study, as research is a dynamic process that is often

subject to change. This is something that I endeavoured to achieve throughout

this study. As components of the study changed, e.g. incorporating snowball

recruitment, the ethical implications were discussed at length with my

supervisors prior to action being taken. Relational ethics refers to 'an ethical

self-consciousness' whereby researchers consciously consider the impact that

their actions have on others (Tracy, 2010, p. 847). Recognising and nurturing a

mutually respectful relationship between the researcher and participants is

crucial to ensure that the stories told by the participants are in no way co-opted.

This was something that I was conscious to avoid throughout this study.

Designing an interpretive study, collecting data using un-structured or semi-

structured interview methods, and ensuring that analysis was contextualised to

the individual transcripts; facilitated such relational ethics. Exiting ethics

concerns the ways in which research is conducted subsequent to data

collection. Specifically, how researchers can best present the findings '...to

avoid unjust or unintended consequences' (Tracy, 2010, p. 847). To avoid such consequences, the results of this study are presented as clearly and unambiguously as possible, with direct quotes and raw data to substantiate and contextualise the reported findings.

9.3.8 Meaningful Coherence

To achieve a meaningfully coherent study researchers must ensure that the research 'hangs well together' by accomplishing the research purpose, using appropriate methods and situating the research within the context of existing literature (Tracy, 2010, p. 848). This study has 2 phases with separate aims, which have been outlined throughout the research. Through this thesis I have attempted to clearly signpost how the two phases differentiate in aim, method and results, and have sought to explain how the phases come together where relevant.

9.4 Conclusion

This chapter presented a discussion of the ethical considerations and research quality issues related to both phases of this study. Ethical considerations discussed included informed consent, confidentiality and anonymity, and risk assessment. Issues of research quality were considered in relation to: worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics and meaningful coherence.

9.5 Summary

- **Ethical considerations:** informed consent, confidentiality and anonymity, and risk assessment.
- Ethical approval granted from the School of Healthcare Research Ethics Committee (SHREC) at the University of Leeds.
- Individual **written consent** was sought from all participants. At least 24 hours given between participants receiving information sheets and seeking written consent.
- Participants assured that refusal to participate would not affect their position within the LOUISA study (phase 2).
- **Pseudonyms** were used throughout the research.
- Electronic data e.g. audio recordings and interview transcripts were encrypted and stored on a password protected computer.
- Interview topics were not expected to cause upset however a **distress policy** was put in place in case of such instances.
- The University of Leeds **Lone Worker policy** was adhered to.
- **Research quality:** worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics, meaningful coherence.
- **Worthy topic:** phase 1 unearthed key issues faced by incontinent women. Phase 2 explored the practicalities of co-production and provided recommendations for other researchers.
- **Rich rigour:** sufficient data gathered to support findings, appropriate sample obtained, and research procedures were suitable.
- **Sincerity:** prior to data collection, a process of self-reflection was completed to recognise the researcher role in relation to the study.
- **Credibility:** 'thick description' of the data provided, triangulation of methods for phase 2 (interviews/observations), member checking not completed to avoid undue revisions that could alter accuracy.
- **Resonance:** endeavoured to present the research in a clear and compelling manner throughout.
- **Significant contribution:** both study phases sought to address gaps in the existing literature where research was currently lacking.
- **Ethics:** procedural ethics, situational ethics, relational ethics and exiting ethics all adhered to throughout the research process.
- **Meaningful coherence:** each study phase is clearly signposted throughout the thesis and explanations are provided to demonstrate how the phases come together where relevant.

Chapter 10: Discussion

10.1 Introduction

This is the first study to explore UI and co-production, focusing on the individual perspectives in these areas, both in terms of living with UI and in the ways in which stakeholders experienced co-producing UI research. Phase one of this study uniquely explores the experiences of older women in the UK with UI who have never, or are not currently seeking medical interventions for the condition. Phase two offers a unique perspective on the topic of co-production, by examining the realities of co-producing research related to stigmatised physical illnesses, within the context of a live project focused on UI (LOUISA).

This chapter will firstly provide a summary of the study findings. Following this, the chapter will present an interpretation of the key findings, drawing on existing literature and theory to situate the findings. Next, the strengths and limitations of the study will be considered. Subsequently, researcher reflections will be discussed. The unique contributions to knowledge that this study has produced will then be detailed. Lastly, the recommendations resulting from this study will be presented.

10.2 Summary of Results

Phase One:

Phase one of this study aimed to explore older women's perceptions of living with urinary incontinence. In total 8 superordinate themes were identified as key to illuminating the lived experience of urinary incontinence. *Living with UI (1)* acknowledges the participants' feelings about UI e.g. embarrassment, and also considers the impact of UI e.g. travel restrictions. The *coping strategies (2)*

adopted by the participants was another theme generated from the data, including the perceptions on such approaches e.g. continence products. *Attitudes towards help-seeking* (3), explored feelings about HCPs and views on medicine. The *perceived seriousness of UI* (4) including perceptions of ageing and comparison of health conditions, also demonstrated the participants' perceptions of UI. *Knowledge of UI* (5) was another theme generated, which encompassed issues around misinformation and sources of knowledge about UI. Issues around *personal responsibility* (6) illustrate the self-blame around accidents and the personal responsibility felt around managing the symptoms of UI. *Childhood experiences* (7) related to UI was another theme presented in the data, relating to accidents that occurred during childhood. Lastly, *sharing experiences of UI* (8), including confiding in friends and research involvement were discussed.

Phase Two:

Phase two of this study aimed to examine the principles of co-production within the context of an ongoing research project focused on urinary incontinence. The analysis of phase 2 data identified the facilitators and barriers to using a co-production model of research, in the context of the LOUISA study. In total 4 themes were identified: group roles, competing motivations, funder involvement and communication. Each theme was identified as having components that facilitated and acted as a barrier throughout the project. Additionally, recommendations were developed from the findings of phase 2, related to co-producing research (table 16).

Synthesis of Study Phases:

It was intended that data from each phase of this study would be analysed separately and then synthesised as a whole, to create meaningful

interpretations about experiences of urinary incontinence in the context of co-production. However, the findings from the separate phases were not conducive to this level of in-depth synthesis. Instead, patterns and connections between the data were identified, particularly related to *sharing experiences* and *knowledge of UI*.

Sharing experiences of UI was a theme discussed in the phase one interviews, in relation to research involvement. It was expressed during the interviews, that communicating personal experiences of UI through research involvement may be a way to help others in a similar situation. The ways in which experiences can be shared through research involvement is particularly relevant to the topic of co-production. For the LOUISA study, one of the benefits of conducting co-produced research was the communication of experiences from diverse participants, which added value by contributing to understandings about UI. The phase 2 scoping review also identified several personal benefits that can be experienced from participating in a co-produced study, one of which was combating stigma.

Embarrassment was one of the core themes identified from phase 1 as it was a feeling often associated with UI, which could mean that UI is an ideal condition to research using an inclusive research approach such as co-production. The reasons for wanting to participate in the LOUISA study were varied, however the most prominent motivation identified from phase two, was to help women suffering with UI. This collective motivation for sharing experiences was recognised as a facilitator for the effective working relationships in the group and is one of the ways in which co-production could be used positively for researching a sensitive topic such as UI.

Knowledge of UI was another link between the two phases of this study.

Knowledge of UI was identified as a theme in phase one, concerning misinformation about UI and sources of knowledge. It appeared that some of the participants had a lack understanding about UI at times, e.g. speculating about causes. The sources of knowledge discussed by the participants, in addition to any information they may have received from a healthcare professional, included internet, magazines and local charities. Furthermore, involvement in research was also discussed as an additional mode of support, as there was an opportunity to increase personal knowledge of UI and possible self-management options. Co-production offers participants an opportunity to share experiences in a safe environment, with a diverse group of people with varied experiences. Co-producing research on stigmatised and often secretive conditions such as UI, therefore, presents an opportunity to provide participants with reliable knowledge based on experience.

The identified links between the two phases of the study, relate to *sharing experiences* and *knowledge of UI*. It is hoped that the results of this study will contribute knowledge to the topic of co-producing research in the context of lived experiences of UI.

10.3 Interpretation of Key Results

10.3.1 Embarrassment

The most prominent concept identified within the superordinate theme of *living with UI* related to embarrassment caused by urinary incontinence. Furthermore, the concept of embarrassment permeated across several themes, such as: childhood experiences, views on continence products and using humour as a

coping strategy. Embarrassment was also a key theme throughout the existing literature presented in the qualitative meta-synthesis (chapter 3), despite the varying geographical contexts and date of publication, which illustrates the importance of this concept.

Embarrassment and stigma are often differentiated by the context of either personal or social embarrassment. Goffman (1990) argues that people are either *discredited*, where the cause of stigma is publicly known and 'evident on the spot' (Goffman, 1990, p. 14); or *discreditable*, where the cause of stigma is not publicly known or perceivable, but there is the potential for embarrassment should the stigmatised attribute be revealed. Similarly, Scambler and Hopkins (1986) mark a distinction between *enacted* and *felt* stigma in relation to epilepsy, where stigma is either publicly experienced or privately feared. Whilst 'enacted stigma' refers to instances where discrimination is experienced based on deviation from social conventions (Scambler and Hopkins, 1986, p. 33); 'felt stigma' refers to the apprehension of potential stigma i.e. 'the fear of enacted stigma' (Scambler and Hopkins, 1986, p. 33). Teng et al. (2014) also discuss embarrassment in terms of *personal* and *community* embarrassment, concerning cervical cancer screening in Uganda. Community embarrassment refers to embarrassment based on perceptions within the wider community as a result of deviating from social norms. Personal embarrassment in this context, however, refers to internalised embarrassment based on self-perceptions and an 'uncomfortable feeling with one's self' (Teng et al., 2014, p. 6).

Both personal and social embarrassment can be experienced by women with UI. The coping strategies often adopted to conceal the symptoms of UI, e.g. fluid restriction, are implemented to prevent any visible signal which could cause stigma. As identified from the phase one data for this study, women can

also experience fear related to the potential of UI symptoms becoming visible to others, resulting in internalised embarrassment. As Dolezal and Lyons (2017, p. 258) argue, '...shame creates a sense of heightened visibility and, as a result, has a tendency to provoke concealment—to hide one's shame and to obscure that of which one is ashamed'.

Goffman (1990, p. 13) argues that stigma refers to 'an attribute that is deeply discrediting'. The loss of control associated with managing the perceived discrediting attributes of UI, i.e. uncontrolled leakage, is central to understanding the source of embarrassment connected to this condition. As North and Cooper (2017, p. 146) argue, 'Society expects individuals to gain this control and empty their bladder and bowels at a socially acceptable time and place'. To deviate from these social expectations can therefore result in embarrassment. Notions of embarrassment related to deviating from social norms was also identified in the meta-ethnography conducted by Toye and Barker (2020) who found that 'UI contravened the normal rules of social etiquette and caused shame and humiliation' (2020, p. 12). This resonates with the views expressed by a woman in this study, who explained that she is not embarrassed unless she is in a situation which she cannot control.

Embarrassment within different ethnic groups which related to the appearance of lack of control has also been identified as an issue in similar studies e.g. the study conducted by Hamid et al. (2015) which explores the meaning of UI for Muslim postmenopausal women. This notion of lack of control is also a prominent feature for other similar conditions, as identified in the study conducted by Changole et al. (2017) on the experiences of women living with obstetric fistula in Malawi. The lack of control over bladder and/or bowel functions resulting from obstetric fistula, can lead to embarrassment as there is

a perception that these actions contradict social expectations (Changole et al., 2017).

Interestingly, embarrassment was not identified as a barrier to help-seeking in this study, despite this being reported in much of the literature in this area (Roe et al., 1999; Minassian et al., 2003; Hägglund and Wadensten, 2007). Two of the participants had previously seen a doctor about their condition and neither discussed embarrassment in relation to this. Whilst the third participant had not sought help from a doctor at the time of the interview, her reasoning for this related to her negative views about doctors. The only reference to embarrassment related to seeking help came when one of the participants recalled that her friend had been embarrassed about consulting her doctor about UI as he was male. The personal experiences shared by the participants did not seem to suggest that embarrassment was a barrier to help-seeking.

10.3.2 Normalisation of UI

The normalisation of UI as it relates to perceptions of ageing was another key finding from this study. Normalisation refers to 'the ways in which the individual achieves normalcy despite having a chronic condition' (Joachim and Acorn, 2000, p. 37). Normalisation is a method of coping, both physically and mentally, within the context of experiencing illness. Psychologically, this can involve 'the "bracketing off" of the impact of the illness, so that its effects on the person's identity remain relatively slight' (Bury, 1991, p. 460). Whereas physically, the act of managing and concealing illness can act to normalise the symptoms. For women living with UI, for example, the use of continence products was a coping strategy adopted to minimise physical symptoms. Some researchers view normalisation as a positive approach to coping with illness, as normalisation can

enable the continuation of a person's normal daily life with minimised disruption.

As Thorne (1993) illustrates, the act of normalisation can facilitate a 'positive attitude' towards the lived experience of chronic illness, whilst also helping to prevent the potential negative social effects of illness (Thorne, 1993, p. 58).

However, there are also disadvantages to normalisation, as for some people, this process 'caused them to deny the implications of their illness' (Thorne, 1993, p. 59), which could potentially act as a barrier to help-seeking.

Declining health in old age appeared to be the foundation for the perceived inevitability and normalisation of UI understood by the participants. This is also a prominent theme in much of the existing literature in this area (Eisenhandler, 1993; DuBeau et al., 1998; Robinson, 2000; Creech, 2002; Peake and Manderson, 2003). However, the act of normalising UI seems to be at odds with the embarrassment that is often experienced with UI. On the one hand, older women appear to express the view that UI is a normal part of ageing that should be expected. Yet at the same time, there is great embarrassment and secrecy around the condition, despite the fact that UI is frequently believed to be an ordinary part of ageing.

Normalisation of illness amongst older people is an issue that needs to be addressed more generally. Goodwin et al. (1999) highlight in their study, that many participants (aged 75+) normalised conditions such as arthritis and heart disease due to the perception that they are a normal part of ageing.

Furthermore, in a study conducted by Sarkisian et al. (2002), the researchers identified that 50% of their participants (aged 65-100), expected to experience poor health as a part of ageing; including depression, dependency and pain.

Although these studies were both based in the US and were not exclusively

focused on the views of older women, the findings are still relevant for situating the wider perceptions of normalisation of health related to ageing, outside of UI.

Although the normalisation of UI in old age was identified as a characterising feature of the lived experience of UI for the participants in this study, this perception did not appear to have negatively impacted on the participants' help-seeking behaviour. However, in the surrounding literature, the perceived lack of seriousness of UI is thought to be a barrier to help-seeking (Toye and Barker, 2020). As Teunissen et al. (2005, p. 776) highlight, patients are less likely to seek help if they perceive their condition as 'not very serious or distressing'. Hägglund and Wadensten (2007, p. 309) further this argument when stating that even when UI causes disruption to a person's life, it is still often thought of as 'not enough of a problem to seek help for'. It could be argued that to communicate the significance of living with UI as an older woman, a general shift in thinking is needed regarding the importance and availability of healthcare for such issues, regardless of age.

10.3.3 Biopsychosocial Approach

The findings from this study demonstrate that UI impacts social, psychological and physical aspects of women's lives, which resonates with a biopsychosocial approach. This study identified that alongside the biological features of UI, i.e. the involuntary loss of urine and any associated physical conditions, the psychological and social aspects of UI also characterised the lived experience of this condition. Urinary incontinence relates to psychological aspects of life through the impact that stigmatisation can have on the mental and emotional well-being of women living with the condition. For example, embarrassment was identified as central to the lived experience of UI in this study. Social

implications of UI were also identified in this study, such as travel restrictions and social isolation. To understand the lived experience of UI it is therefore crucial to understand the interplay between these aspects of well-being. A biopsychosocial model would therefore be a helpful approach for addressing this condition, as the emphasis is on understanding illness through a framework that focuses on physical, psychological and social elements of illness.

The biopsychosocial model advocated by Engel (1977, p. 132) argues that *'To provide a basis for understanding the determinants of disease and arriving at rational treatments and patterns of health care, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of illness, that is, the physician role and the health care system'*. This is pertinent for UI because of the social and psychological impacts that often characterise the lived experience of the condition. As North and Cooper (2017, p. 146) argue, the impact of UI is unique to each woman as certain factors must be accounted for, such as *'...a woman's pre-existing state of physical and mental health as well as her social relationships, employment, independence, personal beliefs and relationships to her environment'*. This is important for healthcare providers to consider, as they are in a central position to discuss the experience and educate women about UI (North and Cooper, 2017). However, it is also important for this approach to be considered by those undertaking relevant healthcare research (Edozien, 2015). As Engel (1977, p. 135) highlights, a biopsychosocial model *'...provides a blueprint for research, a framework for teaching, and a design for action in the real world of healthcare'*.

Practically, a biopsychosocial approach *'is a way of understanding the patient's subjective experience as an essential contributor to accurate diagnosis, health*

outcomes, and humane care' (Borrell-Carrió et al., 2004, p. 576). Tanaka et al. (2011) discuss a biopsychosocial approach in relation to irritable bowel syndrome, arguing that healthcare providers should integrate medical and psychological features of the illness, with the aim of providing 'a more satisfactory treatment on this understanding' (Tanaka et al., 2011, p. 137). Bischof and Benson (2004) also discuss how a biopsychosocial approach could provide a suitable framework for childhood enuresis, as interventions are often related exclusively to a biomedical view e.g. bladder capacity, or a psychological view e.g. family disruption (Bischof and Benson, 2004, p. 10).

Whilst the integration of biological, psychological and social aspects of illness could help to create more suitable interventions, the biopsychological model has been criticised for the lack of guidance offered concerning how to prioritise between these aspects of illness (Ghaemi, 2009). Wade and Halligan (2017, p. 1001) also discussed the 'unpredictability and uncertainty' of the biopsychosocial model in comparison with the unambiguous boundaries of a more traditional biomedical model. Another issue related to this approach is the 'greater knowledge and time investment' required to consider the various aspects of health advocated by the biopsychological model (Alonso, 2004, p. 244). A biopsychosocial approach requires healthcare providers to understand a patient's social and psychological circumstances, rather than focusing only on the biological aspects of illness (Alonso, 2004). To facilitate this interaction between patients and healthcare providers, healthcare systems may be required to adapt and offer appropriate resources, e.g. 'communication skills training' (Alonso, 2004, p. 244). Wade and Halligan (2017, p. 1001) argue that 'People may recognize the difficulties with the current system but may prefer to

tolerate it rather than change'. Unless healthcare systems adapt to support this approach, the uncertainty of a biopsychosocial model may act as a barrier.

Co-production could be a useful approach to consider in relation to a biopsychological approach. Research approaches such as co-production give patients a voice and value the opinions and experiences of people with lived experiences of the condition under study, e.g. UI. Through this approach, healthcare providers and researchers are able to reflect on the lesser known social and psychological aspects of illness in-depth, which might not be possible in a traditional research setting. The prioritisation of experts by experience, is crucial when co-producing research, meaning that there is a real opportunity for patients to discuss the aspects of illness that are most important to them. This patient-focused approach could be used as an effective way to conduct needs analysis and ultimately provide more suitable, tailored interventions, taking into consideration the importance of a biopsychological approach.

10.3.4 Concept of Co-Production

Co-production is a relatively new approach to research, that emphasises collaboration and shared-decision making between all parties. Due to the fluidity and adaptability of co-production, tensions can occur between the theoretical underpinnings of co-production and the practicalities of utilising this approach in a real-world setting (Sadler et al., 2017). As this study illustrates, there are benefits and challenges to using this approach that are unique to the circumstances of the project. The arrangements of a co-produced project will vary depending on the project aims, setting, funders and stakeholders. For some studies it is beneficial to involve stakeholders in every stage of the

research process, e.g. dissemination (Fenge et al., 2012). However, it must be noted that the LOUISA project, on which phase two of this study was based, was not structured in this way. This was partly due to practical issues e.g. time restraints and costs of training, and partly because the funders requested that the academic team spearhead the project in close collaboration with the wider group. Therefore instead, the research work (e.g. data collection) was conducted by the academic team whilst all decision-making was shared through extensive group discussions. The dynamic nature of co-production offers the opportunity to adapt the approach to align with the aims of the project, however it is important to consider the possible limits of adapting co-production approaches beyond recognition. As Vennik et al. (2016, p. 165) state, when tailoring a co-production approach 'at a certain point the question can be raised whether we can still speak of co-production'. This is an important point to consider when planning and adapting co-production research approaches.

The tensions that exist between aspiring to conduct 'pure' co-production and having to work within constraints outside of your control e.g. funder requests or university structures, are important to acknowledge. As Oliver et al. (2019) argue, it is important to openly consider the potential costs of co-producing research, as such tensions can highlight the implicit power imbalances present. Openly discussing the tensions and challenges of co-production is therefore an important aspect of co-producing research that should be embraced to aid reflexivity and potentially provide guidance for other researchers engaging in similar processes. The LOUISA project worked to co-produce a self-management package for UI with a range of stakeholders including: service users, HCPs, funders and academics. The project demonstrates the value of the approach adopted, for giving a voice to people living with stigmatised

illnesses such as UI. The LOUISA study also highlights the complex nature of co-production and demonstrates the ways in which this collaborative approach can work in reality, by adapting to account for the practicalities of research. As this study examined co-production within the context of an ongoing project it is possible that the challenges e.g. tensions surrounding expected outputs, were identified by the stakeholders because they were experiencing these incidents in real-time. Had the interviews with stakeholders been conducted after the project outputs had been delivered, these tensions might not have been identified as recall bias could potentially influence the views held by the stakeholders (Althubaiti, 2016).

10.3.5 Power Differentials

Power relationships in research can be viewed as a progressive scale, ranging from 'highly hierarchical' to 'egalitarian' relationships (Karnieli-Miller et al., 2009, p. 281). Some research studies clearly demarcate the roles of researcher and participant, whereas others favour a more co-productive approach where these roles intersect. Addressing power differentials is particularly important within co-production research, as one of the central tenets of co-production is that power and decision-making is shared equally between stakeholders. Co-production seeks to restore balance to the research process, therefore reflections on how, or if, power differentials were redressed is important.

Some argue that promoting the ideal of equal power relationships in research can 'obscure an intricate web of power dynamics that operate in practice' (Farr, 2018, p. 638), as equal power relationships do not necessarily result in all parties having equal decision-making power at all stages of research (Green and Johns, 2019). In an academic setting, for example, responsibility for the

university ethical approval process would usually lie predominantly with a member of the academic team. Hickey (2018, p. 693) also raises the issue of practically ensuring equal power relationships, by asking, 'How, for example, do we share power when it is often a principal investigator who is accountable for decisions?'. Addressing the challenges of practically redressing power differentials in co-produced research is an issue that requires further clarity and reflexivity, as often, research structures do not easily facilitate equal power sharing.

As each co-produced study will be uniquely assembled based on the requirements of the project, power differentials are also likely to vary by project. For the LOUISA project, on which phase 2 of this study is based, there was a clear power imbalance between the funders and the rest of the group. As detailed in chapter 1, the LOUISA project was funded by the Leeds Benevolent Society for Single Ladies (LBSSL), a charity founded to assist elderly single women living in Leeds. The funders took an active role in the co-production process which acted as a facilitator to collaborative working relationships through the genuine interest and passion shown by the funders, as discussed in chapter 8. However, the close involvement of the funders also acted as a barrier to effective working relationships due to the clear power differentials. This study found that despite the principle of shared decision-making in co-production, the funders often felt that their suggestions should be acted on because of the perceived power of financial support. In this instance, power differentials could have been addressed earlier in the process, to clarify that equal power relationships are the underlying intention of co-producing research. Buffel (2018, p. 59) highlights the importance of facilitating 'critical awareness' of power relationships, through training and reflection sessions with stakeholders.

Similarly, Farr (2018, p. 638) emphasises that 'Constantly reflecting upon how different power dynamics are manifesting themselves through co-production processes can support a greater understanding of how to minimise the effects of different inequalities'. Although the aim of co-production is to encourage equal power relationships, it is likely that there will be underlying power differentials present at various times throughout the research process. When co-producing research, it is therefore important to engage in reflexive processes to ensure that power differentials are acknowledged and reduced.

10.4 Strengths of the Study

Several strengths were identified in this study, as illustrated below:

The qualitative meta-synthesis conducted for **phase one** is a strength of this study. This is the first qualitative meta-synthesis to systematically review and synthesise literature focused specifically on the views of older women (aged 55+) living with urinary incontinence. The meta-synthesis provided rich, in-depth interpretations of 45 studies across 15 countries.

The use of IPA as the methodological approach for **phase one** of this study allowed the lived experience of UI to be explored in-depth from the perspectives of those under inquiry. IPA provided a comprehensive methodological and philosophical grounding for this study through the theoretical underpinnings of phenomenology, hermeneutics and idiography. The methodical approach to analysis offered by IPA also facilitated a systematic, in-depth exploration of the data to create rich and illuminating themes about living with UI.

Another methodological strength of this study is the use of in-depth phenomenological interviews to collect data for **phase one**. The interviews

allowed a small number of cases to be explored in-depth, to generate rich data on the phenomenon of UI. Additionally, this data collection method is compatible with IPA research.

The scoping review conducted for **phase two** is another strength of this study. The scoping review mapped existing literature on co-production in a healthcare context, with a unique focus on literature concerning adults living with non-life threatening LTCs in a setting with a similar healthcare context to the UK. This review provided findings which can inform current knowledge on co-production.

The use of two data collection methods for **phase two** of the study (interviews and observation), enabled a more comprehensive examination of the data related to co-production. The observation of the stakeholder meetings meant that the interaction between stakeholders could be studied; whereas the semi-structured interviews explored the stakeholders' experiences of being part of a co-produced research project first-hand.

The unique position of the study is another strength of this research for **phase two**, as a live project (LOUISA) was the focus, allowing the co-production research process to be observed in action as the project was ongoing. This also meant that interviews were conducted with stakeholders whilst they were still involved in the project, rather than retrospectively, meaning that the views expressed were not affected by recall bias.

10.5 Limitations of the Study

There are also some limitations that have been identified in this study, as illustrated below:

Although the qualitative meta-synthesis conducted for **phase one** encompassed a substantial number of papers across different global settings, one of the exclusion criteria was papers focused on the experiences of women with complicated UI e.g. resulting from neurological conditions. Although this decision was based on the consideration that these experiences would likely be multifaceted and potentially incomparable with the experiences of women with uncomplicated UI, to enhance the comprehensive nature of the meta-synthesis it might have been beneficial to include experiences from all female perspectives.

The transferability of the findings for **phase one** are limited. The setting for this study was limited to the city of Leeds, due to the requirements of the funders. Additionally, due to the phenomenological and idiographic nature of the study, the sample size was relatively small (n=3). The sample was also demographically and physically homogenous; however, this is in keeping with an IPA approach (Smith et al., 2009). The findings are therefore transferable to similar sample settings.

As with all interpretive qualitative research, there is a certain degree of subjectivity regarding interpretations. The findings presented in this thesis, for both **phase one** and **phase two**, therefore reflect one interpretation of the data. This is particularly relevant to IPA research, where the process of double hermeneutics means that researchers must interpret the participants' own interpretations of the phenomenon. However, tables of original text and interpretations are included in the appendices for transparency (appendix

L,N,U). All findings were also discussed with supervisors throughout the analysis process to validate the interpretations. Additionally, many of the research findings from this study resonate with the conclusions made in current relevant literature, e.g. embarrassment of UI, suggesting that the interpretations in this study are well-founded.

Recruitment for **phase one** of the study was challenging and relied on self-selection by the participants. Local charities were initially targeted for recruitment, however no women volunteered to participate through this method. Snowball sampling was therefore employed to recruit the participants included in the study. The sample may have been more representative if participants had volunteered from the various charities across the city. However, the included participants all discussed UI openly and illuminated the phenomenon under study.

Whilst a scoping review was a suitable approach for mapping literature on co-production and producing a detailed analysis of the literature for **phase two**, the lack of quality assessment of the literature is a limitation of the review. Though quality assessment is not an essential component of scoping reviews, assessing the literature to ensure that included papers were of a high quality, could have further strengthened the rigour of the review.

As discussed previously, the timeline of the LOUISA project was delayed due to staff issues, meaning that at the time of data collection for **phase two**, the project was still ongoing. Though it was informative to collect data whilst the project was ongoing, it might have also been valuable to collect data following completion of the project to ascertain whether expectations had been met. Interviewing stakeholders at a different stage in the project timeline, to explore their views in relation to the subsequent project outputs, could have added

depth to the overall findings related to experiences of co-production. Collecting such data could have provided the opportunity to expand the recommendations made by this study to include suggested actions following the completion of a project.

10.6 Researcher Reflections

Throughout this study I have endeavoured to uphold a reflexive stance, to ensure that any potential preconceptions are identified and considered upfront. This research project was my first experience researching both urinary incontinence and co-production. Whilst I had previous experience of researching women's health, these specific topics were new to me. I therefore had no prior knowledge of these areas, which at the beginning of this project was quite daunting. However, after dedicating time to familiarising myself with the topic of urinary incontinence, I realised how prevalent this condition is and the impact that it has on the lives of so many women. Similarly, after exploring co-production research, a term I was not familiar with prior to commencing this PhD, I came to understand that this is becoming a prevalent research approach which needed further research. I was initially anxious to research the topic of UI as I do not have a medical background, however this eased as the project developed and the research aim was focussed towards the lived experience of UI. As I had no previous knowledge or experience in the areas of the study, this meant that I did not have any preconceptions coming into the study and I had no pre-conceived ideas about the outcomes of the research. I was therefore able to explore the research topics from an impartial stance. Whilst prior familiarity with the research topics could have been beneficial, I believe that in

this case, my initial unfamiliarity with the research areas enabled me to maintain an open-minded approach to the research and uphold a reflexive stance throughout. Furthermore, I believe that my lack of clinical knowledge meant that I did not make assumptions about what the participants discussed; which ultimately compelled me to be more inquisitive, to confirm that I had understood the messages that the participants intended to convey.

As this study was funded by LBSSL, the charity ultimately set the agenda for the overall topics of my PhD. The charity requested that the study should focus on the topics of urinary incontinence and co-production, however I was able to decide the overall research aims and methods in collaboration with my supervisors. It was anticipated that the two topics would have strong relationships throughout the research, however as the research progressed it became clear that the topics as they relate to the current study, were less connected than first expected. That being said, the two phases ran parallel to one another rather than being intertwined throughout the PhD. This was challenging at times due to the increased workload, for example, conducting two distinct in-depth literature searches. However, I found that managing a study with two different phases was a good experience which allowed me to explore each research topic in-depth.

During my second year of study, the lead supervisor of my PhD unfortunately experienced a severe injury which meant that she was unable to work for 6 months and subsequently had a gradual phased return over several months. This impacted the progress of my PhD to an extent, specifically phase two of the study, as the lead supervisor was also the PI for the LOUISA study. However, I did have a second supervisor who was able to provide support and guidance during this time.

Conducting this research and studying to obtain a PhD has been a great experience. Prior to embarking on my PhD journey, I had taken a break from academic study to work as a research assistant for three years, so I was initially nervous about returning to full-time study. Whilst at first it took a while to adjust, I soon became accustomed to academic study again. I have had good support from my supervisors throughout, both academically and personally. I have also been able to hone my skills and attend advanced training courses throughout my studies and I am grateful for this experience.

10.7 Unique Contributions

This study has contributed to current knowledge in the following ways:

- This is the first study to explore the lived experience of urinary incontinence for women aged 55+ living in the UK, that uses an in-depth phenomenological approach **(phase one)**.
- This study focuses on the experiences of incontinent women who have either never sought professional help or have previously engaged with medical services but have since disengaged; an area where there is a dearth of literature, specifically in a UK context **(phase one)**.
- This study addresses the lack of research exploring the realities of using a co-production approach to healthcare research focused on stigmatised, physical LTCs. Whilst there is a wealth of knowledge on co-production, there is a lack of research reflecting on the experiences of co-production. **(phase two)**.
- A further unique contribution of this study is the examination of the experiences of key stakeholders currently engaged with an ongoing co-

produced project. Most research focused on co-production is conducted retrospectively which runs the risk of recall bias (**phase two**).

- This study has provided valuable recommendations for researchers conducting co-produced research based on the experiences of stakeholders involved in a live co-produced project. The recommendations made from this study contribute to current knowledge on the relatively new method of co-producing research (**phase two**).

10.8 Recommendations

10.8.1 Practical Recommendations

This study found that there is an apparent lack of knowledge about urinary incontinence, e.g. symptoms of UI, causes of UI and treatments available.

Therefore, a practical recommendation of this study is that wider availability of reliable and consistent information is essential, to prevent uncertainty and misinformation. Practically, this could be achieved through various forms of media such as magazines, leaflets or internet resources, which were identified as current sources of knowledge for the participants in **phase one** of this study.

Although personal preference is central to the ways in which people choose to source such information, more readily available information is important. It was identified in this study, both in the qualitative meta-synthesis and in the interviews, that often women with UI chose not to seek medical help. Self-management may therefore be an appropriate approach for managing the symptoms of UI (Coulter, 1999), meaning that it is important for women to be provided with the necessary knowledge to make appropriate choices regarding their options. Furthermore, an awareness of the condition could help women to navigate the process of consulting a doctor for additional help. A

biopsychosocial model could also be adopted for addressing UI, as this approach emphasises understanding illness through a framework that focuses on physical, psychological and social elements of illness. To understand the lived experience of UI and recommend appropriate interventions, it is important to understand the interplay between these aspects of well-being.

A set of practical recommendations have also been developed from the findings of **phase two** of this study, related to co-producing research in similar areas related to stigmatised, physical LTCs (chapter 8). Firstly, prior to the start of the project it is important to *manage expectations*, by specifying the expectations for involvement and ensuring that the value of each stakeholder's participation is understood. Secondly, it is recommended that *group diversity* is prioritised during the setup of a co-produced project, to ensure that a variety of experiences and perspectives are communicated. Acknowledging the potential competing motivations of the stakeholders in a co-produced project is also recommended. During the project, the main recommendation relates to *communication*. Regular communication between meetings, communicating research processes and updating stakeholders on the progress of the project, were all identified as important in this study. Furthermore, it is also recommended that the *involvement of group members* should be actively encouraged throughout the project, as lack of ongoing involvement and attendance at meetings was a challenge identified by the LOUISA project. Further details of these recommendations can be found in chapter 8.

10.8.2 Research Recommendations

There are several research recommendations that could build on the contributions of this study. Firstly, as the geographical setting for **phase one** of this study was limited to Leeds as per the funders requirements, a similar

qualitative study could be conducted in another region of the UK to assess the transferability of findings, taking into account the potential contextual and cultural differences.

Further research could also be conducted to encompass a more ethnically diverse sample than that presented in **phase one** of this study. Whilst it was not the intention of this study to restrict the sample to white British women, the participants who volunteered to take part were limited to this demographic. It was identified in the literature that there are aspects of living with UI that are unique to people identifying with specific cultures (Siu and Lopez, 2012).

Further research could build on this knowledge and explore the potential commonalities or differences in the lived experience of UI across cultures.

More research is also required to explore the perceived needs of women living with UI, to aid the development of tailored interventions. MacKay and Hemmett (2001) conducted needs assessment research related to women with UI (aged 45+) in London which illustrated women's levels of satisfaction with the UI treatments that they had been offered by their GPs. Further needs analysis research is needed to build on such existing knowledge, accounting for geographical, social, cultural and age differences, to comprehensively understand the perceived needs of women with UI.

Lastly, further research is needed to examine the experiences of conducting co-produced research for other physical LTCs. Whilst the recommendations from **phase two** of this study will likely be applicable to conditions similar to UI, due to the individualised nature of co-produced projects, more information is needed to contribute towards the growing body of literature around co-production.

10.9 Dissemination

The findings from this study will be disseminated via written publications in academic journals and through the publication of this thesis at The University of Leeds. It is also anticipated that the findings will be disseminated via oral and poster presentations.

Table 17: Dissemination Plan

Phase	Format	Topic	Status/Target Journal
Phase 1	Academic journal	Qualitative meta-synthesis of older women's experiences of UI	Ready for submission to Journal of Psychosomatic Obstetrics and Gynecology
Phase 2	Academic journal	Scoping review on co-production in healthcare	Writing in progress/ Patient Education and Counselling
Phase 1	Academic journal	Qualitative findings on the lived experience of UI	Writing in progress
Phase 2	Academic journal	Qualitative findings on co-producing research	Writing in progress/ Health and Social Care in the Community

10.10 Conclusion

This is the first study to explore UI and co-production, focusing on the individual perspectives in these areas, in relation to women's lived experience of UI and stakeholders' experiences of UI related co-production. Phase one of this study explores the experiences of older incontinent women in the UK who have never, or are not currently seeking medical interventions for the condition; an area where there is currently a lack of research. Phase two of this study uniquely explores the realities of co-production within the context of a live project focused on UI (LOUISA). The findings from this study contribute to current knowledge

about lived experiences of urinary incontinence and the practicalities of conducting co-produced research related to stigmatised, physical LTCs. This chapter has presented a synthesis of the findings, including relevant interpretations. The strengths and limitations of the study have also been discussed, along with researcher reflections. The unique contributions made by this study, as well as further recommendations, have been presented.

10.11 Summary

- Interpretation of results:
- Loss of **bodily control** is central to **embarrassment** as it is often considered as a deviation from social expectations.
- UI is often considered as a **normal part of ageing**.
- Normalisation of UI contradicts the notion of embarrassment.
- Normalisation of UI and embarrassment not identified as barriers to help-seeking.
- **Tensions exist between the theory and practical underpinnings of co-production** due to pragmatic considerations e.g. funder requirements, competing motivations and different views on outputs.
- A **biopsychosocial model** is well suited to aid understandings of the social, psychological and physical aspects of UI.
- **Power differentials** should be considered reflexively when co-producing research
- Strengths:
- Use of **IPA** to explore UI in-depth and generate **rich data**.
- Two **data collection methods** enabled a thorough study of LOUISA.
- **Unique position** of the study to research a live project (LOUISA).
- Limitations:
- **Transferability** of findings are limited to a similar sample setting.
- As with all qualitative research the interpretations are **subjective**.
- Unique contributions:
- First study to explore the lived experience of UI for **women aged 55+ in the UK** using IPA.
- Unique focus on the experiences of incontinent women who have either **never sought professional help** or have **previously engaged** with medical services but have since disengaged.
- The **realities** of using co-production to research a stigmatised physical LTC are explored.
- The experiences of stakeholders involved in an **on-going co-produced project** are examined.

Chapter 11: Conclusion

The aims of this study were twofold. The aim of **phase one** of this study was to explore older women's perceptions of living with urinary incontinence. To achieve this aim, in-depth phenomenological interviews were conducted with older women aged 55+ to understand their lived experience of urinary incontinence. An IPA approach was utilised for phase one, to allow rich, in-depth explorations of the lived experiences of incontinence to be understood. The lived experience of UI for the participants in this study related to 8 themes: living with UI, coping strategies, attitudes towards healthcare professionals, perceived seriousness of UI, knowledge of UI, personal responsibility, childhood experiences and sharing experiences of UI.

The results of this study contribute to current understandings of the phenomenon of UI. Uniquely, this study focuses on the experiences of incontinent women who have either never sought professional help or have previously engaged with medical services but have since disengaged; an area where there is a dearth of literature, specifically in a UK context. That being said, the themes identified resonate with those identified in the existing literature. The findings from this study illustrate that UI impacts social and psychological aspects of women's lives as well as the physical impact endured. To tackle the issues associated with UI, a holistic approach is needed. A biopsychosocial approach addresses this need, by concentrating on physical, psychological and social elements of illness. To build on this knowledge, a similar qualitative study could be conducted in another UK region to account for potential contextual differences. Similarly, further research to include a more ethnically diverse sample could contribute further to knowledge in this area.

The aim of **phase two** of this study was to examine the principles of co-production within the context of an ongoing research project focused on urinary incontinence. Two data collection methods were used to achieve this aim. Semi-structured interviews were conducted to examine the experiences of key stakeholders in the LOUISA project and explore their reflections on being part of the research process. Additionally, observations were conducted to examine the interactions between stakeholders at LOUISA advisory group meetings. Thematic analysis was conducted to explore patterns in the data. Several barriers and facilitators to co-producing research were identified. Group roles, competing motivations, funder involvement and communication were recognised by the participants as having both facilitated and also acted as a barrier to the project. Recommendations have been made based on these findings, to contribute to existing knowledge on the realities of conducting co-produced research for similar stigmatised physical LTCs. Whilst this study contributes to existing knowledge on the experiences of conducting co-produced research, further research is needed to examine co-produced research for other physical LTCs.

Although a full synthesis between the separate phases was not viable, there were some **links between phases**, related to sharing experiences and knowledge of UI. Co-production presents an opportunity to exchange knowledge based on personal experiences shared within a research setting. This was identified as a potential form of support that could be important for people living with stigmatised conditions such as UI. Overall, this study has contributed to knowledge and understanding in the areas of UI and co-production. This research also has the potential to contribute to further needs analysis research to aid the creation of tailored UI interventions going forward.

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Appendix List

Appendix A: SPIDER Tool

SPIDER	Current Study
S – Sample	Older women (approximately 55 or above)
PI – Phenomenon of Interest	Urinary incontinence
D – Design	Qualitative design
E – Evaluation	Experiences
R – Research type	Qualitative

(Cook et al, 2012, pp
1435-1443)

Appendix B: Keywords

Urinary Incontinence	Women	Experiences	Methods	Age
Urinary incontinence	Women*	Experience*	Qualitative	Older adult/person*/people
Overactive bladder	Woman*	Motiv*	Interview	Elder*
Incontinence	Female*	Influenc*	Focus Groups	Seniors
Continenence	Lady*	Attitude*	Observation	Mature
Bladder control	Ladies*	Perception*	Personal narratives	Aged
Urodynamic*	Gender*	Perceive*		Aging
Nocturia	Sex difference*	Belief*		Retired
Bladder training/re	Sex factor*	Believe*		Geriatrics
Urine leakage		Opinion*		G nursing
Mixed incontinence		View*		G assessment
Urinary dysfunction		Standpoint*		Over 55+
Neurogenic bladder				
Urinary urgency				

Appendix C: Search Strategy

Database(s): Ovid MEDLINE(R) 1946 to February Week 4 2017

Search Strategy:

#	Search
1	exp Urinary Incontinence/
2	Urodynamics/
3	Urinary Bladder, Overactive/
4	incontinen*.tw.
5	continen*.tw.
6	bladder control.tw.
7	urodynamic*.tw.
8	n#cturia.tw.
9	(bladder adj5 (train\$ or retrain*)).tw.
10	(urin* adj2 leak*).tw.
11	(overactiv* adj1 bladder*).tw.
12	mixed incontinence.tw.
13	urinary dysfunction.tw.
14	neurogenic bladder.tw.
15	urinary urgency.tw.
16	((bladder or detrusor) adj5 (instab* or stab* or unstab* or irritab* or hyperreflexi*)).tw.
17	or/1-16 [urinary incontinence]

18	(wom#n or wom#n's).tw.
19	(lady or lady's or ladies or ladies').tw.
20	female*.tw.
21	gender*.tw.
22	sex difference*.tw.
23	sex factor*.tw.
24	or/18-23 [women]
25	exp Aged/
26	exp Aging/
27	Geriatrics/
28	Geriatric Nursing/
29	Geriatric Assessment/
30	Health Services for the Aged/
31	elder*.tw.
32	(seniors or senior citizen*).tw.
33	(older adult* or older person* or older people).tw.
34	mature.tw.
35	retired.tw.
36	geriatr*.tw.
37	gerontol*.tw.

38	(over adj2 ("55" or "56" or "57" or "58" or "59" or "60" or "61" or "62" or "63" or "64" or "65" or "66" or "67" or "68" or "69" or "70" or "71" or "72" or "73" or "74" or "75" or "76" or "77" or "78" or "79" or "80" or "81" or "82" or "83" or "84" or "85" or "86" or "87" or "88" or "89" or "90" or "91" or "92" or "93" or "94" or "95" or "96" or "97" or "98" or "99" or "100") adj years).tw.
39	or/25-38 [age]
40	exp Qualitative Research/
41	Focus Groups/
42	Interview/
43	Observation/
44	Personal Narratives/
45	health personnel attitudes/
46	health knowledge/ or health attitudes/
47	(interview* or qualitative or theme* or survey* or questionnaire* or focus group*).tw.
48	(experience* or motiv* or influenc* or attitude* or perception* or perceive* or belief* or believe* or opinion* or view* or standpoint*).tw.
49	or/40-48 [adapted LIHS qualitative filter]
50	17 and 24 and 39 and 49 [urinary incontinence and women and age and qualitative]
51	17 and 24 and 39 and 49 [urinary incontinence and women and age and qualitative]
52	limit 51 to yr="1991 -Current"

Appendix D: Quality Appraisal Tool

Author and title: _____

Date: _____

	Good	Fair	Poor	Very Poor	Comment
1. Abstract					
2. Introduction and aims					
3. Method and data					
4. Sampling					
5. Data analysis					
6. Ethics and bias					
7. Findings / results					
8. Transferability / generalizability					
9. Implications and usefulness					
Total					

1. Abstract and title: Did they provide a clear description of the study?

Good Structured abstract with full information and clear title.

Fair Abstract with most of the information.

Poor Inadequate abstract.

Very Poor No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

Good Full but concise background to discussion/study containing up-to-date

literature review and highlighting gaps in knowledge.

Clear statement of aim AND objectives including research questions.

Fair	Some background and literature review. Research questions outlined.
Poor	Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background.
Very Poor	No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?

Good	Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
Fair	Method appropriate, description could be better. Data described.
Poor	Questionable whether method is appropriate. Method described inadequately. Little description of data.
Very Poor	No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?

Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
Fair	Sample size justified. Most information given, but some missing.
Poor	Sampling mentioned but few descriptive details.
Very Poor	No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?

- Good Clear description of how analysis was done.
 Qualitative studies: Description of how themes derived/
 respondent validation or triangulation.
 Quantitative studies: Reasons for tests selected hypothesis
 driven/
 numbers add up/statistical significance discussed.
- Fair Qualitative: Descriptive discussion of analysis.
 Quantitative.
- Poor Minimal details about analysis.
- Very Poor No discussion of analysis.

6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?

- Good Ethics: Where necessary issues of confidentiality, sensitivity, and
 consent were addressed.
 Bias: Researcher was reflexive and/or aware of own bias.
- Fair Lip service was paid to above (i.e., these issues were
 acknowledged).
- Poor Brief mention of issues.
- Very Poor No mention of issues.

7. Results: Is there a clear statement of the findings?

- Good Findings explicit, easy to understand, and in logical progression.
 Tables, if present, are explained in text.
 Results relate directly to aims.
 Sufficient data are presented to support findings.
- Fair Findings mentioned but more explanation could be given.
 Data presented relate directly to results.

- Poor Findings presented haphazardly, not explained, and do not progress logically from results.
- Very Poor Findings not mentioned or do not relate to aims.

8. Transferability or generalizability: Are the findings of this study transferable

(generalizable) to a wider population?

- Good Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling).
- Fair Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.
- Poor Minimal description of context/setting.
- Very Poor No description of context/setting.

9. Implications and usefulness: How important are these findings to policy and practice?

- Good Contributes something new and/or different in terms of understanding/insight or perspective.
Suggests ideas for further research.
Suggests implications for policy and/or practice.
- Fair Two of the above (state what is missing in comments).
- Poor Only one of the above.
- Very Poor None of the above.

Very Poor = 1 / Poor = 2 / Fair = 3 / Good =

Appendix E: Quality Assessment Scores

Reference	Abstract	Intro & aims	Method & data	Sampling	Data analysis	Ethics & bias	Results	Transferability	Implications	Total
Dowd 1991	Fair	Fair	Fair	Poor	Good	Fair	Good	Poor	Fair	27
Lagro-Janssen et al. 1992	Good	Fair	Fair	Fair	Poor	Poor	Good	Fair	Fair	27
Bjurbrant Birgersson et al. 1993	Good	Fair	Fair	Poor	Fair	Very Poor	Good	Poor	Good	26
Eisenhandler 1993	Poor	Fair	Poor	Good	Very Poor	Very Poor	Fair	Fair	Fair	22
Brown et al. 1998	Good	Poor	Good	Good	Fair	Very Poor	Good	Fair	Fair	28
DuBeau et al. 1998	Good	Good	Fair	Good	Good	Very Poor	Good	Fair	Fair	30
Chaliha & Stanton 1999	Good	Fair	Good	Fair	Very Poor	Very Poor	Good	Poor	Good	25
Fitzgerald et al. 2000	Fair	Fair	Fair	Fair	Poor	Poor	Fair	Fair	Fair	25
Robinson 2000	Good	Fair	Good	Good	Good	Fair	Good	Fair	Fair	32
Roe 2000	Fair	Fair	Good	Fair	Good	Poor	Good	Fair	Fair	29
Creech 2002	Good	Good	Good	Good	Good	Good	Good	Fair	Good	35
Fitzgerald et al. 2002	Good	Poor	Fair	Fair	Poor	Very Poor	Fair	Fair	Fair	24

Peake & Manderson 2003	Fair	Good	Fair	Fair	Poor	Very Poor	Good	Poor	Poor	24
Shapiro et al. 2003	Poor	Fair	Fair	Poor	Poor	Very Poor	Fair	Poor	Fair	21
Bradway 2004	Good	Good	Good	Good	Good	Fair	Good	Fair	Good	34
Horrocks et al. 2004	Good	Fair	Good	Fair	Good	Fair	Good	Fair	Fair	31
Diokno et al. 2006	Good	Good	Good	Fair	Poor	Poor	Fair	Fair	Fair	28
Komorowski & Chen 2006	Good	Good	Good	Good	Good	Fair	Good	Fair	Fair	33
Teunissen et al. 2006	Good	Fair	Fair	Good	Fair	Very Poor	Fair	Fair	Fair	27
van den Muijsenbergh & Lagro-Janssen 2006	Good	Good	Good	Poor	Poor	Very Poor	Good	Poor	Good	27
Doshani et al. 2007	Good	Fair	Good	Fair	Good	Fair	Good	Good	Fair	32
Li et al. 2007	Very Poor	Poor	Fair	Poor	Poor	Fair	Fair	Poor	Fair	21
Macdonald & Butler 2007	Good	Good	Fair	Fair	Good	Very Poor	Good	Fair	Fair	29
Andersson et al. 2008	Good	Fair	Good	Fair	Good	Poor	Good	Fair	Good	31
Sange et al. 2008	Poor	Good	Poor	Poor	Poor	Poor	Fair	Poor	Poor	21
Andersson et al. 2009	Good	Fair	Good	Poor	Good	Fair	Good	Fair	Good	31
Srikrishna et al. 2009	Good	Good	Good	Fair	Fair	Poor	Fair	Fair	Fair	29
Zeznock et al. 2009	Good	Good	Good	Fair	Good	Good	Good	Good	Good	35

Bradway et al. 2010	Good	Fair	Good	Good	Good	Poor	Good	Fair	Good	32
Elstad et al. 2010	Good	Good	Good	Fair	Good	Poor	Good	Fair	Good	32
Hayder & Schnepf 2010	Good	Good	Good	Fair	Good	Poor	Good	Fair	Fair	31
Anger et al. 2011	Good	Fair	Good	Good	Good	Poor	Good	Good	Good	33
Smith et al. 2011	Good	Fair	Good	Fair	Fair	Poor	Fair	Fair	Fair	28
Wang et al. 2011	Good	Good	Good	Good	Fair	Good	Good	Fair	Fair	33
Hayder 2012	Good	Fair	Good	Fair	Good	Fair	Good	Fair	Fair	31
Siu & Lopez 2012	Good	Fair	Fair	Fair	Fair	Poor	Good	Fair	Fair	28
Delarmelindo et al. 2013	Good	Good	Good	Poor	Good	Fair	Good	Poor	Good	31
Gjerde et al. 2013	Good	Good	Fair	Fair	Poor	Poor	Good	Fair	Fair	28
Avery et al. 2015	Good	Fair	Good	Fair	Good	Good	Good	Poor	Good	32
Hamid et al. 2015	Good	Good	Good	Good	Good	Fair	Good	Good	Good	35
Pakgothar et al. 2015	Fair	Fair	Fair	Fair	Poor	Poor	Fair	Poor	Poor	23
Róin & Nord 2015	Good	Good	Fair	Fair	Fair	Poor	Good	Fair	Fair	29
Siddiqui et al. 2016	Good	Fair	Good	Good	Good	Poor	Fair	Fair	Good	31
Takahashi et al. 2016	Good	Good	Fair	Poor	Good	Good	Good	Poor	Fair	30
Vethanayagam et al. 2017	Good	Good	Good	Good	Good	Poor	Good	Good	Fair	33

Appendix F: Initial Metaphors

Study	Record of Initial Metaphors
Dowd (1991)	Self-esteem, threat, control, being in charge, dignity, acceptance, unacceptability, normalising, accidents, embarrassment, humiliation, satisfaction, routine, protection, security, preparation, unpredictability, confidence, blame, inevitability, misery, importance, management, time consuming, odour control, participation, usual activities, lifestyle
Lagro-Janssen et al. (1992)	Jobs, household activities, recreation activities, self-perception, shame, self-esteem, embarrassment, odour, fear, confidence, humiliation, inconvenience, anxiousness, future worries, social interaction, inaccessible toilets, restriction, practical issues, protection, sexual relationships, coping, taboo
Bjurbrant Birgersson et al. (1993)	Odour, drinking less, napkins (pads), vulnerability, intrinsic value, autonomy, shame, guilt, punishment, blame, dependency, comfort/discomfort, security, interaction with carers, acceptance, embarrassment, empathy, control, inevitability, age, help, hygiene, nuisance, threat to adulthood, wetness, schedule, anxiety, inferiority, denial, fear, isolation, secrecy, attitude of nurses, well-known nurses, disagreement between nurses and patients, respect, preference of female nurses, stigma
Eisenhandler (1993)	Age, inevitability, shame, pads, visible wetting, secrecy, control, coping, social relationships, sympathy, social isolation, stigma, pride, routines, accident, embarrassment, toilets, security, institutionalised elderly, body, adult status, gender
Brown et al. (1998)	Loss of control, anxiety, disturbed sleep, shame, embarrassment, self-esteem, unattractive, depression, resent, isolation, toilet access, employment restrictions, social activities, sexual relationships, bodily functions, adult status
DuBeau et al. (1998)	Inevitability, age, prevention, self-control, routine, shame, fear, embarrassment, disturbed sleep, self-image, vigilance, fear of ageing, burden, odour, hygiene, other illnesses, restriction of activities, cost, loneliness, dignity, self-esteem, dependency, sexual relationships, legitimacy, taboo

Chaliha & Stanton (1999)	Embarrassment, inevitability, age, preference for female doctors, communication with partners, hygiene, restriction on domestic activity, sexual relationships, odour, religious restrictions, routine, taboo
Fitzgerald et al. (2000)	Embarrassment, disturbed sleep, work interruption, travel limitations, limiting fluids, inconvenience, distress, security, confidence, importance, knowledge, pads, extra clothes, odour, deodorant sprays, self-management, pelvic floor exercises
Robinson (2000)	Annoyance, devastation, support, inevitability, ageing, integrity, protection, dignity, privacy, empathy for staff, limited fluid intake, limiting travel, improvising, learning, monitoring, communication (physicians, carers, visitors), hygiene, attitude, self-image, self-esteem
Roe (2000)	Normalization, control, acceptance, adapting, humour, routine, unpredictable, reliance, travel, reducing liquids, future, self-management
Creech (2002)	Lack of knowledge, preparation, self-management, acceptance, inevitability, resilience, communication, secrecy, communication with healthcare professionals, preference of older doctors, awareness of available options, dissatisfaction with services, lack of intimacy, cleanliness, odour, humour, support from partners, ageing, body
Fitzgerald et al. (2002)	Self-management, odour, limiting fluid intake, precautions, limitation during work, work permissions, accessible toilets
Peake & Manderson (2003)	Female body, 'leaky' bodies, disguise, protection, normalisation, pads, future, inevitability, acceptance, perceptions of old age, stigma, cost, restrictions in sexual relationships, context of leakage, odour, secrecy, humiliation, feeling 'childish'
Shapiro et al. (2003)	Odour, embarrassment, lifestyle restrictions, isolation, self-confidence, cost, attitude of healthcare professionals, helplessness, happiness, childhood experiences
Bradway (2004)	Normalising, stigma, prevention, solution, self-management strategies, individual experiences, shared experiences, interaction with healthcare professionals, neglect, lifestyle restrictions, accessible toilets, lack of knowledge

Horrocks et al. (2004)	Ageing, inevitability, self-management, low-expectations, normalisation, lifestyle restrictions, generational attitudes, acceptance, resignation, shame, disgust, future, hygiene, embarrassment, secrecy, communication, control, self-esteem, attitudes towards seriousness, restricting fluids, pads, clothing, lack of knowledge, gender preferences for choice of doctor
Diokno et al. (2006)	Lack of knowledge, humiliation, shame, anxiety, socially unacceptable, anger, restriction, age, odour, hygiene, inevitability, coping strategies, humour, self-confidence, intimate relationships restricted, restricted social life, work restrictions, fear, perception of seriousness, communicating symptoms
Komorowski & Chen (2006)	Lack of knowledge, misinformation, ageing, self-blame, restriction, isolation, desire for treatment, negative impact on sex life, hygiene, sadness, work, protection
Teunissen et al. (2006)	Embarrassment, anxiety, self-control, fear, odour, wetness, no interference with daily life, precautions, impact on physical activity, travel, impact on sexual relationships
van den Muijsenbergh & Lagro-Janssen (2006)	Faith, prayer, ritual, cleanliness, shame, dirty, bothersome, communication with partners, intimate relationships, lack of knowledge about treatments, female doctor preferred, attitude of GP, communication with GP, lack of knowledge about physiology
Doshani et al. (2007)	Normalising, ageing, inevitability, perception of seriousness, accepting, self-management strategies, avoidance, limiting fluids, interaction with healthcare professionals, unhelpful advice, embarrassment, gender of GP, embarrassment of GP, ethnicity of GP
Li et al. (2007)	Fear of others knowing, embarrassment, control, fear of worsening condition, odour, identity, perception of seriousness, self-management

Macdonald & Butler (2007)	Losing control, bodily control, loss of dignity, loss of independence, restriction on active life, regression to childhood, embarrassment, self-esteem, dependency, lack of knowledge of treatments, secrecy, social isolation, self-management, fluid intake, pads, normalising, rituals, ageism, interaction with staff, lack of choice
Andersson et al. (2008)	Normalised, inevitability, weak body, age, annoying, unpleasant, embarrassment, return to childhood, self-management, sharing experiences with other women, odour, hygiene, other illnesses more important, access to healthcare services, fear of health provider attitudes
Sange et al. (2008)	Lack of awareness, perceived seriousness, embarrassment, religious influences, gender of GP, ethnicity of GP, lack of communication with family
Andersson et al. (2009)	Weakness in the body, shame, embarrassment, not discussed with men, importance of sharing experiences, protection, accessibility of health services, self-management, gender of doctor, religion of doctor, communication difficulties, dependence
Srikrishna et al. (2009)	Limitations in household, limitations in professional work, physical limitations, embarrassment, odour, confidence, femininity, self-image, impact on sexual function, social limitations
Zeznock et al. (2009)	Secrecy, impact on daily life, embarrassment, search for solution, positive encounters with healthcare providers, negative encounters with healthcare providers, sharing experiences with other women
Bradway et al. (2010)	Embarrassment, leakage, ageing, annoyance, inconvenience, odour, comfort, lack of control, frustration, shame, pads, lack of sleep, hygiene
Elstad et al. (2010)	Stigma, embarrassment, shame, normalcy, fear, anxiety, social interruption, control, odour (UI), hygiene, cleanliness, self-responsibility, secrecy, gendered experiences
Hayder & Schnepf (2010)	Control, social interruption, restriction of leisure activities, dependent, sexual relationships, self-management, preparedness, toilet mapping, reduce fluid intake, treatment seeking, acceptance, circle of trust, fear

Mohamed et al. (2010)	Normalcy, gender, pads, self-management, impact on sexual relationships, precautions
Anger et al. (2011)	Self-management, travel, restricted social activities, sleep deprivation, prevention, self-responsibility, self-blame, lack of knowledge, quest for cure
Smith et al. (2011)	Ageing, inevitability, acceptance, lack of understanding, misconceptions, miscommunication between women and healthcare providers, self-management, dissatisfaction with care, expectations
Wang et al. (2011)	Self-management, limiting activities, control, modifying daily life, stress, anxiety, embarrassment, cleanliness, gender of doctor, secrecy, perception of seriousness, lack of awareness of services
Hayder (2012)	Fear, embarrassment, diminishing eroticism, avoidance of sexual activity, lack of sexual spontaneity, protection, pain, communication between partners, acceptance from partners, empathy, self-management, taboo, self-respect, self-confidence, dissatisfaction with health services, attitude of healthcare professionals, isolation
Siu & Lopez (2012)	Disability, impact on work, regression to child-like state, inevitability, secrecy, isolation, sexual relationships, odour, emotional distress, unattractiveness, embarrassment, anger, blame
Delarmelindo et al. (2013)	Suffering, embarrassment, control, fear, odour, limiting activities, vulnerability, disturbed sleep, child-like state, impact on sexual relationships, care experiences, dependency
Gjerde et al. (2013)	Cleanliness, limited access to supplies, odour, housing amenities, fear, embarrassment, secrecy, child-like regression, future, religious beliefs, cultural rituals
Avery et al. (2015)	Acceptance, age, inevitability, supportive relationships, coping, lack of intrusion, resilience, control

Hamid et al. (2015)	Embarrassment, shame, control, secrecy, cleanliness, child-like state, restrictions on religious practice, disturbed sleep, impact on sexual relationships, social isolation, future
Pakgohar et al. (2015)	Self-management, physical environment, wetness, odour, restricting fluids, acceptance
Róin & Nord (2015)	Ageing, inevitability, health practitioner attitudes, blame, self-management, pads, restriction of activities, restricted fluids, social relationships, shame, humour, child-like state, stigma
Siddiqui et al. (2016)	Shame, fear, isolation, sexual activity, lack of knowledge, normalising, secrecy, dissatisfaction with doctors
Takahashi et al. (2016)	Social participation, motivation, embarrassment, secrecy, anxiety, restriction, confidence, self-management
Vethanayagam et al. (2017)	Embarrassment, dissatisfaction with GPs, normalcy, ageing, inevitability, lack of knowledge, self-management, perceived seriousness

Appendix G: Keywords

Ovid MEDLINE(R) 1946 to June Week 2 2018	
1	co-produc*.mp
2	coproduc*.mp
3	co-design.mp
4	co-deliv*.mp
5	Community-based participatory research/ or Research design/ or Qualitative research/ or Research/ or Health Services Research/
6	1 or 2 or 3 or 4
7	5 and 6

Appendix I: Participant Information Sheet (phase 1)

Version 4.0 (Date 17/10/2018)

Participant Information Sheet**Title of the research project**

Co-production in Research: using the exemplar of self-management for urinary incontinence in older women

You are being invited to take part in a research project.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please contact me using the contact details in this document. Please take time to decide whether or not you wish to take part in this research project.

Why is this research being done?

Urinary incontinence is a condition that is thought to affect millions of people in the UK. This study is interested in researching the specific experiences of older women (aged 55+) living with urinary incontinence in the UK. It is expected that findings from this study will expand knowledge in this area. This research is being done as part of the researcher's PhD thesis.

Who will conduct the research?

Rebecca Wood, PhD student at University of Leeds.

The researcher will be supervised by three experienced researchers (Professor Linda McGowan, Professor Andrea Nelson and Dr Philip Esterhuizen).

Who can take part in the study?

You can take part in the study if you are:

- Female
- Aged ≥ 55
- Currently have urinary incontinence
- Currently living in the Leeds area
- Not currently seeking medical help to treat symptoms of urinary incontinence

However, not all those who volunteer will be guaranteed inclusion in the study. If you volunteer after the required number of participants has been reached then you will not be interviewed.

What would I be asked to do if I took part?

If you decide to take part in the research, you will be interviewed about your experiences of living with urinary incontinence. Only 1 interview will be carried out with each participant. Participants will be offered the choice to have the interview be conducted at their home, place of work, or in the University of Leeds. Interviews are expected to last approximately 1 hour.

Will I be recorded, and how will the media be used?

Interviews will be audio recorded as part of this research, so that the researcher can type up a transcript of the interview. The audio recordings made during this research will be used only for analysis.

What are the possible disadvantages of taking part?

When discussing your experiences of urinary incontinence with the researcher, it is possible that you may feel anxious or distressed. If you were upset and did not want to answer any more questions, the researcher would stop the interview immediately.

What are the possible benefits of taking part?

Whilst there are no direct benefits for those people participating in the project, it is hoped that this work will benefit future research and lead to a better understanding and increased knowledge of the day to day experiences of older women with urinary incontinence.

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 will be asked to sign a consent form.

Will I be able to withdraw my data if I change my mind?

You will be able to withdraw from the study during or up to two weeks after the interview. If you choose to withdraw from the research, all of the data about you will be destroyed. If you choose to withdraw later than two weeks after the interview, it will not be possible to withdraw the data.

Will my taking part in this project be kept confidential?

Your personal details will be stored securely at the University of Leeds. They will be destroyed securely after 5 years.

Your name or other identifying features will not be used in the research. Pseudonyms (false names) will be used when writing about the research. All interview data will be kept confidential. The only exception to this is if something you say suggests that:

- There is a risk of harm to yourself or someone else
- A law that may have been broken

In any of these situations, the researcher has a duty to report concerns to the PhD supervisors at the University of Leeds.

Who is funding the research?

This research is being funded by the Leeds Benevolent Society for Single Ladies (LBSSL, www.lbssl.org).

Will I be paid for taking part in the study?

No.

What is the duration of the research?

The research will be completed by June 2019

Will the outcomes of the research be published?

The research findings will be submitted to the University of Leeds in the form of my PhD thesis. Results will also be published in report form on the LBSSL website. Research will also be published in academic journals.

What should I do now if I am interested in taking part in the study?

If you are interested in taking part in the study please contact Rebecca Wood.

You can contact Rebecca by:

- Sending an email to: hcrl@leeds.ac.uk
- Phoning: 07538450243

Writing to: Rebecca Wood,
School of Healthcare, Baines Wing,
University of Leeds,
Leeds, LS2 9JT

Contact details

PhD Researcher	Rebecca Wood	hcrl@leeds.ac.uk	07538450243
PhD Lead Supervisor	Professor Linda McGowan	l.mcgowan@leeds.ac.uk	0113 34 31339

Appendix J: Consent Form (phase 1)

School of Healthcare

Version 2.0



UNIVERSITY OF LEEDS

Co-production in Research: using the exemplar of self-management for urinary incontinence in older women

Written Informed Consent Form: Interviews (urinary incontinence)

Participant Identification Number:

Add your initials next to the statement if you agree

I confirm that I have read and understand the information sheet dated 22/01/18 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason and without there being any negative consequences. I understand that if I withdraw from the study within two weeks of data collection, then all associated data will be destroyed. After this period, it will not be possible to withdraw the data.	
I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential. The only exceptions are if any information disclosed suggests that myself or another person may be at risk of harm, or if there is a possible breach of the law.	
I understand that the researcher's PhD supervisors will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	
I agree for the data collected from me to be stored securely for 5 years and used to support relevant future research.	
I understand that interviews will be audio-recorded and transcribed. I agree to the use of direct quotations that are anonymised.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date	

Appendix K: Topic Guide (phase 1)

Interview Topic Guide

Women's lived experiences of urinary incontinence

In keeping with the phenomenological approach of the study, interviews will be guided by the overarching question: how do women experience urinary incontinence? The interviews will be respondent led and will focus on women's accounts of living with urinary incontinence.

Introductions/setting of ground rules

- Introduce self
- Explain study
- Explain audio-recording/transcription
- Explain use of pseudonyms
- Explain that it is possible to refuse to answer any question
- Explain that the interview can be stopped at any time
- Opportunity for questions
- Collect and check consent form
- Set tape recorder to record

Interview Questions

Overarching question:

- Please can you describe, in as much detail as possible, how urinary incontinence has affected your life?

Prompt questions:

- *Please can you describe a situation where you experienced urine leakage?*
 - *Can you tell me more about this incident?*

- *Exactly what happened?*
- *What impact did this experience have on your life?*
- *Have you ever talked to your GP about your symptoms of urinary incontinence?*
 - *Can you tell me about your experience of this?*
 - *What influenced your decision to talk/not talk to your GP?*
 - *Did this have any kind of effect on your life?*
 - *Have you ever received any treatments for urinary incontinence?*
- *Have you ever talked to anyone else about your symptoms e.g. family, friends, community, internet?*
- *How does having urinary incontinence affect your self-image? How you think about yourself*
- *Is there anything that I haven't covered in the interview that you would like to discuss/think is important?*

End of interview

- Researcher will thank participant for their time
- Researcher will complete reflexive diary

Appendix L: Initial Notes/Emergent Themes Example (phase 1)

Phase 1: Interview 1

<p><u>Background:</u> Has seen a GP & has a recurring prescription for Oxybutynin Hasn't seen GP for 18 months Has previously engaged with incontinence services (diary) No family</p>
--

Stage 2: Initial Noting

Descriptive	Linguistic	Conceptual
Holidays	Given up (holidays)	Childhood memories of 'accident'
Planning journey	Disappointing (missing out)	Similar feelings to childhood (embarrassement)
Worse at night	Hopeless	General health decline in old age
Quite an impact	Stuck with it	Chicken and egg
Planning around toilets	Makes a difference (to life)	x don't talk about UI so it's not well known so i
Walking club	Others in the same boat	
Losing friends	She tried (GP)	
Continence pads	She did her best (GP)	
Cost	I admire her (GP)	
Sanitary towels/Continence pads	Best they could do (charity)	
Fluid restriction	Crept up on me gradually	
Dehydration	Hope	
Lots of things wrong (not just UI)	Hope for the best	
Oxybutnlin	Not where I wish to be (incontinence pants)	
Adjustments to prescription	Doesn't bare thinking of (leaking/using pants)	
Side effects	Very embarrassing	
GP thought prescription was the answer	Learn to live with it	
GP not offering anything else	Not attractive option (pants)	
Nothing effective	Delicate area (to talk about)	
Mentined to GP more than once	The sky would fall in (childhood)	
LOPF	Disastrous (accidents)	
Toilet mapping	Unless I'm being stupid (accidents)	
Trust in doctor	Perhaps I'm naughty (adjusting prescription)	
Uncomfort (pads/pants)	Jokey (talking about UI)	
Leaking (pads/pants)	Swept under the carpet	
Take UI for granted		
UI features in old age		
Coping strategies		
Habits		
Out of the house (impact)		
Embarrassement		
Nothing encouraging (treatments)		
Obvious (coping strategies)		
Sharing the experience (LOUISA)		
Exchanging ideas (LOUISA)		
IBS comparison (worse than UI)		

Stage 3: Emergent Themes

Holidays
Forward planning
Hopelessness
Losing friends
Assumption that UI is a feature of ageing
Continence products
Fluid restriction
Declining health in old age
Limited treatment options
Gradually worsening
Hope
Ineffective treatments
Charity research outcomes
Trust in GP
Admiration for GP
Social conventions
Humour (communication)
Embarrassment
Childhood experiences
Developing strategies
Sharing the experience
Comparison to other health conditions
Raising awareness
Funding
Impact of accidents
Feelings from childhood
Self-blame
Personal responsibility to manage
Disappointment
Sympathy towards GP
Adjusting prescription
Humour (coping)
Misinformation about UI

Appendix M: Initial Themes (phase 1)

Stage 4: Searching for Connections

Initial Notes	Emergent Themes	Connections
Embarrassment Hopeless Stuck with it Makes a difference (to life) Quite an impact IBS comparison (worse than UI) Crept up on me gradually Doesn't bare thinking of (leaking/using pants) Very embarrassing Disastrous (accidents)	Hopelessness Gradually worsening Embarrassment Impact of accidents	<i>Living with UI</i>
Holidays Worse at night Walking club Losing friends Out of the house (impact) Given up (holidays) Disappointing (missing out)	Holidays Losing friends	<i>Social restrictions</i>
Should talk more to raise awareness Comparison to cancer research Not life-threatening Chicken and egg (don't talk about UI so it's not well known so then not a focus for funders) Causes of UI (loss of nerves)	Raising awareness Funding Misinformation about UI	<i>Knowledge of UI</i>
Personal responsibility Unless I'm being stupid	Self-blame Personal responsibility to manage	<i>Responsibility</i>
Not something you normally talk about Delicate area (to talk about) Jokey (talking about UI) Swept under the carpet	Social conventions Humour (communication)	<i>Confiding in family and friends</i>
Lots of things wrong (not just UI) Take UI for granted UI features in old age Just one more thing (health issue) Others in the same boat General health decline in old age	Assumption that UI is a feature of ageing Declining health in old age Comparison to other health conditions	<i>Seriousness/Perceptions of ageing</i>
Planning journey Continence pads Cost Sanitary towels/Continence pads Fluid restriction Dehydration Adjustments to prescription Side effects Uncomfort (pads/pants) Leaking (pads/pants) Coping strategies Habits Obvious (coping strategies) Humour Not where I wish to be (incontinence pants) Learn to live with it Not attractive option (pants) Perhaps I'm naughty (adjusting prescription)	Forward planning Continence products Fluid restriction Habits Developing strategies Adjusting prescription Humour (coping)	<i>Coping strategies</i>
Oxybutnin GP thought prescription was the answer GP not offering anything else Nothing effective Mentioned to GP more than once Nothing encouraging (treatments) Hope for the best	Limited treatment options Hope Ineffective treatments Uncertainty of future	<i>Treatment options</i>
Trust in doctor She tried (GP) She did her best (GP) I admire her (GP)	Trust in GP Admiration for GP	<i>Feelings towards HCPs</i>
Mother 'furious' (childhood) The sky would fall in (childhood) Childhood memories of 'accident' Similar feelings to childhood (embarrassment)	Childhood experiences Feelings from childhood	<i>Childhood</i>
LOPF Toilet mapping Sharing the experience (LOUISA)	Charity research outcomes Sharing the experience	<i>Research involvement</i>

Appendix N: Identifying Patterns Example (phase 1)

Stage 6: Identifying Patterns

	Interview 1
	Interview 2
	Interview 3

Table 2: Identifying Patterns

Initial Notes	FEELINGS ABOUT UI Very embarrassing/Not embarrassed/Embarrassed if it showed/Wetness
	Inconvenient/Inconvenience/Annoying/Annoying/Nuisance/Control("Annoying in that I can't control it')
	Crept up on me gradually/Crept up on me
	Hopeless/Stuck with it/Cope with it/'learnt to live with it'/Exercises helping it not get worse
	Doesn't bare thinking of (leaking/using pants)/Disastrous (accidents)/No accidents outside of home/embarrassed if it showed/afraid
	IMPACT OF UI
	UI partly limits life/Not worried/Not impinging on life/Quite an impact/Makes a difference (to life)/Out of the house (impact)/Worse at night/Little impact during day Holidays/Given up (holidays)/Holiday with friend/Holiday abroad (aware of UI)/Preparation for holiday/Worries about travel Losing friends/Walking club/Disappointing (missing out)/Social life not affected
Emergent Themes	FEELINGS AROUND UI Embarrassment Annoyance Gradually worsening Hopelessness Accidents IMPACT OF UI Impact of UI on daily life Travel restrictions Social restrictions
Connections	Living with UI

Appendix O: Participant Information Sheet (phase 2 - observation)**Participant Information Sheet: Observation****Title of the research project**

Co-production in Research: using the exemplar of self-management for urinary incontinence in older women

You are being invited to take part in a research project.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please contact me using the contact details in this document. Please take time to decide whether or not you wish to take part in this research project.

Why is this research being done?

Co-production research emphasises shared decision-making between professionals and the public. Co-production research is becoming increasingly popular, however there is a lack of research into the realities of this approach. There is also a lack of research into how co-production research can be used when researching long-term physical illnesses such as urinary incontinence. This study aims to explore co-production in the context of the Leeds Older women Urinary Incontinence Self-mAnagement study (LOUISA). This research is being done as part of the researcher's PhD thesis.

Who will conduct the research?

Rebecca Wood, PhD student at University of Leeds.

Who can take part in the study?

You can take part in the study if you are a member of the advisory group for the LOUISA project.

What would I be asked to do if I took part?

If you decide to take part in the research, you will be observed by the researcher during the advisory group meetings for the LOUISA study. No additional time will be required by the researcher if you take part.

Will I be recorded, and how will the media be used?

Advisory group meetings will not be audio or video recorded. Written notes will be collected on paper during the meeting by the researcher.

What are the possible disadvantages of taking part?

It is possible that during the observation of the advisory group meetings, you may feel anxious or distressed. If you were upset and did not want to be observed anymore, the researcher would stop the observation immediately.

What are the possible benefits of taking part?

Whilst there are no direct benefits for those people participating in the project, it is hoped that this work will benefit future research and knowledge of co-production in research.

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 will be asked to sign a consent form.

If you decide not to take part, then the observation of other group members will still be carried out, but no data will be recorded about you.

As noted above, this research is linked to the LOUISA study. If you do not wish to take part in the current research, this will not affect your participation in the LOUISA study.

Will I be able to withdraw my data if I change my mind?

You will be able to withdraw from the group observations at any time. However, it will not be possible to withdraw the data collected due to the nature of this being group data. Withdrawal from the research will not affect your participation in the LOUISA study.

Will my taking part in this project be kept confidential?

Your personal details will be stored securely at the University of Leeds. They will be destroyed securely after 5 years.

Your name or other identifying features will not be used in the research. Pseudonyms (false names) will be used when writing about the research. All observational data will be kept confidential. The only exception to this is if something you say suggests that:

- There is a risk of harm to yourself or someone else
- A law that may have been broken

In any of these situations, the researcher has a duty to report concerns to the PhD supervisors at the University of Leeds.

Who is funding the research?

This research is being funded by the Leeds Benevolent Society for Single Ladies (LBSSL).

Will I be paid for taking part in the study?

No.

What is the duration of the research?

The research will be completed by June 2019

Will the outcomes of the research be published?

The research findings will be submitted to the University of Leeds in the form of my PhD thesis. Results will also be published in report form on the LBSSL website. Research will also be submitted to a peer review journal.

What should I do now if I am interested in taking part in the study?

If you are interested in taking part in the study please contact Rebecca Wood.

You can contact Rebecca by:

- Sending an email to: hcrl@leeds.ac.uk
- Writing to:
 Rebecca Wood,
 School of Healthcare,
 Baines Wing,
 University of Leeds,
 Leeds, LS2 9JT

Contact details

PhD Researcher	Rebecca Wood	hcrl@leeds.ac.uk
PhD Supervisor	Professor Linda McGowan	l.mcgowan@leeds.ac.uk
PhD Supervisor	Professor Andrea Nelson	E.A.Nelson@leeds.ac.uk

Appendix P: Consent Form (phase 2 - observation)

School of Healthcare

Version 1.0


UNIVERSITY OF LEEDS

Co-production in Research: using the exemplar of self-management for urinary incontinence in older women

Written Informed Consent Form: Observation

Participant Identification Number:

Add your initials next to the statement if you agree

I confirm that I have read and understand the information sheet dated 19/10/17 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason and without there being any negative consequences. I understand that it will not be possible to withdraw any data collected due to the nature of this being group data.	
I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential. The only exceptions are if any information disclosed suggests that myself or another person may be at risk of harm, or if there is a possible breach of the law.	
I understand that the researcher's PhD supervisors will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	
I agree for the data collected from me to be stored securely for 5 years and used to support relevant future research.	
I understand that fieldnotes will be recorded during observation in the form of handwritten notes. I agree to the use of direct quotations that are anonymised.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during the project and, if necessary, afterwards.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date	

Appendix Q: Observation Notes (phase 2 - observation)

Observation Notes: LOUISA Project Advisory Group Meeting

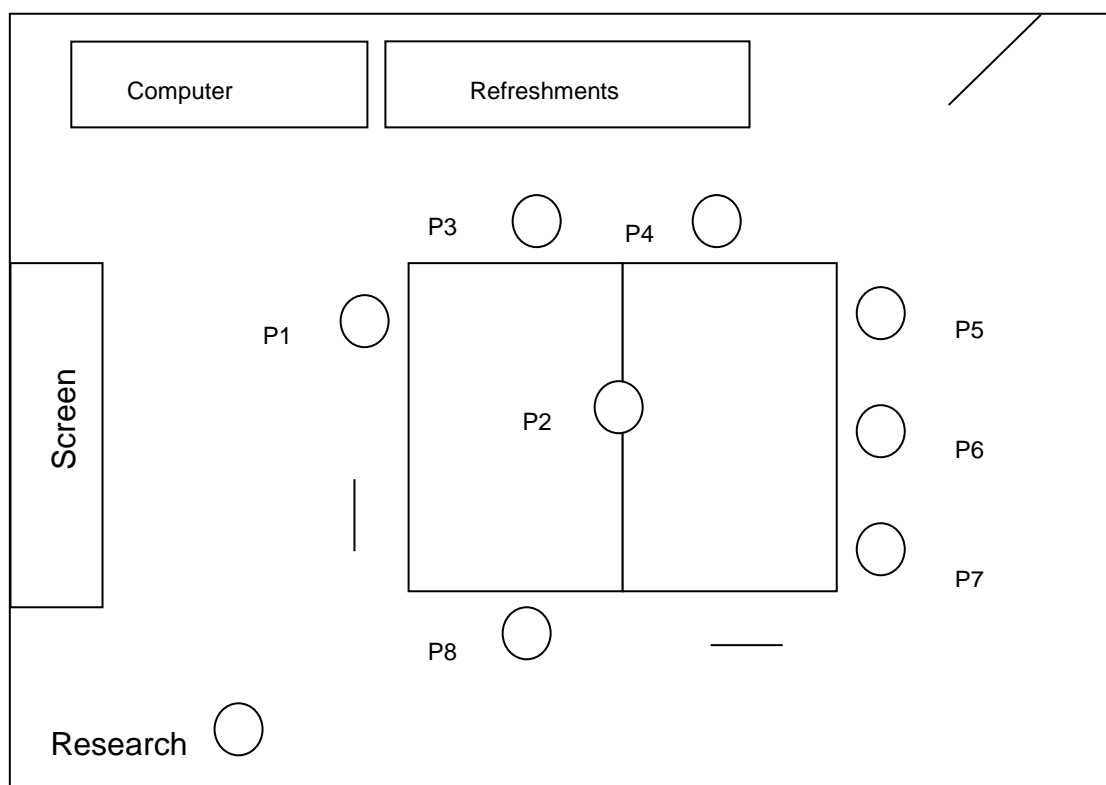
Date: 08/11/2017

Location: Baines Wing Room 2.09, School of Healthcare, University of Leeds

Time: 13.30-16.30

SPACE

- The meeting was held in a meeting room in the University of Leeds Baines Wing
- Heaters were set up in the room in advance so that members were comfortable
- Refreshments provided include: tea, coffee, water (still and sparkling), biscuits and cakes
- Members of funding body sat together and other members spread out around table



*attended remotely

ACTORS

The group consisted of: 2 academics (1 attended meeting remotely), 1 service user, 3 funders, and 2 health professionals

OBJECTS

- Large wall-mounted screen was used so that all members could see presentation slides
- Hard copies of the slides were also given to each member (funders asked for more to take back for other members who didn't attend)

ACTIONS

- Technical terms e.g. data extraction were explained in a non-academic way e.g. 'taking away the noise'
- Members didn't appear to be taking notes during presentation or discussion
- At the beginning of the meeting there were no questions or contributions from members (with the exception of P4 & P6) but as the meeting progressed the discussion opened up
- During discussions some members would direct questions to the health professionals

EVENTS

- Presentation was the main focus of the meeting which was mainly led by academic
- Presentation style was more casual (e.g. sat down with members rather than stood at the front) which encouraged discussion
- Group discussion followed presentation and everyone was encouraged to share their views
- This meeting was more of an update meeting on LOUISA progress because project is not at intervention development stage yet

TIME

- The meeting began with refreshments
- Due to late arrival of some members the meeting started a little bit late (approx. 15 mins)
- Members were asked to introduce themselves to the rest of the group
- The observation of the meeting was explained to the group and they were given an opportunity to ask questions
- Consent was then granted by members through consent forms
- Presentation of overview of PhD – questions directed at me which I answered but after this I took a step back in line with non-participant observation
- Presentation on overview of LOUISA progress
- 1 group member came late to the meeting (during discussion on overview of LOUISA) so there was no opportunity to ask for consent – so no notes were taken about this person
- Discussion on ways forward – members asked for advice/reflections/thoughts/opinions on going forward
- Discussion on progress to date – members asked: Are we on track? Have we done enough? Are we meeting expectations?

- Discussed next meeting – more about intervention components so views and opinions of members will be essential

GOALS

- People opened up a lot during this discussion which is a good indication for next meeting which will be focussed on intervention components
- Members opened a debate about whether people should be made aware of pelvic floor exercises much earlier in life
- Media route suggested by members e.g. magazines, radio, television
- Members agreed that removing taboo is essential (UI discussed as last taboo)
- Discussion around whether self-management could do harm if applied to the wrong type of urinary incontinence
- Focus on 'real' people not just 'academics' seen as important to all members

FEELINGS

- Participants were smiling and laughing during the meeting indicating they are comfortable in this setting

REFLECTIONS

As this was the first time I had conducted research observation, I was nervous about how the session would run. I had met some of the advisory group members at a previous session (not part of observation); however I was meeting some of the members for the first time. As this was the first observation session, I felt that there was a certain level of awareness of my presence, especially at the beginning. This was probably heightened by the fact that I gave another brief explanation to the group about the premise of the observation prior to the meeting. However, as the session went on, the discussion flowed freely and I was able to silently observe.

The members expressed that they were pleased that P2 was able to phone into the meeting; however there were times when the lag in communication seemed to disrupt the flow of conversation slightly and it was sometimes difficult to hear P2. This session was mainly led by P1 as the group were being updated on the progress of the project, which meant that the discussion was left until the last half of the session. The next session will be more discussion led so I will hopefully be able to look at the interactions between members in more detail.

Using the Spradley framework for observation was very helpful for making observation notes, especially as it was my first time observing. I think that this was a good first group observation and I will feel more confident in note taking for the next session.

Appendix R: Participant Information Sheet (phase 2 - interview)**Participant Information Sheet****Title of the research project**

Co-production in Research: using the exemplar of self-management for urinary incontinence in older women

You are being invited to take part in a research project.

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, please contact me using the contact details in this document. Please take time to decide whether or not you wish to take part in this research project.

Why is this research being done?

Co-production research emphasises shared decision-making between professionals and the public. Co-production research is becoming increasingly popular, however there is a lack of research into the realities of this approach. There is also a lack of research into how co-production research can be used when researching long-term physical illnesses such as urinary incontinence. This study aims to explore co-production in the context of the Leeds Older women Urinary Incontinence Self-mAnagement study (LOUISA). This research is being done as part of the researcher's PhD thesis.

Who will conduct the research?

Rebecca Wood, PhD student at University of Leeds.

Who can take part in the study?

You can take part in the study if you are a:

- Service user involved in the LOUISA study
- Funder involved in the LOUISA study
- Academic involved in the LOUISA study
- Healthcare professional involved in the LOUISA study

What would I be asked to do if I took part?

If you decide to take part in the research, you will be interviewed about your experiences of co-production in research. In total, 1 interview will be carried out with each participant. Interviews will take place at a time and location that is convenient for the participant. Participants will be offered the choice to have the interview be conducted at the University of Leeds or their home or place of work. Interviews are expected to last approximately 1 hour.

Will I be recorded, and how will the media be used?

Interviews will be audio recorded as part of this research, so that the researcher can type up a transcript of the interview. The audio recordings made during this research will be used only for analysis.

What are the possible disadvantages of taking part?

It is possible that whilst discussing your experiences with the researcher, you may feel anxious or distressed. If you were upset and did not want to answer any more questions, the researcher would stop the interview immediately.

What are the possible benefits of taking part?

Whilst there are no direct benefits for those people participating in the project, it is hoped that this work will benefit future research and knowledge of co-production in research.

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 will be asked to sign a consent form.

As noted above, this research is linked to the LOUISA study. If you do not wish to take part in the current research, this will not affect your participation in the LOUISA study.

Will I be able to withdraw my data if I change my mind?

You will be able to withdraw from the study during or up to two weeks after the interview. If you choose to withdraw from the research, all of the data about you will be destroyed. Withdrawal from the research will not affect your participation in the LOUISA study. If you choose to withdraw later than two weeks after the interview, it will not be possible to withdraw the data.

Will my taking part in this project be kept confidential?

Your personal details will be stored securely at the University of Leeds. They will be destroyed securely after 5 years.

Your name or other identifying features will not be used in the research. Pseudonyms (false names) will be used when writing about the research. All interview data will be kept confidential. The only exception to this is if something you say suggests that:

- There is a risk of harm to yourself or someone else
- A law that may have been broken

In any of these situations, the researcher has a duty to report concerns to the PhD supervisors at the University of Leeds.

Who is funding the research?

This research is being funded by the Leeds Benevolent Society for Single Ladies (LBSSL).

Will I be paid for taking part in the study?

No.

What is the duration of the research?

The research will be completed by June 2019

Will the outcomes of the research be published?

The research findings will be submitted to the University of Leeds in the form of my PhD thesis. Research will also be submitted to a peer review journal.

What should I do now if I am interested in taking part in the study?

If you are interested in taking part in the study please contact Rebecca Wood.

You can contact Rebecca by:

- Sending an email to: hcrl@leeds.ac.uk
- Phoning or texting: 07538450243

Contact details

PhD Researcher	Rebecca Wood	hcrl@leeds.ac.uk	07538450243
PhD Supervisor	Professor Linda McGowan	l.mcgowan@leeds.ac.uk	0113 34 31339

Appendix S: Consent Form (phase 2 - interview)

School of Healthcare

Version 1.0



UNIVERSITY OF LEEDS

Co-production in Research: using the exemplar of self-management for urinary incontinence in older women

Written Informed Consent Form: Interviews (co-production)

Participant Identification Number:

Add your initials
next to the
statement if you
agree

I confirm that I have read and understand the information sheet dated 27/11/18 explaining the above research project and I have had the opportunity to ask questions about the project.	
I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving any reason and without there being any negative consequences. I understand that if I withdraw from the study within two weeks of data collection, then all associated data will be destroyed. After this period, it will not be possible to withdraw the data.	
I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. I understand that my responses will be kept strictly confidential. The only exceptions are if any information disclosed suggests that myself or another person may be at risk of harm, or if there is a possible breach of the law.	
I understand that the researcher's PhD supervisors will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	
I agree for the data collected from me to be stored securely for 5 years and used to support relevant future research.	
I understand that interviews will be audio-recorded and transcribed. I agree to the use of direct quotations that are anonymised.	
I understand that relevant sections of the data collected during the study, may be looked at by auditors from the University of Leeds where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
I agree to take part in the above research project and will inform the lead researcher should my contact details change during the project and, if necessary, afterwards.	

Name of participant	
Participant's signature	
Date	
Name of lead researcher	
Signature	
Date	

Appendix T: Topic Guide (phase 2)**Interview Topic Guide****Experiences of co-production research project**

The aim of this interviews is to explore the experiences of key stakeholders currently engaged with the co-production research approach used in the LOUISA project. This will involve exploring:

- Previous experiences of co-production research
- Views and experiences related to the co-production of research in the LOUISA study
- Opinions surrounding user involvement

Introduction

- Introduce self
- Introduce aim and purpose of study
- Collect consent form
- Outline key points: length of interview, voluntary, audio-recording
- Any questions

Previous experiences of co-production

- What does co-production in research mean to you?
 - Prompt: core principles?
- What are your views on co-produced research?
 - Prompt: barriers, advantages, disadvantages?
- Have you ever worked on a research project using a co-production approach?
- Please can you tell me about your experiences of using this approach?
 - Prompt: positive or negative feedback from others?
 - Prompt: examples of how this approach positively contributed to study?

- Prompt: examples of negative effects from using this approach

Experiences of co-production within LOUISA

- Can you describe your experiences so far within the LOUISA project?
- More specifically, can you describe your experiences of working within the co-production approach adopted by LOUISA?
 - Prompt: what do you think works well?
 - Prompt: what do you think doesn't work well?
 - Prompt: improvements

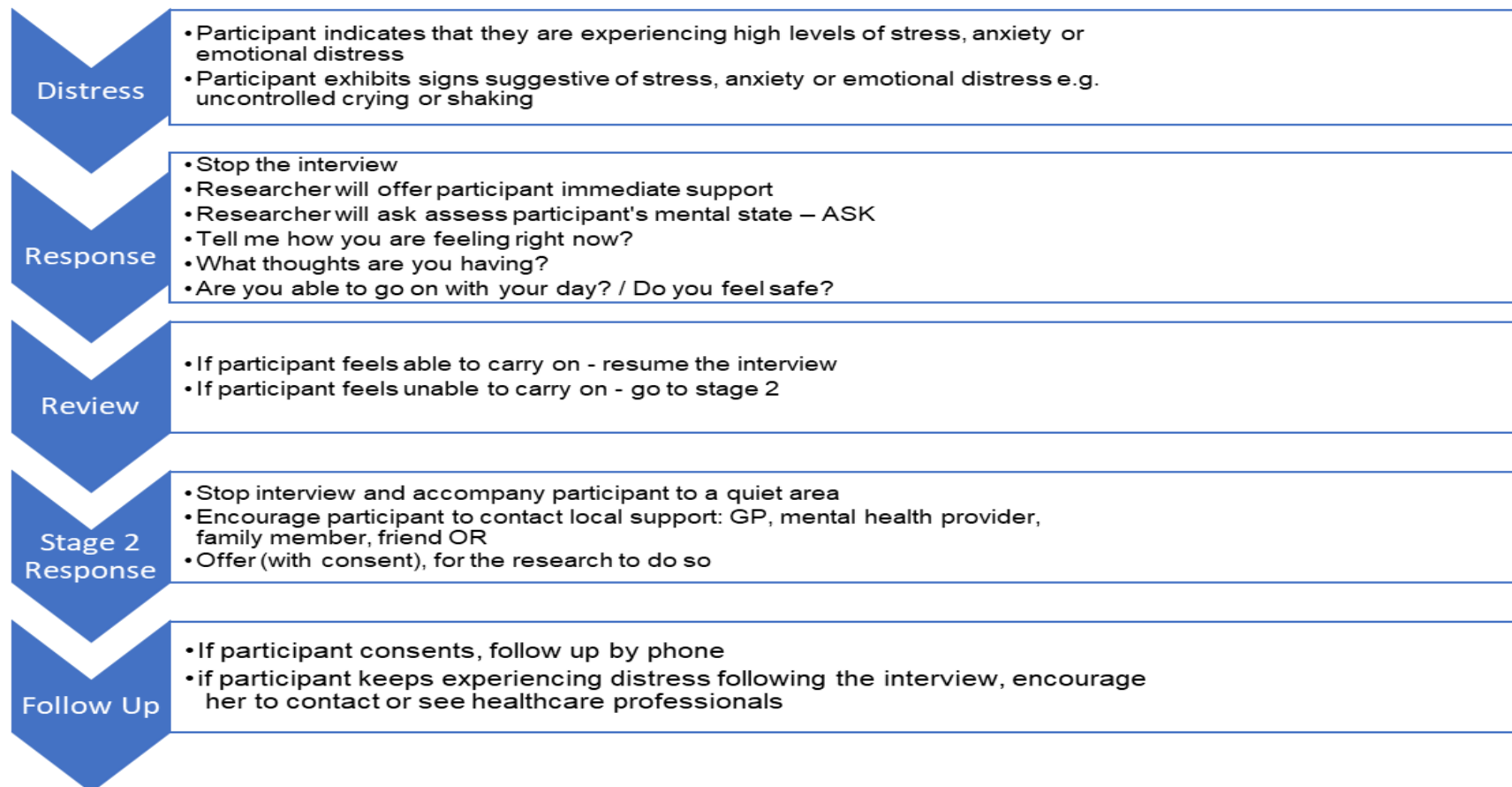
End of interview

- Thank participant for interview
- Opportunity for questions

Appendix U: Analysis Phase 2

PHASE 2 ANALYSIS (INTERVIEWS and OBSERVATION)		
Initial Codes	Themes	Connected Themes
Different viewpoints	Diversity of members	Group Roles
Good group make up		
Interesting		
Respectful		
Accepting group	Group dynamic managed well	
Knows opinions are important		
Welcoming group		
Comfortable to share		
Equal viewpoints		
Well organised		
Well chaired		
Making sure everyone has a voice		
Relaxed atmosphere *		
Accommodating *		
Members engaged *	Unclear expectations/roles	
No expectations		
Didn't know was was expected of her		
Not sure what to expect		
Not sure what to expect		
Not known what role is at times		
Time commitment		
Need to be clear about roles	Doubts about value of contributions	
Worried about contribution		
Not sure about personal value	Lack of involvement	
Wanted more involvement from other charity members		
Had to go between charity and rest of group		
Political		
People not voicing questions		Competing Motivations
Contributing		
Helping women		
How can funding help women		
UI taboo that needs addressing		
Would like to be involved in publication		
Goal to create something helpful		
Don't want just an academic paper		
Something for the public		
Academic work important	Desired outputs	
Would have liked to provide financial incentives	Financial motivations	
Funders interested	Engagement with funders	Funder Involvement
Not funded by big corporation		
Want to help with what they are paying for		
Hold the purse strings	Power relationships	
Don't want to waste money		
Impact of funders felt at meetings		
Funders sat together *	Impact on principles of co-production	
Complication of having funders involved		
Is it true co-production with funders involved?		
Funder roles not clear		
Good at consulting	Communication during meetings	Communication
Clear on study aim	Communicating issues	
Opportunities for questions or input throughout *		
Communicated when not happy		
Staffing issues	Communication between meetings	
Don't feel ignored		
Long time between meetings		
More communication between meetings		
Reminder in-between meetings	Communicating research processes	
Challenging to communicate research processes		
Held sessions to communicate complex issues		
Technical terms explained *		

Appendix V: Distress Policy



(adapted from the distress protocol designed by (Draucker et al., 2009))