

**Understanding women's attitudes to their experience of urine leakage and the use of absorbent textiles.**

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## Intellectual property and publication statements

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Chapter 5 of this thesis refers to work that has been published in a jointly authored publication. Details of the publication are as follows:

- Hunter, A. E., Nelson, E.A, McNichol, E., Holt, J (2017) *Using Q methodology to determine attitudes of women to their experience of urinary incontinence and use of absorbent pads*. In: *Neurourology and Urodynamics*. ICS 2017, 12-15 Sep 2017, Florence, Italy. Wiley, S396-S398.

The primary author of the above publication was the PhD candidate, Amy Hunter. The research that the above publication refers to was designed and conducted by Amy Hunter, under the supervision of Andrea Nelson, Elaine McNichol and Janet Holt. The oral presentation that the publication is associated with was given by Amy Hunter in September 2017. Andrea Nelson, Elaine McNichol and Janet Holt provided advice on the content and structure of the publication.

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## Abstract

**Background:** Urinary incontinence can be socially challenging for many women. It is often shrouded in secrecy due to social and cultural stigma. To overcome some of these challenges women may choose to use absorbent textile products as a coping strategy, to maintain social continence.

**Aim:** This research aimed to take an integrated approach to exploring women's attitudes towards their experience of urinary incontinence and the use or non-use of absorbent products, building on work by Getliffe et al. (2007).

**Methods:** A scoping review was undertaken to identify how women use absorbent products. Experts-by-experience were then invited to join the study as members of a reference group, providing valuable insight throughout the research process. Socially acceptable terminology was used to recruit a convenience sample to two empirical studies. Qualitative semi-structured interviews were undertaken (n=11), which were thematically analysed. A sociotechnical analysis considered implications for absorbent product development. Interview data was used to develop a Q methodological study. Twenty women ranked statements by level of agreement, placing items onto a quasi-normal distribution grid. By-variable analysis generated factors which were interpreted to explain collective viewpoints between participants.

**Results:** The scoping review identified that women used absorbent products, but that their use was affected by a number of considerations. The review highlighted that absorbent product use was challenging for women. Many of the concerns about urine leakage intersected with concerns about product

use. This knowledge led to the development of the empirical studies. Three themes were identified in the interview study. '*Maintaining identity*' considered the continuation of self and routine. Positive personal characteristics were prioritised by participants. '*Communication*' was the second theme, highlighting the importance of verbal and non-verbal strategies to negotiate difficult situations. '*Information and help-seeking*', influenced understanding and expectations for the future. The sociotechnical analysis suggested women would favour more personalised products, designed for the full product lifecycle. The Q study identified four distinct viewpoints. '*Trial and error*' focussed on being proactive by dealing with urine leakage alone; '*Carry on regardless*' provided a view of continuation in spite of urine leakage. '*Shameful secret*' typified a lack of willingness to share information about experience due to the threat posed by leakage. '*Wanting change*' considered leaking urine as normal ageing and viewed new products as a method to improve coping. Integration of both study findings revealed opportunities for improving care and products for women. Recognition of the social influences affecting help-seeking women requires further exploration.

**Conclusion:** The findings of this novel study have clearly demonstrated differences in attitudes between women. In addition to highlighting a number of key issues which were important to all, such as the threat of stigmatisation, this study also explored diversity between women. This discernment supported characterisation of four viewpoints. It provided strong justification for personalisation of care. The benefits of understanding women's attitudes are numerous. Attitudinal awareness can support healthcare practice and absorbent product development by facilitating more personalised provision.

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## Abbreviations

<b>ANT</b>	Actor Network Theory
<b>AQP</b>	Any Qualified Provider
<b>CASP</b>	Critical Appraisal Skills Programme
<b>CCG</b>	Clinical Commissioning Group
<b>FGS</b>	Faculty Graduate School
<b>GP</b>	General Practitioner
<b>ICIQ-UI SF</b>	International Consultation on Incontinence Questionnaire Urinary Incontinence Short Form
<b>ICS</b>	International Continence Society
<b>IT</b>	Information Technology
<b>LUTS</b>	Lower Urinary Tract Symptoms
<b>MMR</b>	Mixed Methods Research
<b>MUI</b>	Mixed Urinary Incontinence
<b>NHS</b>	National Health Service
<b>NICE</b>	National Institute for Health and Care Excellence
<b>OAB</b>	Overactive Bladder
<b>PCA</b>	Principle Component Analysis
<b>PFE</b>	Pelvic Floor Exercises
<b>PPI</b>	Patient and Public Involvement
<b>SDDU</b>	Staff & Departmental Development Unit
<b>SHREC</b>	School of Healthcare Research Ethics Committee
<b>SoH</b>	School of Healthcare
<b>SUI</b>	Stress Urinary Incontinence
<b>UI</b>	Urinary Incontinence
<b>UUI</b>	Urge Urinary Incontinence
<b>UK</b>	United Kingdom
<b>USA</b>	United States of America



## Chapter 1 Introduction

This thesis reports a PhD study undertaken in the School of Healthcare, University of Leeds. The study explored women's attitudes towards their experience of urinary incontinence and use of absorbent products. The study utilised a Patient and Public Involvement (PPI) strategy from the beginning, by involving women who experienced urinary incontinence in the development of the study. The study was informed by women who had not sought professional help for symptoms. In the first of two empirical studies, a qualitative study was undertaken which identified pertinent themes relating to the experience of urinary incontinence and absorbent product use. A second empirical study using Q Methodology then highlighted four discrete attitude types, developing understanding of the previously identified themes.

This introductory chapter begins by describing urinary incontinence and provision of continence care within UK healthcare systems. Then an overview of self-care for urinary incontinence is given, considering societal influences which may affect women. Further detail about absorbent products, and their importance as a method of self-care will be given. Finally, an overview of the rest of the thesis will be provided.

### 1.1 Urinary incontinence

Urinary incontinence is defined by the International Continence Society (ICS) as '*the complaint of any involuntary leakage*'. It defines the symptom as a subjective self-report given by individuals, rather than being indicative of a particular condition (Abrams et al., 2002). When referring to urinary incontinence or leakage in this thesis, reference is being made to the symptom as reported by women, rather than a sign or diagnosis of a condition or disease, unless otherwise specified.

Challenges relating to the collection of accurate prevalence data have meant that researchers do not currently have a robust understanding of prevalence

of urinary incontinence (Fultz and Herzog, 2000; Milsom et al., 2013). However, large epidemiological studies have in the past suggested that prevalence could be between 14.9 – 69.0% for women in the United Kingdom (Hunskar et al., 2004; Irwin et al., 2006; Coyne et al., 2012). The known prevalence of urinary incontinence is increasing globally, with expectation that numbers will continue to rise in the future as populations age (Irwin et al., 2011). Whilst the risk for urinary incontinence increases with age (Seshan et al., 2016), it is not a symptom limited to older women (Akil et al., 2014; van Breda et al., 2015). Despite this, there are risk factors for urinary incontinence which are more likely to occur with age. Some of these will be explored in the following section.

### **1.1.1 Risk factors of urinary incontinence**

There are numerous risk factors for urinary incontinence in women, only some of which are related to the ageing processes. The most clearly defined risk factor for women developing urinary incontinence is obesity (Hunskar, 2008; Subak et al., 2009). Other lifestyle risk factors include diet; smoking and lack of moderate physical activity (Hannestad et al., 2003; Kikuchi et al., 2007; Townsend et al., 2007; Jura et al., 2011). These risk factors are modifiable and are also significant risk factors for other health conditions, making them important to wider Public Health policy (Department of Health, 2013).

Female-specific risk factors may also increase risk of urinary incontinence. Pregnancy can be the time when urinary incontinence is first experienced (Brown et al., 2010). It may also be an indicator of whether leakage will be experienced in middle-age, irrespective of whether continence is regained immediately after birth (Wesnes and Lose, 2013). The number of pregnancies and method of delivery are also independent risk factors (Rortveit et al., 2001; Boyles et al., 2009). Women who have had vaginal births have been shown to be more likely to experience urinary incontinence than those who have a caesarean section (Thom and Rortveit, 2010; Tähtinen et al., 2016). However, the evidence for assisted vaginal delivery (e.g. forceps; ventouse) as a risk factor for urinary incontinence is not clear

(Glazener et al., 2006; Gartland et al., 2012; Johanson et al., 2014). Other female-specific risk factors include hormone replacement therapies; oral oestrogen therapy is thought to increase risk (Grady et al., 2001; Cody et al., 2012), though some evidence supports prescription of topical oestrogen as a treatment for urinary incontinence at menopause (Weber et al., 2015). In addition, undergoing hysterectomy (removal of the uterus) may increase the likelihood of urinary incontinence (Kudish et al., 2014; Bohlin et al., 2017).

Co-morbidities such as diabetes, cognitive impairment and urinary tract infections are also thought to be associated with risk of urinary incontinence (Thom et al., 1997; Moore et al., 2008; Hunskaar, 2008; Byles et al., 2009; Subak et al., 2009). As the numbers of people with diabetes or cognitive impairment have increased significantly (Prince et al., 2013; Guariguata et al., 2013), it is possible that incidence will also increase as prevalence of these conditions increase.

In addition to health-related risk factors there is a growing evidence base which suggests race may influence which women experience urinary incontinence (Fultz et al., 1999; Duong and Korn, 2001; Komesu et al., 2016). The most compelling evidence for racial difference suggests that black women are at greater risk of experiencing urgency incontinence but less likely to experience stress incontinence than white women (Townsend, 2010). In addition to stress urinary incontinence (SUI) being more prevalent in white populations, it may be more likely to affect middle-aged women than urge incontinence (Minassian et al., 2008b). In older age, racial differences may not be as evident but further research is required to substantiate this (Bliss et al., 2015). Types of urinary incontinence will be explained further in section 1.1.2.

Despite the prevalence of urinary incontinence, help-seeking rates are low with a large number of women not seeking professional help to address symptoms (Hannestad et al., 2002; O'Donnell et al., 2005; Koch, 2006). It has been suggested that there are a range of influences affecting help-seeking behaviour (Apostolidis et al., 2012). Reasons for not seeking help include attitudes towards symptoms, for example the normalisation of symptoms and prioritisation of other health concerns (Horrocks et al., 2004;

O'Donnell et al., 2005; Teunissen et al., 2005). Help is more often sought when symptoms increase in severity or when managing symptoms becomes problematic (Schreiber Pedersen et al., 2018). As symptoms begin to affect daily life Quality of Life may be reduced, and this may also be a factor in help-seeking behaviour (Koch, 2006; Howard and Steggall, 2010; Margalith et al., 2004; Gil et al., 2009).

### **1.1.2 Types of urinary incontinence**

Urinary incontinence is one of a number of lower urinary tract symptoms (LUTS), and may be experienced in isolation or alongside other symptoms. Urinary incontinence describes a sign or symptom of underlying cause. There are a number of types of urinary incontinence, the three most common of these are stress urinary incontinence, urge urinary incontinence (UUI) and mixed urinary incontinence (MUI).

The symptoms of stress urinary incontinence are urine leakage occurring when coughing or sneezing, or upon effort or exertion (for example during exercise or when lifting), all of which increase abdominal pressure (Abrams et al., 2002). Reduction in pelvic floor strength is a major contributing factor to stress urinary incontinence as it can lead to hypermobility, creating a lack of support for the bladder neck and urethra. Other causes of stress urinary incontinence can be attributed to intrinsic sphincter deficiency, although diagnostic criteria for this are not yet standardised (Hillary et al., 2015). Originally presented as two dichotomous causes of stress urinary incontinence, contemporary theories suggest that a continuum exists between hypermobility and intrinsic sphincter deficiency in many cases of stress urinary incontinence (Blaivas, 1983; Kayigil et al., 1999; Segal et al., 2006).

Urge urinary incontinence occurs when there is an irrepressible need to urinate which cannot be controlled and which results in loss of urine (Abrams et al., 2002). It is most common in post-menopausal women, although as already noted black women may be more likely to report this type of incontinence (Rohr et al., 2005; Thom et al., 2006). The pathophysiology behind the symptom of urge incontinence is complex. Urge incontinence is related to the condition of overactive bladder syndrome (OAB); however

overactive bladder syndrome does not always result in incontinence. Whilst the aetiology of overactive bladder syndrome is not fully understood, it is likely that a range of neurogenic, myogenic and idiopathic (nerves, muscle, and unknown) factors exert some influence on the condition (Chu and Dmochowski, 2006; Banakhar et al., 2012). The smooth muscle fibres of the detrusor in an overactive bladder may exhibit enhanced spontaneous contractions or respond differently to electrical stimulation, often at low bladder volumes and leading to lowered functional capacity (Ouslander 2004). In addition, denervation of bladder muscle bundles can cause destabilisation of the bladder resulting in urgency. Changes to neuroplasticity may also affect normal voiding, by altering sensation or bladder functioning (Steers, 2002). There is also suggestion that the sensation of urgency is not necessarily one distinct sensation and therefore this may be indicative of more than one cause (Blaivas et al., 2009). Data relating to urge incontinence is often combined with that for overactive bladder syndrome, and according to Milsom et al. (2014) is less well studied than overactive bladder syndrome. Their review of the literature suggested that by 2018 approximately 127 million people would experience either urge or mixed urinary incontinence globally, and that the economic burden of urge incontinence is increasing significantly.

In some cases women experience symptoms of both stress and urge incontinence. This is known as mixed urinary incontinence (Myers, 2014). The prevalence of mixed incontinence is higher than if stress and urge incontinence were independent conditions, yet little is known about the mechanisms behind it (Minassian et al., 2008a). Investigations to determine type of incontinence have shown that mixed incontinence is less reproducible using urodynamic testing, which may have implications for treatment options (Digesu et al., 2008). Mixed urinary incontinence is thought to affect Quality of Life more than stress and urge incontinence separately (Coyne et al., 2008; Minassian et al., 2013). Often one symptom is more dominant than the other and treatment options may focus on the most bothersome symptom first (NICE, 2013), however debate about optimum management continues amongst experts (Brubaker et al., 2009; Khoo et al., 2017).

## 1.2 Treatment of urinary incontinence

In the United Kingdom, management of urinary incontinence by the National Health Service (NHS) is directed by guidelines produced by the National Institute for Health and Care Excellence (NICE). The NICE guidelines are updated as required, based on the best available research evidence. The most recent clinical guideline (CG171) relating to the management of urinary incontinence in women was published in 2013 (NICE, 2013). However there are other NICE guidelines which may influence care for women experiencing urinary incontinence, for example in the case of neurological disease (CG148; NICE, 2012a), or after childbirth (CG37; NICE, 2006). Other professional bodies interested in promoting best practice and who publish guidelines relating to the management and treatment of urinary incontinence include the European Association of Urology and the International Consultation on Incontinence amongst others (Syan and Brucker, 2016). Alongside clinical guidelines which are used by health professionals, those commissioning continence services within the NHS are led by policy documents and reports which outline the necessity for appropriate and specialist continence services (Harari et al., 2013; NHS England, 2018).

As is standard in the NHS, women can access continence care which is free at the point of delivery. In addition to the services offered by the NHS, there are other forms of provision for women experiencing symptoms of incontinence. Some women may prefer to access the services of registered private healthcare providers, either through large companies offering a range of services (for example Nuffield Health or BUPA), or via individual private practitioners such as physiotherapists. There may also be women who prefer to use complimentary or alternative therapies to treat symptoms prior to, or as an adjunct to conventional healthcare, however, this may be an under-reported practice (Slavin et al., 2010).

Current NICE guidelines state that there are a number of treatment options available to women who experience urinary incontinence. Conservative measures are advised in the first instance. Lifestyle interventions include weight loss for those with a BMI over 30; a reduction in caffeine, and modification of fluid intake for women who have high or low intake. A course

of pelvic floor training may also be prescribed for women with stress or mixed incontinence (Bø, 2012). For those women who are unable to contract their pelvic floor sufficiently to perform pelvic floor exercises adequately, biofeedback or electrical stimulation may be offered to aid motivation and adherence with therapy. Bladder training is a behavioural therapy which assists women with urgency or mixed incontinence. It facilitates change to bladder habits by providing a routine of toileting aiming to reduce frequency of urination (Newman and Burgio, 2016). There are also a number of pharmacological interventions for over-active bladder and for stress urinary incontinence which may be considered after or alongside other conservative measures.

If conservative interventions are unsuccessful invasive procedures may be considered appropriate. For over active bladder this includes use of Botulinum toxin A (Botox) (Schulte-Baukloh et al., 2005). However use of Botox as a bulking agent is only suitable for women able to perform clean intermittent catheterisation (NICE, 2013). Percutaneous sacral nerve stimulation may be tried if Botox is unsuccessful. If all other treatment options fail, surgery may be offered to those women who are suitable (NICE, 2013). NICE recommends a number of surgical procedures, dependant on diagnosis. These procedures are outside the scope of this thesis.

### **1.2.1 Help-seeking for urinary incontinence**

However, whilst guidelines exist to support professionals, they may only benefit a minority of women as help-seeking behaviours are low in this population (Hägglund and Wadensten, 2007; Apostolidis et al., 2012). Despite accessing primary health services for other health concerns women may not seek help for urinary incontinence (Shaw et al., 2006). Some people may never seek help for their symptoms (Hägglund et al., 2003; Norton and Brubaker, 2006). Barriers to seeking care are complex but include assumption that symptoms are normal; that other health conditions take priority; and fear of not being taken seriously by health practitioners (Hägglund et al., 2003; Sengezer et al., 2010). Embarrassment may also prevent women from being able to disclose (Hägglund and Wadensten, 2007). Moreover, there may be cultural differences which influence help-seeking behaviours (O'Donnell et al., 2005; Sande et al., 2009). Help-

seeking has been shown to be associated with symptom severity, how bothersome symptoms are and reduced quality of life (Apostolidis et al., 2012; Rozensky et al., 2013; Xu et al., 2015). As associated costs for treatment are known to increase with severity of urinary incontinence (Moore et al., 2013) there may be short and long-term benefits for both healthcare providers and patients by identifying and treating women experiencing urinary incontinence in a timely manner.

### **1.2.2 Nursing care**

Nurses in all settings have a responsibility to care for patients' continence needs, with referral to specialist services where appropriate (Royal College of Nursing, 2006). Nurses are often involved in personal care for patients, and so it is important that the culturally sensitive nature of tasks relating to continence care should be considered alongside the practical aspects (Health, 2009). The influence of culture on women experiencing urinary incontinence will be explored further in section 1.4.

Many NHS Trusts have specialist continence teams that advise and care for people who have been referred to the service. Continence teams may be nurse-led, and are often multidisciplinary, however there is no standard model of care in the UK. A number of studies have shown that nurse-led specialist care is effective and some have suggested this model may be cost effective in comparison to other models of care (Williams et al., 2005; Du Moulin et al., 2007; Wagg et al., 2014; Choi et al., 2015). Referral to specialist continence services is often through general practitioners (GPs), or other healthcare professionals. Based on NHS England (2015) recommendations, it is possible that a self-referral model based in the community will replace other operating models in the future. As many nurses work in roles which provide opportunity to enquire about health status they are often well placed to help women experiencing urinary incontinence, however they may require further education to ensure that care is timely and appropriate (Wagg et al., 2014).



### **1.3 Self-care for urinary incontinence**

Irrespective of whether women seek treatment or not, many individuals will also self-care, dealing with symptoms themselves using a range of techniques. Self-care is distinct from self-management, which involves varying levels of professional support to enable people to manage their condition (Corben and Rosen, 2005). Not all women may recognise the strategies they use to cope with symptoms as self-care, and they may normalise behaviours associated with self-care practices (Klemm and Creason, 1991). This makes researching self-care particularly challenging as in addition to non-recognition some strategies may mask symptoms, for example reducing fluid intake may reduce urine output.

Coping strategies for urinary incontinence have previously been defined as confrontational, avoidant, or accepting/resigning (Xu et al., 2016). This stratification suggests that whilst women may have similar concerns regarding symptoms their methods of dealing with them may be very different. There are a range of coping strategies used by women that are well documented in the literature and are similarly reported across many cultures. These include use of absorbent products (which will be discussed further in section 1.5.1); regulation of attitudes and behaviours; frequent voiding; and fluid restriction (Anders, 2000; Li et al., 2007; Blasco et al., 2017).

The importance of toilet accessibility is noted by a number of studies (Hermansen et al., 2010; Wang et al., 2011; Takahashi et al., 2016). In addition to a requirement of availability of toilets, toileting practices more generally have been shown to differ between women experiencing urinary incontinence and those that do not (Willis-Gray et al., 2016). Those who experience incontinence may be more likely to urinate without urge; or strain during urination (Willis-Gray et al., 2016). Moreover, frequency of urination may be overestimated by self-reports particularly by women who report voiding more than ten times a day (Stav et al., 2009). Despite possible misjudgement of frequency, the importance of toilet access as a coping strategy remains significant (Pakgothar et al., 2015a).

Women are also very aware of odour caused by leaked urine, which can be a particularly distressing aspect of incontinence due to its stigmatising nature and perceived social threat (Getliffe et al., 2007; St John et al., 2013). Self-care practices often include strategies which will eliminate or minimise odour, in addition to self-care of physical symptoms (St John et al., 2013). Fear may drive some coping strategies, which could account for the hypervigilance exhibited in some circumstances (Mota et al., 2017; Molinuevo and Batista-Miranda, 2012). There is suggestion that carers of people experiencing incontinence also have similar concerns, resulting in them also becoming hypervigilant (Tseng et al., 2015) Some self-care practices may be culturally dependant (Higa et al., 2008; Gjerde et al., 2013). Culture and societies affect how individuals deal with health needs, this will be discussed in the following section.

#### **1.4 Social influences on urination and incontinence**

The social and cultural influences on women experiencing urinary incontinence have been noted by many authors (Wilson, 2004; Higa et al., 2008; Bradway et al., 2010; Porrett, 2010). Generally, incontinence is perceived as a stigmatising condition resulting in shame and embarrassment (Lowder et al., 2012; Southall et al., 2015; Vethanayagam et al., 2016). There has been call to reduce the stigma relating to incontinence in healthcare (Wan et al., 2014) however there seems to be a paucity of practical suggestions of how this might be effectively carried out (Garcia et al., 2005; Larouche et al., 2016), despite a recognition that stigma creates health inequality (Hatzenbuehler et al., 2013).

The reasons for stigmatisation may be due to the perceived threat that incontinence may bring to individuals and others within society. Moral codes define rules to which members of societies are expected to adhere, but women experiencing incontinence are sometimes unable to meet those societal expectations, leading to stigmatisation. For stigmatisation to occur there has to be a shared understanding of the circumstances (Kurzban and Leary, 2001). The stigmatised individual and the stigmatiser take on the

roles which cultural rules suggest are appropriate (Kurzban and Leary, 2001). Leaked urine is morally challenging for individuals who experience incontinence but also for those who are aware of it (Garcia et al., 2005; Tseng et al., 2015). It is often perceived as dirty and as a result socially problematic (Brittain and Shaw, 2007; Ostaszkiwicz et al., 2016). In addition to urine being understood as dirty, those who are unable to conform to culturally acceptable practices are judged and may be subject to ostracism by others (Li et al., 2007; Gjerde et al., 2013). This process is something often engrained within cultures and is potentially reinforced by malodour from stale urine as it raises the threat of identification (Andersson et al., 2008; Radziszewski et al., 2011).

Historically, urination practices were not as they are in contemporary society. Social rules were often defined by social class (Gillingham, 2002). With increased social mobility there was a desire to adhere to the rules governing toilet practices of the upper classes (Elias, 1978). Socially accepted rules relating to urination changed over time. The moral codes of urination have been passed from generation to generation, adapted as other aspects of culture shift. It could be argued that there is now a dominant culture in contemporary society which prioritises Western cultures' toileting practices. These practices may be particularly pertinent to women. With the advent of the flushable toilet and public restrooms women in particular were held account for upholding respectability (Todd, 2012). Public toilets were seen as a method of safeguarding (primarily middle class) women's propriety by protecting them from dirt and from those with whom society suggested they may not wish to come into contact (Kira, 1976). Using the toilet became perceived as a private event. Doors on toilets became lockable as a result of the societal norms which sought to protect women from perceived danger. The belief that women should urinate privately continues to this day. In contemporary society when using a toilet cannot occur in private, for example in hospital, it is often associated with a lack of dignity (Logan, 2012). Dignity is concerned with status, value and behaviours indicative of character (Rosen, 2012). All three aspects of dignity may be called into question when urination does not follow the culturally accepted form, not

because of the physical act of urination but because of its meaning within cultures.

The rules of urination are learned from an early age, children are taught the rules of culturally acceptable toilet routines as toddlers. Their adherence to these rules may be used as a marker of 'good' parenting; positive and negative reinforcement techniques are used in Western society to promote acceptable toilet behaviour (Kiddoo, 2012). Toileting rules are further enforced throughout the life course, including through the media, which vilifies anyone not following morally acceptable, or legal, toileting practices (Wainwright, 2009; Kelly, 2012; Evans, 2014; Wilkinson, 2014). In the UK, public urination is governed by local by-law but offenders may also be charged using Section 5 of the Public Order Act 1986. When reporting such crimes journalists often focus on the impact that public urination has upon the community, or on the character of the perpetrator, highlighting the deviance of the individual, and conforming to the role of stigmatiser. Public perception is skewed towards moral outrage through use of terms such as '*anti-social*', '*revulsion*' and '*shocking*' used to describe situations. With such derision evident towards public urination, it is unsurprising that women ordinarily choose to avoid occasions where urination outside of the normal context might be witnessed. By containing the problem, self-esteem may be preserved (Crocker and Major, 1989). Whilst publicly women may seek to conform to social rules, privately moral disengagement may occur by minimising the risk, removing responsibility of personal agency and by use of language which desensitises the situation (Bandura, 2002).

Language used to discuss urination, and to describe other situations using idioms for urination, have historical foundations (Ayto, 2000; Jolly, 2000). Even within contemporary society there are phrases which pertain to the historical, but which may continue to subtly influence the views of those who are familiar with them. The word 'piss'; a colloquial term for urine was widely used as a prefix to other words in the early half of the 20<sup>th</sup> century to emphasise meaning. The practice of using 'piss' as an intensifier continues in many societies today and its negative and morally challenging connotations remain. Discussing urination is considered impolite, which may

not be due to the health or hygiene issues associated with it, but due to moral codes which have continued through generations (Pinell, 1996). It has been suggested that when the media removes language normally associated with urination to advertise incontinence products, help-seeking using similar language increases (Garcia et al., 2005). Women who publicly discuss symptoms of incontinence on the internet tend to frame themselves positively and avoid language which may stigmatise them (Saiki and Cloyes, 2014). Despite this slight shift in attitudes some groups of women continue to be marginalised, particularly older women, as incontinence in old age may be considered as ineffectiveness (Mittiness and Barker, 1995).

Conversely, there are instances where urine and urination are viewed positively. Urine samples used within healthcare are covered by the Human Tissue Act 2004. By regulating the use of urine through law, its value in certain circumstances is maintained. It is considered to be the property of the individual providing the sample, and cannot be used for any purpose without consent. Urine, in this context, has a value which must be protected from misuse. Urine is used as a diagnostic tool, providing data from which clinical decisions are based. Giving a urine sample for assessment is a gateway act, options available to healthcare professionals for diagnosis and treatment may be increased. Infection prevention and control measures are taken to reduce risk (Dougherty and Lister, 2015); and the process is viewed as an acceptable use of urine in Western culture. Whilst the urine is contained in a sterile sample bottle, it has value to both healthcare practitioners and to the individual.

Within healthcare settings challenges to moral norms relating to urination may occur. In addition to environmental challenges due to the toileting facilities available in some settings, individuals may experience reduced functional ability, requiring assistance to use the toilet. Toileting privacy is a cultural norm and therefore experiencing anything other can cause embarrassment for those subjected to it (Woogara, 2001). Healthcare culture may supersede societal culture in this context. Those working in healthcare environments may not fully appreciate the moral complexity of using the toilet in such circumstances. There may be some over-reliance on

products for continence care including absorbent products, rather than seeking to understand the factors affecting continence status (Zisberg, 2011; Bitencourt et al., 2018). This over-reliance on absorbent products could be partly influenced by cultural factors which promote private urination.

## **1.5 Absorbent products for urinary incontinence**

Absorbent textile products are used within healthcare settings but they are also a culturally accepted way of containing leaked urine within society. They are available to individuals to buy from a number of outlets, including online, from pharmacies and in supermarkets. Throughout the rest of this thesis they will be known as absorbent products. Absorbent products for urinary incontinence are used by women to absorb leaked urine discreetly. There are a number of key designs which are available in the UK, the most commonly used of these are disposable inserts (Fader et al., 2014). Often described as pads or body-worn products, they are designed to fit within underwear to absorb leaked urine and are disposed of after use. In addition to absorbent products which insert into regular underwear, other body-worn items exist for the containment of leaked urine including adult diapers and reusable pants (Clarke-O'Neill et al., 2002; Fader et al., 2008a). Table 1 gives an overview of body-worn product designs for women.

Secondary absorbent products, such as non-woven absorbent bed sheets can also be purchased, however for the purposes of this thesis these will not be considered. In the UK, the NHS spends approximately £80million a year on absorbent products (NHS England, 2018). Globally the incontinence product market was worth approximately US\$8 billion dollars in 2015, with an expected rise of 5% to 2021, with much of the spend by individuals rather than by healthcare providers (Forma-care, 2016; PR Newswire, 2017). Approximately 830,000 people in the UK were using disposable incontinence products in 2017, with over 12 million people using other types of body-worn absorbent products (PR Newswire, 2017), some of whom may have been dealing with incontinence (Mintel, 2012).

**Table 1 Types of body-worn products for women**

<b>Product Type</b>	<b>Description</b>
<b>Inserts (e.g. pads, liners)</b>	These products are held close to the body by underwear. There are a number of shapes of inserts but commonly inserts are longer than they are wide to fit anatomically between the legs. Disposable inserts often have an adhesive strip on the back which fixes the insert to underwear. Inserts are available in a number of different sizes and can be suitable for different severities of symptom.
<b>Diapers</b>	These include adult-sized varieties of baby nappies. Diapers have elastication around the waist and legs and resealable fasteners. Often disposable versions of these products have a wetness indicator. In addition to the traditional nappy design, there are also T-shaped designs which have a waist belt which is fastened before the absorbent crotch is passed from back to front and secured to the belt. This design enables the diaper to be applied while standing. Diapers are suitable for moderate to heavy symptoms.
<b>Pull ups</b>	Disposable pull ups are similar to toddler training pants and have an absorbent core built into them. They are in the form of non-woven underwear. They can be used for a range of symptom severities.
<b>Washable pants</b>	Washable pants contain an absorbent layer hidden within the product; they have the appearance of regular (if slightly bulky) underwear and can be used for light to heavy symptoms.
<b>Homemade products</b>	Women may choose to make their own products, for example from towelling fabric or from tissue. Often these are placed in underwear and used similarly to inserts.

Adapted from Cottenden et al. (2013)

Using similar technology to sanitary towels, absorbent products for urine leakage look comparable to products for menstruation. Absorbent products for both urine and menstruation are primarily non-woven, manufactured

using fluff pulp with a super-absorbent polymer core and a waterproof backing. Both types of product are similarly merchandised by retailers in the UK, often occupying shelf space in the 'feminine hygiene' aisle, rather than with health-related products. Unlike symptoms of many other health conditions, self-care is actively promoted by commercial companies of absorbent products (Newman, 2012).

Close associations between development (and marketing) of incontinence products and menstrual products may further the belief by some women of normalising urinary incontinence, as a life process to be negotiated. Like menstruation urinary incontinence is stigmatised within many societies (Johnston-Robledo and Chrisler, 2013; Southall et al., 2015). These cultural attitudes may compound the idea that self-care particularly by use of absorbent products is essential to maintaining a socially-acceptable self. Although widely used absorbent products are thought to affect users' Quality of Life (Fader et al., 2008a). A recently published Quality of Life tool may improve the measurement of the impact of absorbent product use (Yearwood Martin et al., 2018).

Within this thesis, there will be a focus on body-worn products, which are among the most common absorbent products used by women coping with urinary incontinence. They are easily commercially available and are a known management strategy for women who have and who have not sought help.

### **1.5.1 Absorbent products for self-management**

NICE guidelines (2013) do not recommend the use of absorbent products as a management strategy except in circumstances when an individual is waiting for treatment; when treatment has been unsuccessful or as an adjunct to treatment. However this guidance only relates to women receiving NHS care, which as previously noted, is unlikely to be representative of all women experiencing urinary incontinence due to a lack of help-seeking.

The broad approach taken to absorbent product use within CG171 does not take into account the variances between symptoms, nor psychosocial factors. Recognition of the many factors which can affect absorbent product



use is something which Getliffe et al. (2007) and Fader et al. (2008a) have sought to establish. The use of absorbent products is sometimes necessary for peace of mind, even for those women who do not meet the criteria listed in the NICE guideline.

Despite the limitation of recommended use by NICE, large numbers of women do use absorbent products (PR Newswire, 2017). In addition to appropriate usage suggested in the NICE guidelines, there is evidence that absorbent products are used as an alternative to treatment (Andersson et al., 2008). Some women choose to buy absorbent products, rather than access healthcare (where in some instance products can be provided free of charge). There is limited market evidence to show that some women with mild UI prefer smaller, thinner pads designed for menstruation, rather than products designed for urine (CompaniesandMarkets.com, 2015). The reasons for this are largely unknown, however some business commentators point towards social factors (CompaniesandMarkets.com, 2015). Incontinence products are generally more expensive than menstrual products. It may be that they are also less socially problematic to buy for some women (Mintel, 2012).

## **1.6 Focus of investigation**

The focus of this investigation was to explore the attitudes of women living in the community towards their experience of urine leakage and use of absorbent products. These topics were integrated within the study as it was perceived that cultural norms relating to urination may affect both. Combining both aspects could lead to important new insight on the topic.

This research was based on the premise that improvements could be made to products and services for women with urinary incontinence, by first understanding women's experience of urine leakage and the use of absorbent products during their daily lives.

### 1.6.1 Rationale

Despite there being evidence suggesting that the social consequences of urinary incontinence are of great concern to those who experience it (Berglund et al., 1996; Garcia et al., 2005; Esparza et al., 2018), symptom and healthcare-focussed literature still dominate the evidence base. This might be considered problematic when large numbers of women are self-caring for symptoms assumed to be normal (Peake et al., 1999; Róin and Nord, 2015). As the global market for absorbent products is continuing to increase, there is more necessity than ever to identify and, where appropriate, assist women who self-care without intervention to prevent delayed help-seeking and increased severity of symptoms (Koch, 2006; Vethanayagam et al., 2016; Mallett et al., 2018). Improvement of the evidence base for women who are not engaging with healthcare professionals regarding their symptoms increases opportunities to understand their needs. By recognising social influences and understanding that coping styles may be different between women provides a prime opportunity for furthering knowledge (Hayder and Schnepp, 2010; Yu et al., 2016).

Furthermore, there are opportunities to improve products for women who self-care. Fader et al. (2010) suggested that qualitative studies were needed to understand absorbent product use to identify user priorities and in turn support product development. By focussing on women's lived-experience, and by incorporating the use of absorbent products into the understanding of lived-experience, more can be learned about daily living with urinary incontinence, expanding similar research (Getliffe et al., 2007; St John et al., 2013; Southall et al., 2015). Due to the complexity of the phenomena, the research question requires a mix of technological, biomedical and social understanding to fully explore the subject.

## 1.7 Overview of the thesis

The thesis is sectioned into six chapters, which present different aspects of the research (Figure 1).

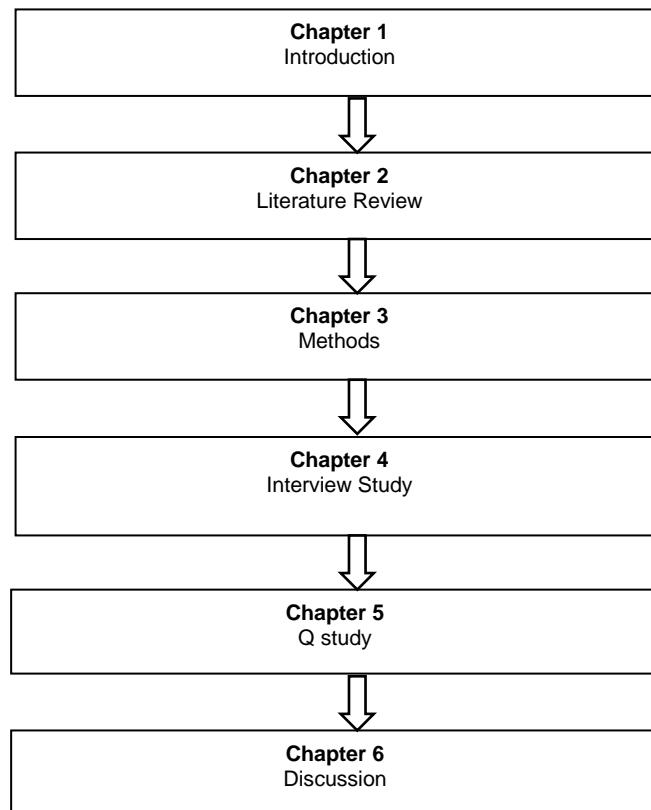
**Chapter 2** describes the scoping literature review which critically considers evidence relating to women's experience of using absorbent products.

**Chapter 3** describes the methods used for the empirical studies undertaken. It explains the use of methods and the socio-technical design framework.

**Chapter 4** presents the findings of the in-depth qualitative study which explored women's experiences of urine leakage and their use of absorbent products.

**Chapter 5** presents the findings of the Q study, which culminated in four attitude types, based on the findings of Q-sorting.

**Chapter 6** provides an evaluation of both empirical studies, comparing and contrasting some of the most pertinent findings. Relevance to future policy, practice and product development are considered.



**Figure 1 Overview of thesis chapters**

## **1.8 Summary**

This chapter introduced the subject under investigation from a physical and societal perspective. An overview of the symptom of urinary incontinence was given, alongside the guidelines which currently direct clinical practice and treatment. This was followed by a brief description of absorbent products used to contain leakage urine.

The chapter ended with a discussion of the societal understanding of urination and women's experience, ending with the rationale for this thesis

## **Chapter 2 Literature review**

Community-dwelling women's use of absorbent products for urinary incontinence: a scoping review

### **2.1 Background**

The exact number of women experiencing urinary incontinence is unknown, with contrasting prevalence rates likely due to differences in data collection methods and symptom-reporting rates (Milsom et al., 2013). Prevalence of all types of urinary incontinence in the UK has been measured between 14.9% - 69% (Hunskar et al., 2004; Irwin et al., 2006; Coyne et al., 2012). It is believed that the true number of people experiencing continence issues could be much higher than those that seek help (Apostolidis et al., 2012). As incidence increases with age, the number of women experiencing urinary incontinence is likely to increase with an ageing population (Irwin et al., 2011). As previously noted in section 1.5 market data provides evidence that feminine hygiene product sales are increasing globally and that women are purchasing continence products and sanitary wear to manage urine leakage (Mintel, 2012). This may suggest that absorbent products are a key coping strategy for many women. Due to the cultural understanding of incontinence, there are women who may be affected psychologically and socially by their experience, in addition to the physical effects of urinary incontinence (Wilson, 2016).

The aim of this chapter within the research plan overall was to systematically review the existing literature to determine the size and nature of current evidence for women's use of absorbent products, identify gaps in the literature and inform the research plan.

### **2.2 Rationale for the review**

A comprehensive review was undertaken in September and October 2017, as a refinement of two smaller reviews which were conducted in 2014 and 2016. Having established that there were psychosocial dimensions to women's

understanding of symptoms and absorbent product use (Sections 1.4 and 1.5), it was important to gain a broader understanding of the use of products as a strategy for containing leaked urine.

The review required the inclusion of a range of literature to gain a broad understanding of the evidence base informing absorbent product use. There were a number of review methodologies which were appropriate to the review to be undertaken. The most appropriate type of review is dependent on the review question. It has been suggested there are fourteen types of literature review (Grant and Booth, 2009). Some of the more common of these include critical reviews, scoping reviews, narrative reviews, meta-analyses and systematic reviews (Grant and Booth, 2009). Systematic reviews aim to systematically search, appraise and synthesise data collected from comparable empirical studies (Grant and Booth, 2009; Clarke, 2011). Systematic reviews require a focussed review question and a systematic and comprehensive search strategy, which have clearly defined inclusion and exclusion criteria (CRD, 2009). Inclusion of appropriate literature is assessed as part of the review, which considers the quality of literature to minimise bias (CRD, 2009). Synthesis and reporting should also follow a systematic structure (Liberati et al., 2009; Committee on Standards for Systematic Reviews of Comparative Effectiveness et al., 2011). Regardless of the review type, working systematically increases the quality of the review.

## **2.3 Methodology**

A scoping review was selected as the most suitable type of review for this study, as the purpose of a scoping review is to identify gaps in the existing evidence-base (Tricco et al., 2016). Scoping reviews are conducted when sources are “*disparate or heterogeneous*” and consider evidence regardless of quality (The Joanna Briggs Institute, 2015, pp.8). A strength of the scoping review approach is the systematic mapping of evidence on a given subject (Arksey and O'Malley, 2005). The publication of scoping reviews has increased significantly since 2012, however methodological inconsistency between disciplines occurred in the past (O'Brien et al., 2016; Tricco et al., 2016). To overcome this inconsistency, The Joanna Briggs Institute (2015) introduced

reviewer guidelines for researchers conducting scoping reviews to increase rigor of scoping reviews.

The inclusion of peer-reviewed literature and grey literature is deemed appropriate within a scoping review due to the exploratory nature of the review (Khalil et al., 2016). Ordinarily quality of evidence is not appraised as part of a scoping review, however Daudt et al. (2013) suggest that it may be beneficial for quality to be considered in some instances. Levac et al. (2010) noted that for quality to be assessed scope may be reduced, leading to bias due to removal of grey literature and over reliance on peer-reviewed empirical studies. Therefore decisions have to be made about the purpose and necessity of quality appraisal on a study-by-study basis. In this instance, full reports of empirical research documented in peer-reviewed journals were assessed for quality to ensure the outcomes of the PhD could be met (see also 2.5).

The objective of this scoping review was to examine and map the range of literature relating to women's use of absorbent products to deal with symptoms of urinary incontinence. The objective was broad enough to guide the study and underpin the review question (The Joanna Briggs Institute, 2015). A single objective is deemed appropriate for scoping reviews. To facilitate systematic working (following a pre-defined method) and clarity, a question was formulated and protocol developed to guide the review.

### **2.3.1 Review question and objectives**

It is the review question which will ultimately guide protocol development and so it must be clear and answerable. Search tools can help format the review question and ensure appropriate levels of sensitivity and specificity of searching for the chosen review type (Methley et al., 2014). Unlike systematic reviews which may use the Population, Intervention, Comparator and Outcome (PICO) search tools or similar to structure the review question, scoping reviewers use Population, Concept and Context (PCC) to outline the review topic (The Joanna Briggs Institute, 2015; Butler et al., 2016). Sub questions can support development of the reporting structure by highlighting areas of particular relevance (Squires et al., 2013; The Joanna Briggs Institute, 2015).

The population under investigation in this study was community-dwelling women. The concept under investigation was absorbent product use. The context was management of urinary incontinence, leading to the title of 'Community-dwelling women's use of absorbent products for urinary incontinence: a scoping review'.

The question leading this review was -

- What are community-dwelling women's experiences of using absorbent products for urinary incontinence?

This review required a research question which was then further divided into sub-questions

- Do women use absorbent products for urinary incontinence?
- How are absorbent products used for urinary incontinence?
- What are women's thoughts about using absorbent products?

### **2.3.2 Development of a protocol**

A clear protocol was necessary to ensure transparency of the review method and limit researcher bias throughout the process of review (CRD, 2009; Moher et al., 2015). A protocol enables replication of the review, increasing the validity of the review process. It facilitates those reading the review to develop an understanding of how review findings were obtained. Protocols are commonly developed for other types of review, including systematic reviews focusing on healthcare interventions (National Institute for Health Research, 2017). However, the benefits of developing a review protocol are not limited to systematic reviews and meta-analyses of interventions. By explicitly stating intentions prior to conducting the search and then adhering to the protocol, additional reliability is provided (Butler et al., 2016). Scoping review protocols conducted by The Joanna Briggs Institute and their partner review organisations are published prior to reviews being conducted as a means of providing transparency and to avoid replication (Peters et al., 2017).

A number of frameworks have been offered to aid researchers in developing scoping reviews (Arksey and O'Malley, 2005; Levac et al., 2010; Peters et al.,



2017). There have been recent efforts to improve the quality of scoping reviews (The Joanna Briggs Institute, 2015). For this literature review a review protocol was developed using the The Joanna Briggs Institute (2015) scoping review methodology. It is congruent with the recently published PRISMA-ScR guidance (Tricco et al., 2018), a checklist specifically for scoping reviews which is consistent with the Joanna Briggs methodology (Peters et al., 2017). The Joanna Briggs methodology draws on the knowledge of experienced methodologists and previous literature to outline current best practice.

## **2.4 Inclusion criteria**

Clear inclusion criteria should be stipulated prior to undertaking a literature review to ensure that only studies which meet the review objectives are included for analysis. They may also reduce outcome reporting bias which could skew the findings of the review by reporting literature based on the “*nature and direction*” of results (Sterne et al., 2008, pp.298; Verbeek et al., 2017). The inclusion criteria should allow the literature search to be undertaken again in future by providing clarity about permissible content for inclusion. The inclusion criteria of a scoping review need to consider the population, concepts and context of the review question (The Joanna Briggs Institute, 2015).

### **2.4.1 Population**

The review focused specifically on the use of products by women. The only age limit applied was that study participants should be aged eighteen (18) years or above. Broad age criteria ensured that a range of evidence about women’s absorbent product use was captured. Study participants were community-dwelling and not institutionalised which excluded hospitalised women and those living in long-term care facilities. Studies conducted in any country were included. It was recognised that research had previously been undertaken which included both male and female participants. Therefore, studies which included both male and female participants, but where data had been analysed by gender and could be extracted, were included in the review.

### 2.4.2 Definition of concepts

Urinary incontinence was defined using the International Continence Society standardised terminology outlined by Abrams et al. (2002), which states urinary incontinence as '*the complaint of any involuntary leakage*'. Literature which relied on self-report of symptoms by participants, in addition to literature which considered diagnoses was deemed suitable for inclusion to the review. The inclusion criteria did not make distinction between types of urinary incontinence (as described in section 1.1.2). All types of urinary incontinence were considered eligible for review.

Current government and NHS policy focusses upon individuals' responsibility for self-management (Department of Health and Social Care, 2015; NHS England, 2017). Therefore, it was important that the review considered women who experienced urinary incontinence and were likely to self-care, either alone, or alongside input from health care professionals. Self-care refers to strategies employed by an individual without help from professionals. Self-management refers to strategies employed by an individual with professional help. However, as noted by Richard and Shea (2011), not all authors make this conceptual distinction and caution is therefore needed when reviewing literature. This review sought to consider self-care, not self-management.

Community-dwelling women refers to those women who live in their respective communities, within a home environment. Authors of similar work on this topic have described this concept as "resident in the community" (Fader et al., 2014). Level of in/dependence was not focused upon within the review, and therefore data relating to a broad range of women could be included. Literature relating to women who were institutionalised in any way was not included in the review, which is congruent with other community-dwelling adults' self-care literature (Lommi et al., 2015).

Absorbent products allow women an element of social freedom (Getliffe et al., 2007) and whilst they are not a treatment for urinary incontinence, they do provide a coping strategy which may be implemented relatively easily, compared to other interventions which may require professional input prior to initiation. In this literature review, absorbent products referred to all products which had absorbent properties and which were used by women to wick away

and contain urine after an episode of urinary incontinence. Further differentiation is made as necessary in the findings. All types of absorbent product used by women for managing urinary incontinence were included in the review. Data relating to products specifically designed for urinary incontinence, products designed for other primary use (e.g. sanitary towels); in addition to home-made products were all considered pertinent. Frequency of absorbent product use (e.g. daily use) was not added to the inclusion criteria to ensure that all appropriate literature was included.

### **2.4.3 Date limit**

Searching for literature within predefined date limits ensures that the literature captured is appropriate and provides additional control of specificity to searching. A date limit of the year 2002 was set for this review. As the way in which products are made and marketed changes over time, data regarding product use prior to 2002 may have referred to obsolete products. Research prior to this date would also have been conducted in a different socio-political and healthcare landscape, which may have diluted the relevance of the information gained. It has been suggested that the economic crisis of 2008 affected generational attitudes more generally (Timonen and Conlon, 2015), as has the increased influence of social media on buying behaviours (Taylor et al., 2011). These considerations provide appropriate justification for a date limit.

### **2.4.4 Context**

To maintain relevance to the review question, only studies which were conducted with participants who were community-dwelling were included. As noted in section 2.4.2 this did not include women who were institutionalised. Studies did not have to be conducted in the United Kingdom, but did have to be reported in English, due to time and financial restrictions.

## **2.5 Sources included**

The sources used for a scoping review can be varied and may include reports of primary studies, other peer-reviewed journal articles, guidelines, websites, personal correspondence, and any other sources of grey literature that the reviewers believe will be pertinent to the review.

In this review peer-reviewed reports of research studies and systematic reviews were included as well as grey literature from sources which were perceived to have information which could directly answer the review question. This was to ensure that the specificity of the search was appropriate to a scoping review, taking into account the search strategy to be employed (see 2.7).

## **2.6 Exclusion criteria**

The exclusion criteria were generated to ensure that only literature which could answer the review question were searched for, by increasing specificity of the searches (Petticrew and Roberts, 2006). Literature relating to men, or research conducted with both male and female participants but where findings could not be separated by gender was excluded. Literature which related to children (under the age of 18) was not included, nor were studies relating to institutionalised women.

Literature relating to products which were used to manage urinary incontinence, but were not absorbent (e.g. urinary catheters) was excluded. Information relating to continence issues other than urinary incontinence was also excluded. Therefore studies which considered both faecal and urinary incontinence were excluded.

## **2.7 Search strategy**

A clear search strategy is required to improve rigor. Having a defined search strategy alongside clear inclusion and exclusion criteria ensures that the search is replicable, and provides evidence of a systematic approach to searching. The search strategy should include detail of search terms and the methods of

combining the terms. In this review search terms were generated from the inclusion criteria and included words which related to the population, concept of interest and context. To improve the efficiency of many electronic databases, common search terms are collected under subject headings. Literature is defined by relevant subject headings which, if applied during the search can increase the sensitivity of searching. Search terms including women; female; urinary incontinence; incontinence pads; absorbent pads; diaper, health behaviour, self-management, self-care, self-efficacy, quality of life, daily activities; and health were inputted into electronic databases. Where possible relevant subject headings were also included in the searches conducted. Search terms were combined with Boolean operators which are a series of functions designed to improve the sensitivity of searches. Common Boolean operators include AND and OR, which allow terms to be found in conjunction, or instead, of one another. Additional operators such as \$ and \* ensure that terms with alternative spellings or endings are also included within search results (Karimi et al., 2010). Previous studies have sought to optimise literature searching for patient values and knowledge research, to overcome the low specificity of search strategies suggested by nationally recognised bodies (Wessels et al., 2016). It is important to reduce bias when conducting a literature review by accessing as much relevant literature as possible, whilst not compromising review quality (Egger et al., 2003).

In this study, the inclusion of PsychINFO electronic database to the search strategy was imperative to diversify the range of scientific literature included (Löhönen et al., 2010), as was the inclusion of appropriate sources of grey literature. Appropriate sources of grey literature were identified and selected based on the likelihood of yielding relevant results.

As is standard for scoping review search strategies, there were three stages to the searching. Initially a search on two electronic databases should be conducted to identify all key words to be used as search terms, this is followed by a comprehensive search of all identified sources using all search terms. Finally hand searching of reference lists should be performed. For this review, firstly an initial search using two electronic databases was undertaken. An analysis of terms used in the titles, abstracts and index terms of the retrieved articles was undertaken. A second search using all identified keywords was

made across all selected databases. Finally a search of reference lists from included articles was made (Peters et al., 2017).

**Table 2 Electronic databases/ sources searched**

<i>Name</i>	<i>Years</i>	<i>Scope</i>
<b>MEDLINE</b> (via Ovid)	2002 – 2017	Provides records of articles from medicine, nursing and dentistry journals, from global sources.
<b>EMBASE</b> (via Ovid)	2002 – 2017	Provides records of articles from biomedicine, psychiatry and pharmacy. Has a European bias.
<b>PsychINFO</b> (via Ovid)	2002 - 2017	Provides records of articles from psychology, behavioural and social sciences.
<b>Scopus</b> (via Elsevier)	2002 – 2017	Provides records from a range of scientific journals including medicine and the social sciences; however not all articles cited are peer-reviewed.
<b>CINAHL</b> (via EBSCO)	2002 – 2017	Provides records of articles from nursing and allied health journals.
<b>All EMB reviews</b> (via Ovid)	2002 - 2017	Provides records from Cochrane, NTA, DARE, NHSEED and ACP review databases
<b>Continenceproduct advisor.org</b>	2012-2017	Provides evidence based information, and user perspectives about a continence products
<b>Opengrey.org</b>	2002-2017	Provides a simple search engine for grey literature on a range of topics including medicine and health.

The first search was undertaken using MEDLINE and PsychINFO electronic databases to retrieve articles which were used to generate keywords. The second search included searching all the selected sources with all the appropriate search terms. A full list of search terms can be found in Appendix A. Searching of reference lists was performed on the articles which met the review inclusion criteria.

## **2.8 Extraction of the results**

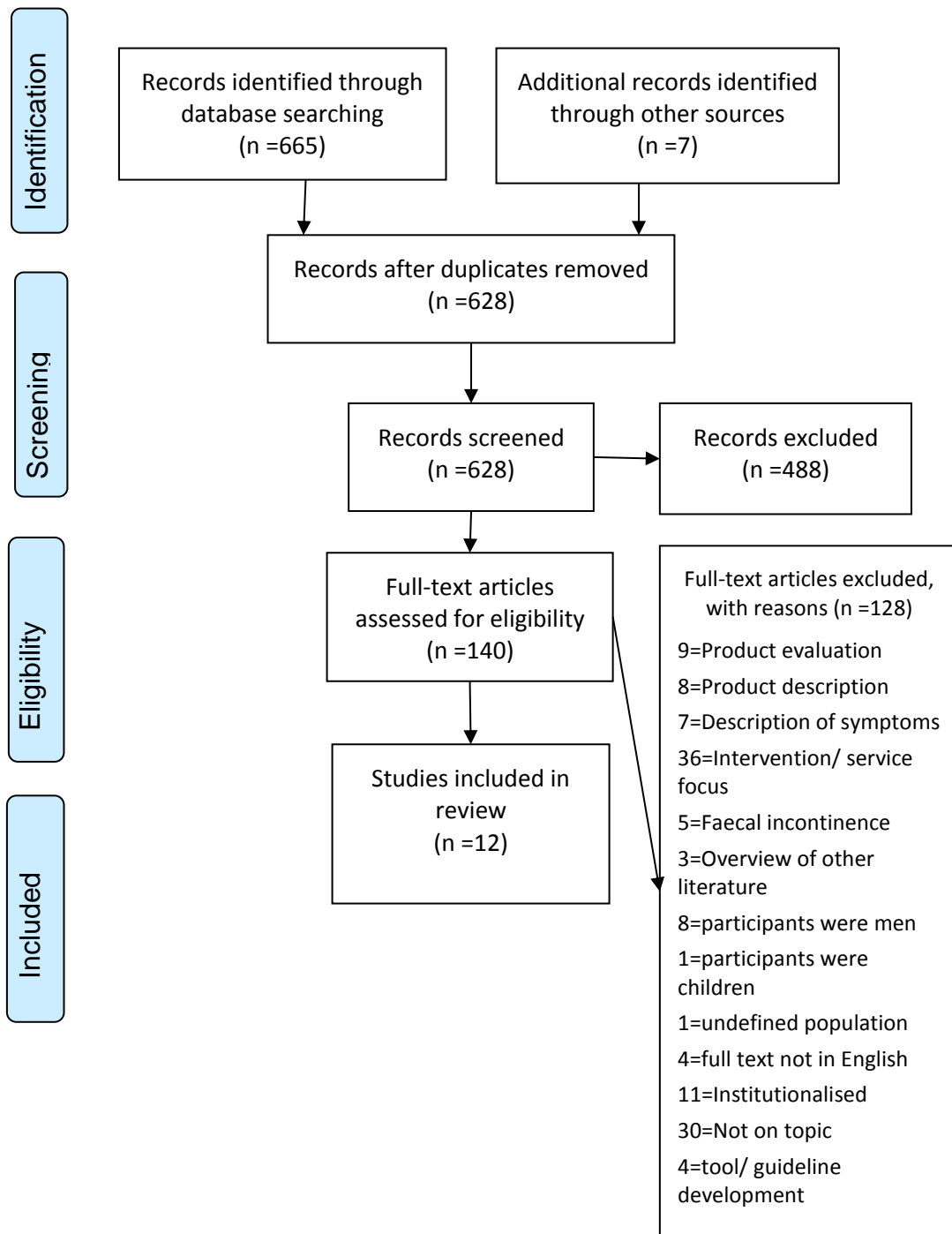
After all sources had been searched and duplicates had been removed 628 unique records were identified. These records were screened by reading titles and abstracts, after which 488 records were excluded as they did not meet the inclusion criteria. The 140 records which remained were read in full, and another 128 were then excluded as they did not meet the inclusion criteria. Reasons for excluding the 128 records can be seen in the PRISMA diagram in Figure 2. Twelve studies remained for inclusion into the review, these were extracted in a process known as charting (Peters et al., 2017). A descriptive summary was written to provide an overview of what was found (section 2.10). This narrative approach was considered appropriate due to the likelihood of heterogeneity of literature.

## **2.9 Collation and appraisal**

### **2.9.1 Description of studies**

Twelve pieces of literature met the inclusion criteria of the review after screening had taken place (Figure 2). Despite screening a variety of literature, only research articles and abstracts met the inclusion criteria after full texts had been read. The literature meeting the review criteria included one systematic review, two conference abstracts and nine original research articles. An overview of the included literature is shown in Table 3.

Searches performed=04.10.17 Scopus; 05.10.17 CINAHL; 05.10.17 ContinenProductadvisor.org; 05.10.17 Opengrey.org; 04.10.17 MEDLINE, Embase, All EBM, PsychINFO via Ovid



**Figure 2 PRISMA diagram of search process**



**Table 3 Charted literature for review**

	<i>Country</i>	<i>Study type</i>	<i>Methods</i>	<i>Setting</i>	<i>Participants</i>	<i>Participant type</i>	<i>Outcomes</i>
<i>Andersson et al (2008)</i>	Sweden	Qualitative	Phenomenology interviews	Primary healthcare	11 Caucasian women	Pads on prescription but chose no active treatment	Absorbent products used amongst other coping strategies. Wanted 'proper & tested' products for security. Changed regularly as fearful of odours. Increased hygiene practices.
<i>Anger et al (2011)</i>	US	Qualitative	Focus groups	Outpatients of secondary care	33 Caucasian women	OAB patients	Perceptions of OAB were varied but included the theme 'wearing pads'. Pads seen as "most trustworthy and successful treatment"
<i>Fader et al (2014)</i>	UK	Quantitative	Mixture -	Community	85 interviewees 74 shoppers	Men and women with moderate- heavy UI	Pull-ups design preferred by women, even with higher costs. Design strengths were comfort, ease of change (except with trousers), no leakage and discreet.
<i>Fader et al (2007)</i>	UK	Review	Systematic literature review	Unknown	85 women	Light UI 5+ times/week	Disposable inserts are most preferred design despite cost. No dominant design for cost-effectiveness. Some women may prefer alternative designs to disposable inserts.
<i>Getliffe et al (2007)</i>	UK	Qualitative – 2 phase	Focus group Interviews & Ranking exercise	Community	15 women in focus group 99 interviews	Light UI at least daily	Top pad characteristics were all physical properties. Anxiety regarding UI and pad failure. Odour and discreetness were pad priorities. Psychosocial themes were highlighted.
<i>Higa and Lopes (2007)</i>	Brazil	Mixed methods	Questionnaire Interviews	Nursing Personnel	291 questionnaires 75 interviews	Female Nurses working in secondary care	Interviews - 1/3 participants used pads at work. Frequency of pad change was variable. Wet pads caused skin irritation, dermatitis, and allergy.
<i>Grzybowska and Wydra (2017)</i>	Poland	Quantitative	Questionnaires	Urogynae clinic	265 women	Outpatients of LUTs clinic	Absorbent product use is an important aspect of QOL. Abstract suggested QOL was significantly reduced for women who wear absorbent products all the time.
<i>Grzybowska et al (2015)</i>	Poland	Quantitative	Questionnaires	Urogynae clinic	147 women	Women with SUI.	Use of absorbent products increased with severity of SUI.
<i>Li et al (2007)</i>	China	Qualitative	Interviews	Continence clinic	9 women	New referrals to clinic, after 1 <sup>st</sup> appointment	Preference to make own products, despite absorbent products available commercially. Some products considered unsuitable for use in hot weather.
<i>Lodowski et al (2011)</i>	US	Quantitative	Cross sectional internet survey	Unknown	5023 women	Aged 18-70 years with internet access	Self-'treatment' using absorbent products was most common way for women between aged 50-59 to deal with symptoms of OAB.
<i>St John, et al (2013)</i>	Australia	Quantitative	Cross sectional questionnaire	Community	207 women	103 >65 years 104 <65 years	Absorbent products used by majority alongside other strategies. Different products for different activities, but some women used absorbent products too small for leakage. Planning important.
<i>Teunissen &amp; Lagro-Janssen (2009)</i>	Netherlands	Quantitative	Interviews & questionnaires	Community	56 men 314 women	Participants in a larger project – all reported UI previously	87% women used absorbent products, with 50% using them at night. A range of products were used, but dissatisfaction because of leakage & discomfort for some women.

### **2.9.2 Heterogeneity**

Although similarities in the populations under investigation did exist between studies, there remained too much disparity to collate findings. Perhaps most importantly to this review, the ways that urinary incontinence was identified and expressed was not consistent between studies making results incomparable. Nine of the included studies appeared to rely on self-reporting of symptoms by participants, although six included results from various questionnaires to elicit further information about symptoms. In five of these studies, background information was provided which suggested some research participants were, or could be, patients of specialist services and therefore may have had a diagnosis of a condition resulting in urinary incontinence prior to participation (Getliffe et al., 2007; Andersson et al., 2008; Teunissen and Lagro-Janssen, 2009; St John et al., 2013; Fader et al., 2014). Only four studies explicitly considered diagnosis (Li et al., 2007; Anger et al., 2011; Grzybowska et al., 2015; Grzybowska and Wydra, 2017).

The concept of 'urinary incontinence' was not used as defined by the International Continence Society in all studies (Abrams et al., 2002). Whilst the majority of authors considered urinary incontinence to be a symptom, two articles by the same lead author appeared to use the term inconsistently (Grzybowska et al., 2015; Grzybowska and Wydra, 2017).

There were considerable differences in age of participants between the studies. Due to the different aims and reporting styles of the included studies, there was not enough information to be able to assess similarity between populations. In addition to the sources of heterogeneity mentioned above, differences in methodologies and methods also existed so no two pieces of literature were directly comparable. Therefore data could not be synthesised.

### **2.9.3 Methodological quality**

As part of the charting process of this review, an overview of quality was provided for full reports of empirical research studies, as justified in section 2.3. A number of quality assessment tools were required due to the differences in methods used in the included studies. Quality assessment tools used included the systematic review and qualitative checklists from the Critical Appraisal

Skills Programme (2017). Quantitative studies were appraised using the checklist from the Effective Public Health Practice Project (1998). As the review was not focused upon a healthcare intervention, use of a tool which would grade the evidence such as the Oxford Centre for Evidence-Based Medicine's Levels of Evidence (OCEBM Levels of Evidence Working Group, 2011) would not have been congruent with the aim of the review. The methodological quality of the included literature was variable as would be expected from the disparate range of literature that was included in the review. As previously noted (section 2.3) quality of literature is not a barrier to inclusion in scoping reviews.

## **2.10 Results**

### **2.10.1 Do women use absorbent products for urinary incontinence?**

All studies reported use of absorbent product use by women (Table 4). Two of the studies stated a primary or secondary aim of ascertaining prevalence of product use by women (Teunissen and Lagro-Janssen, 2009; Grzybowska et al., 2015). Four studies selected participants because of their product use, or to use products as part of the study (Fader et al., 2007; Getliffe et al., 2007; Andersson et al., 2008; Fader et al., 2014). Consequently, 100% of participants in these studies were product users. In studies where participants were recruited because of their continence status (experiencing urinary incontinence), products use varied between 25% and 90.9% of participants. Two studies reported that products were used by participants but did not report detail relating to usage (Li et al., 2007; Anger et al., 2011).

Two studies considered age and absorbent product use; both found that older women were more likely to use products than younger women (Lodowski et al., 2011; St John et al., 2013). However due to the differing populations (one study included women experiencing the symptom of leakage, the other included women only with a diagnosis of OAB), and the age categories used by the authors to group participants, no further extrapolation could be made.

**Table 4 Absorbent product use by study participants**

	<i>Absorbent product use</i>	<i>% of participants using pads</i>	<i>Prescription for pads</i>
<i>Andersson et al (2008)</i>	Yes	100	On prescription 100%
<i>Anger et al (2011)</i>	Yes	Unknown	Unknown
<i>Fader et al (2014)</i>	Yes	100	Yes but % unknown
<i>Fader et al (2007)</i>	Yes	100	Yes but % unknown
<i>Getliffe et al (2007)</i>	Yes	100	On prescription 34.3% Buys own products 65.7%
<i>Grzybowska and Wydra (2017)</i>	Yes	90.9	Unknown
<i>Grzybowska et al (2015)</i>	Yes	89.6	Unknown
<i>Higa and Lopes (2007)</i>	Yes	25.0	Unknown
<i>Li et al (2007)</i>	Yes	Unknown	Unknown
<i>Lodowski et al (2011)</i>	Yes	Age 60-70 – 65% Age 50-59 – 69.8% Age 40-49 – 58.5% Age 30-39 – 33.8% Age 18-29 – 23.4%	Unknown
<i>St John, et al (2013)</i>	Yes	Age >65 – 87.1% Age 18-65 – 72.5%	Unknown
<i>Teunissen &amp; Lagro-Janssen (2009)</i>	Yes	87.0%	Unknown

### 2.10.2 How are absorbent products used for urinary incontinence?

Use of absorbent products was generally considered in simplistic terms. In most studies there appeared to be a dichotomy between product use and no product use. There may have been assumption that women would use products in the same way on a daily-basis by some authors, with little consideration made to other factors which may influence product use (Table 5).

Five studies considered time of product use in a 24 hour period, differentiating between day and night time use (Fader et al., 2007; Getliffe et al., 2007; Teunissen and Lagro-Janssen, 2009; Fader et al., 2014; Grzybowska and Wydra, 2017). One study considered type of absorbent products being used (Teunissen and Lagro-Janssen, 2009). Two studies considered in what specific circumstances products might be used (St John et al., 2013; Grzybowska et al., 2015). Both these studies used quantitative means to gather data, and therefore other than outlining that products were specifically used for a number of activities, this knowledge was not explored further.

Due to the lack of reporting it was not possible to ascertain frequency of product use either within a 24hour period, or over longer periods of time. The study of Grzybowska et al. (2015) did seem to suggest with increased stress urinary incontinence symptoms, it was more likely that women would use products more often; however the methods used to collect this data mean that the finding cannot be interpreted with certainty.

Fader et al. (2014) evaluated absorbent product designs by day and night time use. This was a user-acceptability trial of both washable and disposable products, but was not indicative of participants' everyday use of products due to the product range being selected by the researchers. Despite this, the study did provide evidence that product performance was considered alongside cost of product by some women when making choices about which products to use. For example, the majority of women preferred a pull up design (61% preferred pull ups for daytime use and 53% preferred pull ups for night time) compared to an insert design (17% preferred inserts for daytime and 19% preferred inserts for night time). This changed when cost of product was disclosed (59% then preferred pull ups for daytime and 47% preferred pull ups for night time), with shifting preference towards inserts (28% then preferred inserts for day time and 30% preferred inserts for night time) despite acceptability of design being much higher for pull ups (95% preferred this design for day time/ 92% preferred this design for night time) than inserts (83% day time and 77% night time).

Participants in this study were allowed to choose a range of products to suit their needs, rather than relying on a single product type for all circumstances. Using a range of products was also seen in the Anger et al. (2011) study "*I buy the underwear. I buy the little pads, I buy the big pads...*", and was highlighted by Li et al. (2007) who found participants made their own products from a range of absorbent materials to meet the needs which were unmet by commercially available products.

The qualitative studies did give further indication that decisions relating to use of absorbent products was multifactorial. This included decisions whether to commence product use, how products should be used and which products should be used. Getliffe et al. (2007) found that absorbent products were used to maintain '*normality*' and that products were relied upon in everyday situations particularly in circumstances away from the home environment. The

psychosocial impact of absorbent product use was evident in several studies, but was often reported with the psychosocial impact of urinary incontinence. Absorbent products were used to reduce the negative impact of urinary incontinence, which included physical and psychosocial elements (Higa and de Moraes Lopes, 2007; Li et al., 2007; Andersson et al., 2008; Anger et al., 2011).

Anger et al. (2011) found that participants also made decisions about additional actions required to enable product use, in particular the need to carry products when away from home. The theme of carrying absorbent products, spares and additional items to facilitate product use was evident in other literature too (Getliffe et al., 2007; St John et al., 2013).

**Table 5 Temporal patterns of absorbent product use by study participants**

	<i>24hr/ day</i>	<i>Day</i>	<i>Night</i>	<i>Other</i>
<i>Andersson et al (2008)</i>	Unknown	Yes	Unknown	Unknown
<i>Anger et al (2011)</i>	Unknown	Yes	Yes	Travel
<i>Fader et al (2014)</i>	Unknown	100%	100%	n/a
<i>Fader et al (2007)</i>	n/a	Yes	Yes	n/a
<i>Getliffe et al (2007)</i>	81.8%	100%	81.8%	Unknown
<i>Grzybowska and Wydra (2017)</i>	29%	53.7%	Unknown	Unknown
<i>Grzybowska et al (2015)</i>	Unknown	Unknown	Unknown	In and outside home 66% Only outside home 18.6% Occasional 2.8% For hygiene reasons 2.1%
<i>Higa and Lopes (2007)</i>	Unknown	Unknown	Unknown	At work 25%
<i>Li et al (2007)</i>	Unknown	Yes	Unknown	Unknown
<i>Lodowski et al (2011)</i>	Unknown	Unknown	Unknown	Unknown
<i>St John, et al (2013)</i>	Unknown	Yes	Unknown	For specific activities older=57.7%, younger=53.5% Different products in/outside home older=39.2%, younger 30.7%
<i>Teunissen &amp; Lagro-Janssen (2009)</i>	Unknown	82%	50%	Day time - Use of menstrual pads 22%; Use of Panty liners 48%; Use of incontinence products 48%, Other products 3% Night time - Use of menstrual pads 17%; Use of Panty liners 32%; Use of incontinence products 51%, Other products 4%

### **2.10.3 What are women's thoughts about using absorbent products?**

All studies suggested use of absorbent products was just one coping strategy used by women, who often employed a number of strategies to deal with their urinary incontinence. Those studies that considered women's thoughts or feelings towards using products, focused mainly on the physical aspects of product use, although there was recognition that other factors did affect product use (Fader et al., 2007; Getliffe et al., 2007; Higa and de Moraes Lopes, 2007; Li et al., 2007; Andersson et al., 2008; Teunissen and Lagro-Janssen, 2009; Anger et al., 2011; Fader et al., 2014). Table 6 shows the thoughts and considerations towards product use by study participants.

The most comprehensive study detailing women's thoughts towards products was that of Getliffe et al. (2007) whose study illuminated the factors that women with light urinary incontinence had to deal with on a day-to-day basis. Whilst the products enabled women to get on with their everyday activities, their use came at personal and emotional cost. In proactively dealing with the negative aspects of urinary incontinence, women also had to deal with the less favourable aspects of absorbent product use.

The positive aspects of absorbent product use noted by participants in Anger et al. (2011); Getliffe et al. (2007); Andersson et al. (2008) showed that women felt that absorbent products provided them with safety. Security was paramount, knowing that leakage outside of the absorbent product would not occur. Successful use of absorbent products allowed a normal routine to be maintained and for social continence to be gained.

Conversely, absorbent products also caused women a great deal of anxiety and mistrust. Confidence in absorbent products was lost when leakage occurred, or in situations where the user felt outside of their comfort zone, for example too far away from toilets, or in an unknown environment. Using appropriate absorbent products meant the difference between being able to work, or not for some women (Getliffe et al., 2007). Some commercially-available products were considered so negatively that women made their own products which met more of their needs in hot weather (Li et al., 2007).

Absorbent products had the power to challenge women's identity. As well as recognising that the women may behave differently towards relationships, particularly sexual relationships because of absorbent product use, participants of Getliffe et al. (2007) spoke of absorbent products not being 'sexy'.

As noted in the previous section, product use included associated actions that were necessary for absorbent product use to be successful. The nurses surveyed by Higa and de Moraes Lopes (2007) struggled to find time to change products during their working shifts. Getliffe et al. (2007) found less dexterous participants struggled with product packaging, and some products were difficult to get into the correct position. Wearing loose clothing, or dark coloured clothing was a strategy used to prevent leakage being visible should it occur, but also prevented others seeing the outline of any product being worn.

Carrying spare clothing/ products/ additional continence aids when away from home was a strategy used when it was likely that leakage might occur (St John et al., 2013). Carrying spares suggests that women's confidence in products to contain leakage was limited and had to be negotiated. In this instance, carrying spares was primarily planning for product 'failure'.

In all but three of the studies (Fader et al., 2007; Getliffe et al., 2007; Fader et al., 2014) there was a lack of clarity about what products were being considered. As explained in 1.5, there are a number of absorbent products types and designs. In both of Fader et al.'s studies disposable designs were preferred; however women had differing priorities depending on whether the product was to be used at daytime or night time.



**Table 6 Thoughts about products and product use**

	<i>Positive</i>	<i>Negative</i>	<i>Other</i>
<i>Andersson et al (2008)</i>	Proper and tested products made users feel secure. Allowed continuation of life/ activities	Fear - Regular changing to prevent odour	Discussion with friends regarding 'what protection to use'
<i>Anger et al (2011)</i>	Life saver. Trustworthy Successful. Enable travel Prevent leakage onto bed at night	Unknown	A legacy
<i>Fader et al (2014)</i>	Disposable insert – comfort when dry, stays in place, fewer skin health problems, little effect on daily activities	Disposable insert double the cost of menstrual pad. Washable pants/ inserts more expensive and low acceptability. More likely to smell	n/a
<i>Fader et al (2007)</i>	Pull up design most acceptable In order (day use) - Pull ups, inserts, all in ones, T-shaped, washables	Washable product design less acceptable	n/a
<i>Getliffe et al (2007)</i>	Importance of carrying on with 'every day' Pads hiding the problem. Effective products give confidence. Top 5 daytime characteristics of absorbent products – hold urine; contain smell; stay in place; discreetness; comfort when wet.	Anxiety with product use. Self-conscious, especially when absorbent product is wet (bulks up). Confidence in absorbent products is damaged when leaks occur or absorbent product visible through clothes. Packaging difficult to open. Products difficult to get on Discomfort when wet. Chaffing to legs. Affects sleep. Skin irritation. Absorbent products break up when wet. Buy clothes to hide absorbent product. Wet absorbent products smell. Unsexy. Interfere with sexual relationships	Relationship between discreetness and effective absorbency. Mediate relationships to take into account use of absorbent products Effective absorbent products dictate whether some women can work. Home is safe. Prepare before going out. Take spares.
<i>Grzybowska and Wydra (2017)</i>	Unknown	Unknown	n/a
<i>Grzybowska et al (2015)</i>	Unknown	Unknown	n/a
<i>Higa and Lopes (2007)</i>	Unknown	Difficulty finding time to change absorbent products during working hours	n/a
<i>Li et al (2007)</i>	Wide choice of products available	Products don't meet need	Made own products
<i>Lodowski et al (2011)</i>	Unknown	Unknown	n/a
<i>St John, et al (2013)</i>	Unknown	Unknown	n/a
<i>Teunissen &amp; Lagro-Janssen (2009)</i>		Satisfaction reduced because of leakage; irritation; discomfort, and other unspecified reasons	Always satisfied with products 67%; Mostly satisfied 20%; Sometimes 12%; Mostly not 1%

## 2.11 Discussion

This scoping review was conducted to investigate the literature base supporting women's experience of using absorbent products for urinary incontinence.

Three sub questions were asked of the literature, considering whether women did use absorbent products, how women used products and what women thought about using products. Academic and grey literature was searched, before twelve pieces of literature meeting the inclusion criteria were critically analysed and included within the review.

The results of this scoping review show that whilst a significant proportion of women enrolling in urinary incontinence research do use absorbent products to manage their symptoms, there are women who choose not to use these products as a coping strategy. Not all women indicated that they used products as suggested in the studies by Teunissen and Lagro-Janssen (2009) and Grzybowska and Wydra (2017). Reasons for not using absorbent products were not fully explored by any of the included literature, although there was suggestion that commercially available products did not meet the needs of some participants (Li et al., 2007). This could be due to the context in which the study was set and therefore the transferability of these findings may be limited. Some women found that the products were not discreet enough when in situ, and when being transported pre- or post- use (Getliffe et al., 2007). There may also have been a possibility that whilst absorbent products enabled some women to "*live the life they wanted*", they may have also acted as a barrier to that life for others (Andersson et al., 2008). The stigmatising nature of urinary incontinence and in particular the odour from stale urine is known to have negative effects (Pakgohar et al., 2015b). These are concepts that may also have relevance to women's use of products (St John et al., 2010; Southall et al., 2015). The fear of odour is an example of where the intersection between the psychosocial impact of products and the psychosocial impact of leakage is not clear in the included literature. The studies reviewed did not always make distinction between effects of product use and effects of symptoms. There is opportunity for research which stratifies product and symptom psychosocial impact. Without this distinction, the use of products by women experiencing urinary incontinence may not be fully understood.

As indicated by Fader et al. (2014) there are women who may prefer different products for a variety of circumstances for example product use may be influenced by time of day, or for environmental factors. Other literature has shown women's concerns about leakage is often context dependant and it stands to reason that these contexts may also influence product use (Higa et al., 2008; Palmer et al., 2012; Akyuz et al., 2014), particularly if urinary incontinence is 'normalised' or expected as part of womanhood (Mittiness and Barker, 1995; Peake and Manderson, 2003). It might be possible that the reasons for only choosing to use absorbent products in some situations (for example when undertaking a particular activity) may provide additional evidence for women's priorities for product use. As Teunissen and Lagro-Janssen (2009) have suggested there is possibility that knowledge of menstrual product affects women's decision making when deciding whether to use absorbent products for incontinence. This familiarity with other products may also explain why some women prefer to use menstrual products, instead of products designed for urine leakage (Fader et al., 2007). In addition to the physical properties of menstrual products being familiar to women, they tend to be much cheaper than products specifically designed for incontinence, and previous cost analyses show financial cost of products is a consideration for some women (McClish et al., 1999; Fader et al., 2014).

The majority of studies included in this review considered absorbent products as a single coping strategy amongst other strategies. It was clear that for many women absorbent products are one way of dealing with leakage, but that they are not used in isolation. This is consistent with other research which has found that minimising and containing leakage are two priorities for women experiencing urinary incontinence, with some women adopting maladaptive practices such as restricting fluid intake (St John et al., 2010; Siddiqui et al., 2014). Coping strategies have also been shown to have an impact on Quality of Life, but palliative and avoidant coping styles may mediate the effect of symptom severity on Quality of Life (Xu et al., 2016).

There are opportunities for researchers to understand much more about how women use products. As explained in section 2.10.2, although there are some studies that consider day and night time use or use for specific activities, there is no consistency between studies on how this data is collected. Potentially,

more could be learned about use of products as a coping strategy if more was known about when and why products were used. Therefore, in addition to more opportunities for research into the topic, there is also opportunity to improve methods used and in particular data collection tools which could take into account product use routines. The critical analysis undertaken to inform this review highlighted a number of areas where studies have been of questionable design and therefore negatively affect findings due to poor validity and reliability of tools. Two studies included within the review were interested in new data collection tools. St John et al. (2013) created a new questionnaire to elicit data on daily living strategies, whilst Getliffe et al. (2007) were using their study to inform domains to be included in a Quality of Life measure for people using absorbent products (Yearwood Martin et al., 2018). Fader et al. (2007) and (2008b) noted that there was too little trial evidence which met the standard required for high quality systematic reviews.

The choices and types of behaviour relating to absorbent product use by women found by this review have also been reported elsewhere. Research by Hayder and Schnepf (2010) outlines a graduated “*trial and error approach*” to selecting absorbent products, beginning with a product which will be least “*noticeable*”. Hoogsteyns and van der Horst (2015) also suggested that their participants had a similar approach to finding the correct products for individual circumstances. Some participants organised their dressing routines to minimise the visibility of absorbent products, and to take into account any leakage which might occur, which is consistent with the findings of Getliffe et al. (2007).

This review has clearly shown that women have concerns about the physical properties of the products, in addition to psychosocial needs affecting product use. Absorbent products are often used to maintain social continence, and it is important to future absorbent product research to explore this future.

### **2.11.1 Strengths and limitations of the review**

The review is strengthened by the use of the Joanna Briggs methodology for scoping reviews and its consistency with PRISMA-ScR guidance. The review is reproducible because of the clarity of methods used; validity was enhanced by implementation of a clear protocol.

The review does have some limitations however. Due to the heterogeneity of the literature reviewed, direct comparisons between studies could not be made. Included studies were conducted using a range of methods to meet differing aims. They also ranged in quality. As a consequence, a clear synthesis of the literature could not be carried out.

Despite an appropriate range of electronic databases and other sources searched, it is possible that not all literature was included. As explained in section 2.7 steps were taken to make the search as sensitive as possible, whilst maintaining specificity. It became apparent during the review that literature which considered the use of absorbent products did not always focus on only women, or only urinary incontinence. Due to the specificity of the inclusion and exclusion criteria for this review, including date limits some relevant literature may have been excluded.

The search was conducted by one researcher, and all literature extracted was appraised by the same researcher. Ordinarily it would be good practice to engage at least two researchers in a literature review; however for the aims of the PhD it was appropriate that only the thesis author conducted this review.

Despite the limitations noted this is the first review which has sought to map the evidence focusing on women's experiences of absorbent product use and as such provides additional insight to the literature base for this subject. It is also an appropriate foundation on which to build the empirical research as it sets out the areas of uncertainty that this thesis will explore.

## **2.12 Conclusion**

This review found that women use absorbent products as a strategy to manage urinary incontinence. The literature suggests that the use of absorbent products is not simplistic. In addition to choices about when to wear a product, women also make choices about the type of product and whether to use products as an adjunct to other coping strategies. Product use involves a number of stages from selection of product to disposal. The psychosocial implications of product use are distinct but intersect with the psychosocial implications of urinary incontinence. By creating social continence women may encounter other

issues, not least fear of product failure or detection of incontinence by others, as a result of using a product.

Absorbent products have the capacity to challenge women's identity, and relationships. Women's thoughts about absorbent product use range from highly positive, to negative. The literature included in the review was disparate, and highlighted gaps in the evidence base considering how women understand their product use.

Due to the heterogeneity and methodological quality of the included literature, the conclusions about women's product use drawn from this review are not generalizable; however there may be transferability to similar settings. Despite this, the review has highlighted important gaps in knowledge. It has also furthered the understanding of absorbent product use by women by highlighting the complexity of absorbent product use.

## **2.13 Implications for practice and research**

The review has been able to provide insight into women's experiences of absorbent product use, and therefore will be of use to practitioners who work with women experiencing urinary incontinence. Due to the review methods employed the implications for practice arising from this review are restricted, the aim of a scoping review does not seek to change practice. However, the findings are highly informative and may further the knowledge of practitioners who encounter women utilising absorbent products for urinary incontinence.

This scoping review has highlighted gaps in the evidence base, providing justification for the research phases of this study to be undertaken. As illustrated by other authors who have approached this subject, women's experience of urinary incontinence, and the absorbent products they use to regain social continence, are inextricably linked. It is clear that trying to understand women's experience of products without understanding their experience of urinary incontinence would be limited and is unlikely to add value to the existing evidence base.

Following on from the work of Getliffe et al. (2007) which provided the most comprehensive understanding of women's attitudes towards absorbent products, the empirical studies described in the rest of this thesis will aim to provide additional depth to the knowledge base which considered women's attitudes to their experience of urinary incontinence and absorbent products.

## Chapter 3 Methodology

### 3.1 Introduction

In the previous chapter, the literature was critically reviewed. The scoping literature review found that there was very little evidence which considered women's absorbent product use in-depth. However, from the evidence which was analysed it was possible to ascertain that some women used absorbent products as a coping strategy; that absorbent products were used alongside other coping strategies; and that the experience of using absorbent products is intertwined with the experience of urinary symptoms. The literature review was able to indicate that product use may vary between day and night-time and be dependent on activities undertaken. The reasons for using absorbent products were multifactorial and related to the psychosocial consequences of urinary incontinence. Absorbent product use was considered through the product life cycle, including purchase, storage and disposal of products. The literature reviewed did not provide a clear answer to how women feel about absorbent product use, as the majority of studies mostly considered data relating to the physical aspects of absorbent products, however it did highlight the work of Getliffe et al. (2007) who provided the most comprehensive study on women's use of absorbent products. Getliffe et al. (2007) proposed that there were positive and negative effects to absorbent product use, including the impact upon the identity of users.

As noted in section 1.2.1 severity of incontinence may increase before help is sought, therefore benefits of early intervention might be missed due to women's attitudes towards symptoms (O'Donnell et al., 2005; Sande et al., 2009; Sengezer et al., 2010). Attitudes towards urinary incontinence may also incorporate the use of absorbent products, as demonstrated by Getliffe et al. (2007). Therefore, understanding more about women's attitudes towards absorbent product use is particularly pertinent when women may be less likely to help-seek, despite urinary incontinence perhaps being a predictor for increased mortality in later life (John et al., 2016).



Understanding how women cope with symptoms prior to help-seeking may inform improved service provision. This research project builds on the work of Getliffe et al. (2007) whose study aims included examining the impact of absorbent products on women. Development of the Getliffe et al. (2007) study will be established by demonstrating differences in attitudes towards absorbent product use. Product use will be considered holistically, alongside the experience of urinary incontinence.

This chapter will commence by describing the aim and objectives of this study before considering methodological approaches to the topic. It will go on to discuss the development of the study using a multi method design (section 3.11). The use of patient and public involvement strategy will be explained (section 3.4) before providing an overview of sampling and recruitment used in the main study (sections 3.5 and 3.6). The chosen methodological approaches for the research will be explained in brief; Qualitative interviews in section 3.8 and Q methodology in section 3.9. Use of a socio-technical design model will also be justified. Further detail about the methods used in each study will be provided in the subsequent chapters (sections 4.2; 5.3 and 5.10).

## **3.2 Aim and objectives**

### **3.2.1 Aim**

A clear research aim is important as it allows systematic planning and execution of research which is appropriate, addressing a specific question (Doody and Bailey, 2016). From the review findings it became evident that there were gaps in the literature pertaining to everyday use of absorbent products by women. This became the study focus as large numbers of women experience urinary incontinence and many may use absorbent products to cope with symptoms. Understanding women's attitudes towards their experience of urinary incontinence and use of absorbent products may be informative for future intervention; it may also have positive impact on future product design. Therefore, the aim of this research was to understand

women's attitudes to their experience of urinary incontinence, and the use or non-use of absorbent products.

### **3.2.2 Objectives**

The objectives of the research were to –

- Describe and understand experiences of women with urinary incontinence.
- Understand the use or non-use of absorbent products for containing urine.
- Characterise women's attitudes to urinary incontinence and use of absorbent products.
- Discuss how the findings may influence future absorbent product design and healthcare practice.

### **3.2.3 Justification for the study**

Evidence for women's absorbent product preferences exists, however much of the research has focused on effectiveness of absorbent products or the interplay between intervention and coping using products. For example there is evidence which highlights the preferences of women who engage with professionals regarding their continence needs (Macaulay et al., 2004; Scobie et al., 2012), as well as evidence which considers the most practical aspects of absorbent products and their use (Fader et al., 2008a). There is limited evidence which considers the experience of women who are coping with urinary incontinence without intervention from health or social care professionals, despite evidence to suggest large numbers of women are likely to be in this position (Shaw et al., 2006; van Breda et al., 2015).

By considering use of absorbent products as a reality of daily-living there is potential that more could be learned about women's priorities for using, or not using, these products. Figure 3 provides an overview of the process of

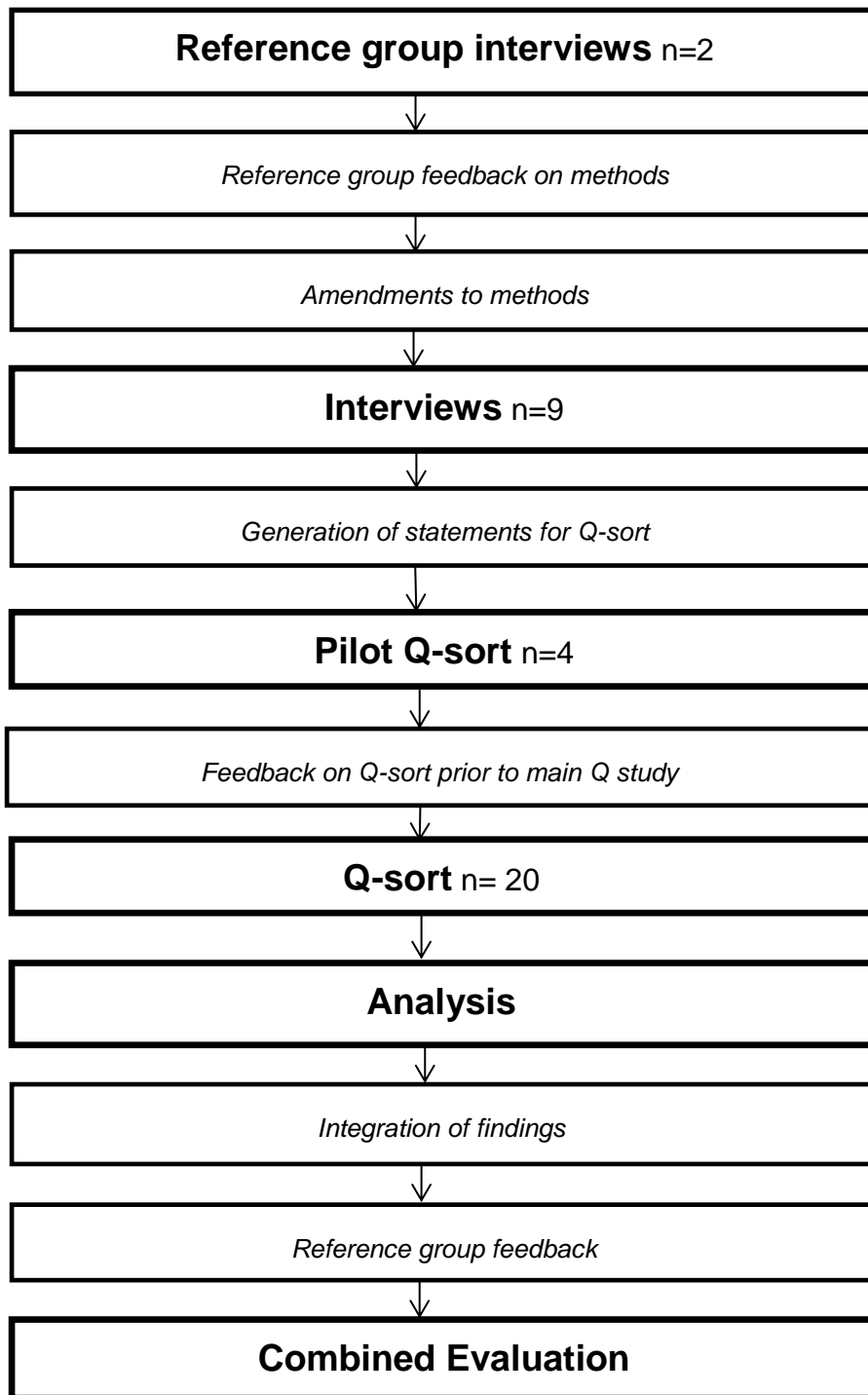


Figure 3 Plan of Research

the study, including the input of the reference group throughout the research process. More detail about each of the stages will be provided throughout the rest of this chapter, and in the subsequent chapters.

This study will add to the existing evidence base, providing deeper understanding about women's attitudes to urinary incontinence and absorbent products. To ensure that the research aim could be met a number of philosophical and methodological approaches were considered, these will be explained in the next section.

### **3.2.4 Understanding methodology**

Methodology is a link between the philosophy or worldview of the researcher and the research design. It provides coherence to research, enabling rigour and validity (Perri and Bellamy, 2011). Novikov and Novikov (2013) describe methodology as "*the theory of organization of an activity*". By appreciating that methodology has a theoretical underpinning concerned with the organisation of an activity (in this case research activity), rather than simply the process of undertaking the activity; the concepts which need to be understood prior to selecting a methodology can be discerned. Before a methodology can be decided upon, an awareness of philosophical positioning is required so that research can be planned, conducted and evaluated effectively. Objective philosophical positions include positivism, post-positivism and functionalism. These philosophies suggest that reality is fixed and laws have the ability to explain human behaviour, although some positions recognise that whilst ideal, total objectivity is not necessarily achievable (Laudan, 1990). There are those who argue positivism still shapes social research because of dominant social understandings of what science should be (Hasan, 2014). Objective philosophies often align with quantitative methodologies and methods.

Subjective philosophical approaches on the other hand are more concerned with the social construction of reality (Perri and Bellamy, 2011). Where objective research often seeks to deduce or reduce, subjective research is often inductive and understands truth as a social construct (Schnelker, 2006;

Bourgeault et al., 2010; Petty et al., 2012). Subjectivity is often the foundation for qualitative methodologies and methods which seek to uncover the meaning of data that is collected. To comprehend the meaning of data the researcher must be aware of their own and others understanding of relevant concepts and interpretations; for instance differing worldviews, motivation and recall (Hollway and Jefferson, 2000).

Pragmatic philosophical positions account for some of the discord between objective and subjective philosophies. Underlining all pragmatic philosophy is the notion of '*what is tangible and practical*' (Bacon, 2012, pp.14). Rorty (1991) suggests that pragmatic research should look for as much intersubjective agreement as possible whilst still recognising the limitations of the situation. Therefore this research was undertaken pragmatically, recognising that to understand the experience of women required subjectivity, whilst retaining some objectivity to facilitate the categorisation of attitudes necessary to meet the research objectives. After a philosophical position had been assumed, consideration was given to theoretical lenses.

### **3.2.5 Theoretical lenses considered for the research**

Consideration of theoretical lenses was made prior to methods being selected. A theoretical lens allows a researcher to view the research from a range of perspectives. There were a number of approaches which could have been taken which would have been appropriate to the topic under investigation. Different theories can be applied to the philosophical framework chosen, to help the researcher identify the most appropriate approach for developing methodology (Sherwin, 1999). Some theories have better synergy with particular philosophies and worldviews. The reasons for this are numerous, but include the theorist's philosophy being similar to the researcher's; and theories which cover a particular aspect of the topic of investigation (Sherwin, 1999). Consideration of theoretical lenses in the research design stage allowed further exploration of a priori beliefs, in addition to consideration of dominant discourses that exist within the literature.

An increased philosophical awareness at the beginning of this study highlighted assumed imbalances of power between women experiencing urinary incontinence and –

- healthcare providers;
- other members of the societies to which they belong;
- absorbent product manufacturers.

Despite there not being a strong history of feminist research into women's experiences of urinary incontinence, using a feminist methodology was initially considered for this study. Due to the shifting meanings of concepts such as 'gender' and 'sexuality' over the past few decades, feminism can no longer be viewed as a single paradigm interested in women as defined by their body; even determining the concept of 'body' has been a debated subject amongst some feminists with individualist feminists arguing for more abstract interpretations (Offen, 2000). Currently there is no agreed definition of feminism. Hannam (2008, pp.4) proposes that there are three defining characteristics to feminism, which are overarching but which do not address some of the more political issues within feminism.

1. *A recognition of imbalance of power within the sexes, with women in a subordinate role to men.*
2. *A belief that women's condition is socially constructed and therefore can be changed.*
3. *An emphasis on female autonomy.*

Different factions of feminism vary in their other objectives and values but provide a consistently clear approach towards removing negative power-imbalance (Calás and Smircich, 1996; Dryden, 2010). Fotaki (2010) argues that feminist theory is particularly suited for assessing issues of inequity in healthcare due to its ability to tackle political dimensions, power balance and barriers to good health. Feminism is an appropriate lens for use with both quantitative and qualitative methods, and can bring coherence and direction (Shapiro et al., 2003). Feminist research can itself cause power-balance

between researchers and participants due to the hierarchical nature of research, causing similar problems to the ones the researcher seeks to redress (Wolf, 1996; Womersley et al., 2011). It was important therefore that these issues were considered during the research design stage, which extended to selecting methods which would retain women's voices and reduce power imbalance. Ponc et al. (2010) considered the best ways of creating partnerships between women and health researchers. This literature was crucial in developing understanding the dynamics of researcher/ participant interaction. Read alongside other works by Ponc and Frisby (2010), Gatenby and Humphries (2000) and Langan and Morton (2009) the ethical and methodological consequences of undertaking such research were explored, highlighting the idealistic assumption that women are 'free' in their autonomy. Understanding of this literature led to the development of the reference group, a group of women involved in the research process and were distinct from the participants (section 3.4)

Contemporary feminist literature was used to inform decisions about the most appropriate methods to use. Methods which were not primarily feminist but which met the objectives of the study without compromising the integrity of the research were considered. Due to the cross-disciplinary nature of the proposed study research methods used for product design including socio-technical methods (Davis et al. 2013) and inclusive design (Cassim and Dong 2013) were reviewed to explore methods which could meet all necessary research outcomes.

Historically there have been instances of antagonism towards feminism (Mills, 1997; Epstien, 2012; Reikai, 2013). It was important therefore that using feminist theory to inform the research enabled empowerment for the participants involved, without being at the expense of the overall research objectives which may be subject to political influences. With that in mind, an overt feminist lens was removed from the study after the PhD Transfer process. The rest of this chapter will consider the research methodologies used in relation to the population under investigation.

### **3.3 Population characteristics**

A key aspect of the research was to identify potential participants who may not have sought help for urinary incontinence, enabling the voices of women receiving care and those self-caring to be included, as a proportion of women experiencing urinary incontinence do not access healthcare for symptoms (Teunissen et al., 2005; Doshi et al., 2010). Much of the research conducted within the UK has been conducted within healthcare settings, or used recruitment strategies which relied on healthcare systems to provide potential participants. By recruiting, or solely focusing on women who have accessed healthcare for continence problems, evidence may not be representative of the population as a whole. Recognising that women self-caring for urinary incontinence may form a hidden population, this study was designed to promote their involvement, as they may have been under-represented in the literature to date (McKinlay and Link, 2007).

#### **3.3.1 A hidden population**

Given the decision to recruit women who were not receiving healthcare as well as those who were, represented the challenge of accessing what might be considered a hidden population. A hidden population differs from a hard to reach population (Sydor, 2013). A hard to reach population describes a group whose characteristics are known but who choose not to engage with research for a variety of reasons. Hidden populations, in addition to being hard to reach, do not have easily identifiable members (Sydor, 2013). This is made all the more difficult for researchers as population 'membership' may be affected by perception; whether individuals identify themselves with the population under investigation (Heaphy et al., 1998). Precise numbers of people within a hidden group are unknown, making targeted recruitment particularly difficult (Faugier and Sargeant, 1997).

The population under investigation, women experiencing urinary incontinence, were considered hidden because of a lack of obvious identifying features which would typify them from women not experiencing



continence issues; in addition to a lack of evidence which accurately predicts population size and characteristics. Throughout this thesis 'women' refers to non-patient populations.

In this case, it appears likely that the population remains hidden, at least in part, due to the sensitive nature of the subject under investigation. Social norms and expectations may impede women's desire to identify themselves to researchers, particularly if there is no perceived benefit from doing so. If, as is suggested by Koch (2006), only a minority of women seek healthcare for urinary incontinence, it may be reasonable to assume similar trends may be found in women identifying themselves to researchers. Women are reluctant to seek healthcare for a variety of reasons including health beliefs about urinary incontinence and embarrassment (Koch, 2006). Absorbent products amongst other coping strategies are used to self-manage urinary incontinence, minimising, if not eliminating, tangible signs of the symptoms experienced.

It was determined based on the literature review, that women may be reluctant to identify themselves to the researcher, as this may have involved a large amount of risk, not only in 'public' identification, but also undermining self-identity. Whilst recruitment through healthcare settings, where women have already had to admit the problem of urinary incontinence to access help, could have negated some of the possible recruitment issues, it would have limited the scope of the research. Despite the importance of research already conducted with this sub-population to inform healthcare providers and professionals, researching them in isolation could not meet the aims and objectives of this study.

### **3.4 Patient and public involvement**

Patient and public involvement (PPI) in healthcare provision and research has increased steadily over recent years and is now legislated for in the *Health and Social Care Act* (2012). Experiential knowledge provided by people who are, or who have previously experienced the phenomenon under

investigation is considered vital to ensuring that outcomes meet the needs of populations. These individuals are able to provide detailed accounts of living with a condition or providing care for someone else and are able to advise researchers and policy makers.

Patient and public involvement has the power to shape outcomes by putting the needs and expectations of the public at the forefront of research and service development (Boote et al., 2011; Roberts et al., 2012; Chiu et al., 2013; Tritter and Koivusalo, 2013; Parkes et al., 2014). It also increases public confidence in research (HRA, 2013). Despite limited evidence regarding the impact of patient and public involvement, it remains an important concept for researchers and funders (Staley, 2009; Barber et al., 2012; NIHR, 2013). As well as healthcare literature supporting the use of patient and public involvement, design disciplines are also being challenged to involve the public in their work (Bate and Robert, 2006). With this in mind, it was appropriate that public involvement should inform this study.

Due to the nature of the study, recruitment to the public involvement aspect of the research was undertaken in a community setting. Patients were not sought instead members of the public who experienced urinary incontinence were engaged with the project. These women, experts-by-experience, became known as the reference group.

### **3.4.1 Reference group**

As previously explained in 3.3.1 the study needed to connect with a hidden population if it were to meet the research aim. Working with a reference group of women from the target population was perceived to be a method of helping engage with the population under investigation and improve recruitment (Whitstock, 2003). Siassakos et al. (2015) recognised that the information that members of the public could bring to their sensitive subject research study could not be provided by other professionals. The purpose of the reference group was to collaborate with the researcher, ensuring that the research priorities were relevant to those it sought to engage with (Ives et

al., 2013). Ethical approval for the use of the reference group was gained from the School of Healthcare Research Ethics Committee (SHREC/RP445/09.06.14). Despite funders' enthusiasm for public involvement in research, there has been criticism of the tokenistic approach taken by some (Madden and Speed, 2017). To avoid such alleged tokenism, reference group members informed the design of the recruitment strategy, the design of the Q study, acted as pilot participants and made recommendations for change. The group provided sense-checking throughout the study. They also provided feedback on anonymised data and analysis, to minimise researcher bias. Reference group members were remunerated for their time and expertise, using INVOLVE principles for guidance (Steel and Simons, 2010).

#### **3.4.1.1 Reference group sampling and recruitment**

Reference group members were self-selected. Their involvement was initiated in response to advertising. Use of a convenience sampling method was appropriate, as it has been successfully used for other PPI research (Lovegrove et al., 2017). Convenience sampling is described in further detail in section 3.5. Advertisements were disseminated by activity club gatekeepers within the local area, a city in the north of England. Activity clubs were targeted which were assumed to have female members.

The range of clubs were broadly categorised as -

- Older people's groups
- Exercise groups
- Groups assumed to have predominantly female membership, e.g. choirs, baking clubs
- New parent groups

A request for 'women with undiagnosed urinary incontinence' to become reference group members was made. This wording was used in response to the terminology used in the literature. The focus of the study prior to

reference group participation was predominantly to understand women's priorities for the development of absorbent products, however this was changed for recruitment to the main study after discussion with reference group members suggested it was more important to understand how current products were used in daily life. The need to understand women's priorities for future absorbent product development has previously been noted by Fader et al. (2010).

#### **3.4.1.2 Reference group membership**

There is no agreed procedure for deciding upon how many people to engage with during Patient and Public Involvement activities, and participation numbers vary widely (Lovegrove et al., 2017). As reference group members were not study participants as such, there was no requirement to predefine the number of women needed for the group. Several women expressed an interest in becoming reference group members, but only two women agreed to become members after reading the reference group participation information sheet. The general lack of engagement could have been due to perceived risks, for example identification and uncertainties about the nature of the research (Kreiger et al., 2001). Reasons for non-participation were not sought in-line with the ethical approval granted. However both reference group members were asked about why they thought the response had been limited and changes were made to the main study recruitment strategy as a result (see sections 3.4.3 and 3.5).

Reference group membership remained open throughout the study and therefore the use of the term 'group' remained appropriate to define the classification of these women within the study, despite only having two members (Oxford English Dictionary, 2014). The term 'group' also prevented indirect identification of the members by each other. Several participants of the main study did express interest but chose not to become reference group members. Despite the limited response to participation in the group, other research has shown that small patient and public involvement initiatives which consider experts by experience as co-researchers can have

a positive effect on research (Williamson et al., 2010). The small size of the reference group was not of concern but it was recognised that not having a representative sample may affect the output of the group. Both reference group members were retired, identified as White British/ English and were between the ages of 65-75 years.

### **3.4.2 Reference group participation**

The reference group members consented to pilot the interview questions. Their interview responses were recorded and were included in the main interview phase of the study. After the pilot interviews had concluded, reference group members were asked to provide any information that might aid recruitment to the main study. Based on the feedback from the reference group, changes to terminology used in recruitment advertising were made for the main study; this is explained further in 3.4.3.

The reference group members also participated in the piloting of the Q study, suggesting changes to statements and to the process of sorting. One reference group member also provided practical help with advertising activity.

### **3.4.3 Information provided by the reference group**

The women of the reference group clearly expressed that using the term urinary incontinence was problematic. In discussion with one member, the question of why women may not want to help with the study was raised. This member explicitly stated that the language of incontinence was not helpful to women who had chosen not to seek help. Her suggestion was to refer to 'leakage', which was subsequently approved by the other reference group member.

Literature already indicates that the social connotations of urinary incontinence are largely negative. Women may associate urinary incontinence with physical decline, which when framed positively suggests

normalcy, or when framed negatively may be considered a lack of control or return to childhood (Peake et al., 1999; Siddiqui et al., 2014).

The group members were given opportunity to suggest phraseology for the PhD, based on the information that had been shared. The title of this thesis was decided upon after discussion with reference group members. Whilst the reference group members did accept leakage and incontinence referred to the same symptom, they were happier with the concept of leakage, as it did not have the same connotations as incontinence.

The reference group also felt that a range of recruitment strategies would be useful. They made suggestions about types of strategies and noted some limitations of these. However, one member in particular felt that using a range of media would ensure that more women were able to hear about the study in a way which was meaningful to them. Using a range of strategies has been shown to have favourable results in recruitment of hard to reach populations (Peindl and Wisner, 2003; Benoit et al., 2005; Bonevski et al., 2014).

### **3.5 Sampling and recruitment - main study**

Effective sampling for research is important to enable selection of sufficient numbers of appropriate research participants. A sampling strategy provides clear direction for the research by specifying characteristics of those who the researcher wishes to target and the methods by which they will be identified (Holloway et al., 2013). There are a number of approaches that can be used to guide sampling for qualitative research. Some of the more common strategies are broadly described as purposeful (or purposive) sampling, snowball sampling, random sampling, convenience sampling, and theoretical (or ongoing) sampling (Robinson, 2014; Gentles et al., 2015). There are three key differences between these sampling strategies which relate to the populations that samples are to be taken from, when sampling will occur (for example before data collection or alongside data collection), and the

characteristics required from the sample to meet the research aims (Robinson, 2014).

Purposive sampling strategies were considered during the design of the research. Purposive sampling selects participants who are likely to be 'information-rich' sources (Devers and Frankel, 2000). As mentioned previously in section 3.3, some population characteristics were unknown, therefore sampling using a purposeful sampling technique was impractical and unlikely to be the most successful method of sampling. Including age or incontinence-related characteristics to the sampling strategy may have been possible, however it may also have restricted the data gathered. Previous urinary incontinence research has tended to concentrate on particular age groups of women or types of urinary incontinence and whilst this very focussed research is important to clinical understanding, in this instance it was hoped to include a broad range of participants to investigate whether attitudes to experience of urinary incontinence and use of absorbent products might be shared by women.

Recruiting enough women from a particular sub-section of the hidden population may also have proved difficult, particularly as recruitment was not conducted through health services and funds were not in place to carry out large-scale advertising. Telephone surveys have been used by other researchers to gather information about women experiencing urinary incontinence (Irwin et al., 2006; Herschorn et al., 2008). This technique has previously uncovered large numbers of women who have not sought help (Berger et al., 2011) however such techniques would not have been viable for use in this study due to the ethical implications of obtaining and calling phone numbers of unidentified women for the purpose of the PhD.

Screening hard-to-reach populations to create a more purposeful sample also raises ethical issues and practical problems (Abrams, 2010). Whilst it may have been possible to undertake some form of screening (such as the use of the ICIQ-UI SF questionnaire, discussed further in 4.3.5), the sample may have been adversely affected by such screening, particularly if certain sub-populations of women were discouraged by questions framed by

healthcare terminology. Inadvertently limiting the sample due to use of healthcare terminology might be considered ethically problematic, as only the women that understood their symptoms in the way defined by the screening tool may be willing or able to take part. This could have led to the marginalisation of some potential participants, particularly those with lower health literacy. A pragmatic approach to sampling was necessary within this study to ensure the research was not limited from the outset by healthcare-defined understanding of the issue under investigation. Moreover, as this research used the terminology of 'urine leakage' rather than incontinence, women who associated their experience with the issue of leakage could have been distinct from those already represented in previous literature focusing on incontinence.

Therefore, sampling followed a convenience sampling method allowing all women who identified as experiencing urine leakage, irrespective of severity, frequency and type of leakage (as might be expected from research into urinary incontinence) to participate. Convenience sampling recruits participants who are "*accessible and available*" to the researcher (Abrams, 2010). As culture has been shown to affect understanding of urinary incontinence previously (Gray, 2003), the area from which women were sampled was restricted to the Yorkshire and Humber region during the main study. It has been suggested that using a convenience sampling strategy limited by geographical area provides adequate justification for its use; transferability may be limited, however credibility is increased (Robinson, 2014). Advertising for the reference group was limited to one area of West Yorkshire, for the pragmatic reason of maintaining contact throughout the course of the study.

The sampling strategy was redefined after recruitment of reference group members. Initial recruitment of the reference group (section 3.4.1) advertised for women with 'undiagnosed urinary incontinence'. Feedback from the reference group found that using terminology from healthcare may create a barrier to participation. This was verified anecdotally after presenting the aims of the research during publicly accessible seminars. Some women



would identify as experiencing leakage but refuted the idea that they may be experiencing incontinence. Further explanation of recruitment can be found in the following section. Full inclusion and exclusion criteria for this phase of the study are explained in 4.3.2.

### **3.6 Recruitment**

The recruitment strategies used were based on information provided by the reference group and are outlined in Table 7. Using advertising which women would view privately provided a level of confidentiality and reduced risk of unwanted public identification.

Posters to be displayed in public toilets were prioritised as a form of advertisement because of the difficulties that direct and face-to-face recruitment may cause. The perceived difficulties were related to the stigma of urinary incontinence which was discussed in section 1.4. Other researchers have also used indirect methods, such as newspaper advertising and approach by third parties to advertise incontinence studies (Getliffe et al., 2007; Fader et al., 2014). Creative strategies to overcome potential communication difficulties within recruitment were developed using Gestalt theory, based on the work of Wertheimer (1912). Planning recruitment in this study was considered a 'wicked' problem. 'Wicked' problems were originally defined by Horst and Webber (1973) to describe the most complex engineering problems. These problems do not necessarily have one 'correct' solution, instead 'wicked' problems may have to be addressed by a number of solutions to meet the differing needs of the end user. 'Wicked' problems recognise the complexity of the systems in which the problem is situated. The concept of a 'wicked' problem has been adapted by many authors, including Farrell and Hooker (2013), to illustrate its usefulness to other complex design and science problems.

**Table 7 Advertising strategy**

Strategy	Example placement
<b>Posters</b>	Toilet cubicles – GP surgeries; community halls; places of worship; local businesses, sports venues
<b>Email</b>	Via gatekeepers – Community groups; sports clubs; new parent groups; women-specific organisations; activity groups.
<b>Leaflets</b>	Handed to individuals in face-to-face encounters. Displayed in instances where posters could not be used. Mailed to potential participants after initial contact.
<b>Articles in press</b>	Article published in North Leeds Life magazine and on associated websites.
<b>Presentations</b>	Information given to groups of women in pre-organised meetings; research events
<b>Websites</b>	South Leeds Life University of Leeds
<b>Twitter</b>	University of Leeds tweeted information linked to university website information
<b>Word of mouth</b>	Women gave study information to others in their networks

Using a number of theoretically informed approaches from Gestalt, five recruitment posters and a number of other communications were developed (Appendix C.2). The posters used a uniform layout, simple language and bold colours. In a society where people can be bombarded with visual information, informed decisions regarding the way in which to communicate the study had to be made. The aim of the recruitment posters was to enhance the message to be conveyed. This included not only the text but the way in which text was presented. Crucially, blank space is essential to meaning making and was therefore considered a design element in its own right (Wong, 2010). Several Gestalt theories were applied to the poster designs. “*Pragnanz*” suggests that the whole is greater than its parts and is based upon the work of von Ehrenfels (1890), although similar ideas have been explored throughout history (Macnamara and Boudewijnse, 1995). Viewers instinctively search for a whole which has meaning to them. A ‘*good figure*’ has a boundary which acts as a closure to the whole (Koffka, 1922). *Pragnanz* was considered in two ways, firstly, the posters were printed within

a white border to frame the design, and secondly colour contrast was used to direct viewers towards the most important information, facilitating interpretation by highlighting the key elements of the design.

Clustering information that 'belongs together' is another technique to assist the viewer to make sense of information. The law of proximity (Wertheimer, 1923) states if there is too much distance between objects they will be considered distinct (Lidwell et al., 2010; O'Connor, 2015). Titles and subtitles were placed closely together, as were the contact details provided. The colours used for the titles and subtitles also served to reflect '*common fate*', which proposes that objects of differing colour will be considered separately, despite being grouped by proximity (Luria and Vogel, 2014).

Using appropriate colour and shapes ensured that a figure-ground segregation occurred, meaning that the background and the foreground of the design were distinct from one another. Lighter and more saturated colours work well for figure objects, whilst darker colours tend to recede into the background (O'Connor, 2015). The posters for this study used yellow-orange and white for the foreground objects and black for the background. These colours are the corporate colours of the School of Healthcare and therefore also had associative value. The benefit of this colour palette was that it was possible that it would generate fixational reflex due to the high contrast, despite having only indirect influence on the oculomotor system (Tse et al., 2002; O'Connor, 2015).

In his seminal paper, Koffka (1922) also described images as having '*associative value*'. In this study, the association of images related to continence were assumed to have largely negative or stigmatising associations and therefore removed from all recruitment materials. Table 8 shows some of the techniques which were employed and how they benefitted communication. Posters were displayed in toilet cubicles, with twelve tear-off strips displaying contact details. These enabled interested individuals to make email or telephone contact at a time convenient to them.

**Table 8 Poster design techniques**

Concern	Design feature	Solution	Benefit
<b>Cultural norms</b>	Images <i>Associative value</i>	Images directly related to UI were not always culturally appropriate, so removed from all posters.	Less likely to offend different cultural groups.
<b>No images on posters</b>	Use of colour <i>Pragnanz</i> <i>Common fate</i>	Colour and shape were used to draw the viewer's eye around the poster and to make it appear attractive from a distance.	Posters more distinctive.
<b>Colours associated with urinary incontinence and absorbent products</b>	Colour palette refined <i>Pragnanz</i> <i>Associative value</i>	Light blues, red and yellow were removed as these were perceived to have some negative connotations.	Colours with no association to the topic were used, reducing stigma.
<b>Stigmatising condition</b>	Language <i>Associative value</i>	Highlighting urinary incontinence made viewers wary of reading the entire poster. 'Leakage' and word play used instead.	Language barriers removed, so subject was understandable and more acceptable to a general audience.
<b>Engagement</b>	Posters adapted for site specific requirements.	One successful research poster used padded fabric. Viewers were encouraged to touch the poster.  Posters to be displayed in toilet cubicles were designed specifically for that location.	Providing a reason to be close to the poster reduced stigma and increased engagement.
<b>Time limitations</b>	Bold headings <i>Law of proximity</i> <i>Common fate</i>	Headings were used to minimise the time needed to get an overview of the study.	Posters could be scan-read in a matter of seconds.
<b>Public identification</b>	'Ready-to-go' contact details <i>Law of proximity</i>	QR codes were used. Tear off strips were added to advertising posters	Viewers could quickly take contact information and respond later.

### 3.6.1 Use of gatekeepers

Gatekeeper, in this study, refers to a person or persons who had the authority to provide assistance to the study on behalf of an organisation. Gatekeepers provided access to women by giving opportunity to advertise the study through a range of methods including posters and group emails (Saunders, 2006). Gatekeepers in this study included practice managers,

receptionists, and GPs working in primary care centres, business managers, owners and administrators. Gatekeepers only enabled advertising of the study within community-based businesses, organisations and groups; participants were self-selecting and were required to initiate contact to express an interest in the study.

Gatekeeper engagement in research has previously been considered a linear process at the front end of data collection, which facilitates the ability to conduct studies effectively (Green and Thorogood, 2014). A linear approach suggests that after contact has been made with a gatekeeper, agreement will be reached and result in the necessary action. However, as others have found, within this study gatekeeper engagement sometimes required ongoing contact and negotiation before action took place, which impacted on the research process (Magolda, 2000; McAreavey and Das, 2013).

Engaging with gatekeepers to advertise the study was imperative to ensuring that the study was advertised widely, to as many women as possible. Negotiating with gatekeepers took considerably more time than had been originally planned for, which will be discussed further in Chapter 6 (section 6.9). Bonevski et al. (2014) found through their systematic review that employing community partnerships was a successful method of recruiting hard-to-reach populations, but that additional time is required for recruiting in this way.

### **3.7 Methods selection**

Understanding attitudes of women experiencing urinary incontinence required a methodology which took into account some of the perceived requirements of the hidden population, whilst also providing a means of collecting appropriate and reliable data (Crowley, 2007).

As outlined in section 3.2.4 a pragmatic worldview was adopted to facilitate study design. Prior to selecting methods thought was given to various

theoretical approaches and methodologies which could uncover the experiences of women including ethnography, participatory action research and grounded theory. These approaches could have elicited data which would have answered the research aim. Consideration for their use and justification for not using these approaches are given in Chapter 4, section 4.2.1. The following sections explain the methods chosen and justification for their selection.

### **3.8 Qualitative research**

Qualitative research increases knowledge through depth of understanding and is largely concerned with interpretation of textual data (Pope and Mays, 2006). There are several philosophical stances such as interpretivism, constructivism and idealism compatible with qualitative research (Schnelker, 2006; Bourgeault et al., 2010, pp.128-130; Petty et al., 2012). Qualitative research seeks to uncover the meaning behind data that is collected from individuals (Berg and Lune, 2014). To understand meaning the researcher must have awareness of their own and others understanding of relevant concepts, and aspects which are likely to affect portrayal of meaning; for instance, differing worldviews, motivation and recall (Hollway and Jefferson, 2000, pp.11-26).

#### **3.8.1 Justification of qualitative research to this study**

Using qualitative methods for this research was imperative, to complement quantitative research which already exists. Whilst quantitative studies may consider social factors, interpretative approaches are necessary to understand why certain groups behave in certain ways within their social structures (Williams and Elliot, 2010). Using qualitative approaches to contextualise women's experience is particularly important when hoping to understand experience of absorbent product use. In describing individuals' experience qualitative findings may be considered transferrable to similar

situations (Lincoln and Guba, 1985). The credibility of qualitative research is maintained by producing a study which implements measures of validity and reliability throughout the course of research, including ensuring '*methodological coherence*' by use of iterative practices (Morse et al., 2002, pp. 18). The methods selected will be described in the following sections.

### **3.8.2 Interviews**

As little is known about the population of women who experience urinary incontinence other than those who seek healthcare, it was appropriate that qualitative research informed this study. It was important that depth of understanding was gained before breadth, to ensure that data would adequately reflect a range of views. Interviews were deemed to be the most appropriate way of collecting data, after considering a number of data collection methods. One-to-one semi-structured interviews were undertaken in the School of Healthcare or in participants' own homes. Interviews used a topic guide that had been piloted by the reference group. Interviews lasted between fifteen minutes and 105 minutes; the average approximately forty minutes. Interviews were recorded onto a digital recorder and the recordings downloaded to the University of Leeds M Drive. Further explanation of the qualitative phase of the study can be found in section 4.2.

### **3.9 Q study**

Q methodology was developed by William Stephenson in the 1930's (Watts and Stenner, 2012, pp.7). It allows a systematic method of objectively categorising subjectivity (Simons, 2013). Stephenson proposed that 'operant subjectivity' could be measured objectively; that research participants' attitudes were measurable. Rather than the subject of study being the variable the participant is the variable, allowing participant attitudes to be characterised using factor analysis.

### **3.9.1 Q-sort method**

In Q methodology, data is primarily collected using one method, the Q-sort. Q-sorting involves the distribution of pre-defined statements into a grid which represents a quasi-normal distribution curve (Thomas and Watson, 2002). Participants were asked to rank forty-three statements by agreement, culminating in placement onto the grid. A more detailed description of the process of Q-sorting can be found in 5.5 and 5.9.1. A condition of instruction was given to participants to help them to categorise the statements in accordance with the research question (Baker et al., 2006).

The Q-sort data was strengthened by additional data collection (Ernest, 2011). In this study a booklet was provided to participants, to allow them to write anything significant about their sorting choices or views on statements (section 5.9.4). The booklet was given to the participants at the start of the Q-sort, however most chose to wait until after the Q-sort had been completed to write anything in it. In addition, brief field notes were made which enabled significant ranking decisions from a researcher perspective, to be recorded. Additional data relating to decisions about the placement of statements within the grid enhanced analysis and interpretation (Malia and Bennett, 2011).

### **3.9.2 Justification for using Q methodology**

Q methodology is a particularly fitting methodology for this research because Q enables attitudes to be understood without personal experience having to be verbally disclosed by participants. This is useful when tensions may exist between the personal and the social understanding of an issue (Stainton Rogers, 1995; Bryant et al., 2006). Q methodology has previously been used in health research to successfully gain understanding of patient and professional views (Westbrook et al., 2013). It has also been shown to reduce social-desirability responses by participants (Fluckinger, 2014).



Forced categorisation of statements, taken from pre-existing data allows women to express their views, without the need for in-depth discussion or personal disclosure. In the context of the hidden population, reducing the risk of disclosure may be of benefit to some potential participants.

Q methodology provided opportunity to add to the evidence base in a novel way. Previous research by Herron-Marx et al. (2007) on women's experience of postnatal perineal and pelvic floor morbidity, used Q methodology to explain women's attitudes retrospectively. No other study has been found which considers women's experience of urinary incontinence using Q methodology.

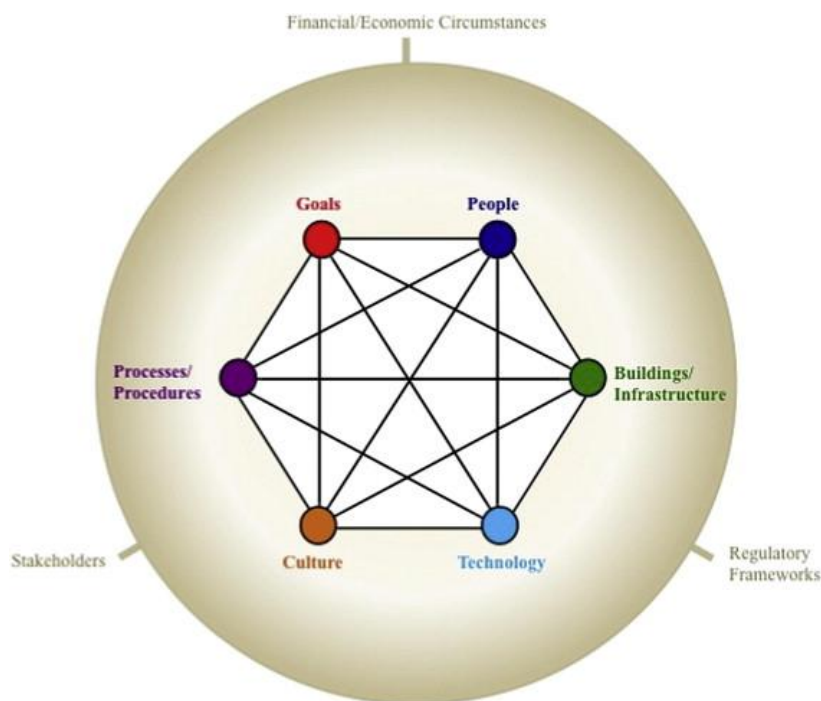
### **3.10 Sociotechnical design**

A sociotechnical design model was used to frame the methods and data collected. Sociotechnical design theory has been used previously in health research and in design industries to create and analyse systems and products (Sheehan et al., 2013; Ulucanlar et al., 2013). As it was hoped that the findings of this research could be useful to both healthcare and the absorbent product industry, a model which could be understood by both was adopted. Sociotechnical design theory can be implemented in research at various stages; at the planning stage as a methodology, at the design stage as a tool for implementation, or at the reflexive stage as a method of analysis.

The nature of a sociotechnical design model is fundamentally objective. Similar to Latour's Actor-Network Theory (ANT) (Latour, 2011), sociotechnical design recognises the human and material actors in a system and enables policy-makers and designers to create systems which are integrated and useful within a social context. Actor-Network Theory can be used to frame sociotechnical systems by recognising that behaviour of individuals is not always 'optimal', and is affected by presiding cultural systems (Kaghan and Bowker, 2001). Often sociotechnical models promote either technical systems or the actors using the systems (de Bruijn and

Herder, 2009). A model was chosen for this study which considered both aspects equally. The model used identifies six nodes and three external factors which impact sociotechnical systems (Figure 4) and is taken from Davis et al. (2013). The key difference between this model and other similar models is the importance of the relationship between each node. Each of the nodes has bearing on the others and should not be considered as an isolated concept.

The model was used as a framework for methods, by providing a basis for the interview topic guide, establishing Q-sort statements and for analysis of data. Consideration was given to each of the six nodes when designing questions and statements for each of the data collection methods.



**Figure 4 Sociotechnical system model. Davis et al (2013)**

### **3.11 Justification of multiple methods research**

The plurality of the objectives meant that two different approaches to collecting data would allow greater understanding to be gained. Using

multiple methods has been used previously to illicit understanding of women's experience of absorbent products (Getliffe et al., 2007; Fader et al., 2008a). Table 9 shows how each of the objectives were addressed by the methods employed. Undertaking the study using a single qualitative method would not have provided the data necessary to develop the attitude characterisation that is possible using Q methodology. Using Q methodology alone could have affected findings by producing characterisation based on statements collected from limited or unsuitable evidence. Therefore use of both approaches was perceived to be suitable to meet the aims of the research. As suggested by Bryant et al. (2006), Q methodology enables attitudes to be elicited using terminology which is accepted by participants. Terminology was highlighted as a key issue by the reference group, therefore using a multi method design allowed the development of statements which were pertinent to the population under investigation, not only in content but also in phraseology. Further discussion about statement development can be found in sections 5.4 and 5.5. A number of social influences may affect understanding of urinary incontinence (Hägglund and Ahlstrom, 2007; Bradway et al., 2010; Burr, 2015), therefore use of qualitative interviews and Q methodology enabled the social aspects to be explored further (Stainton Rogers, 1995; Churruca et al., 2014).

Both methods, qualitative interviews and Q-sorting can be used in isolation, but used together they can produce findings which enhance one another. The use of multi method and mixed method designs in social research is well established. Using qualitative approaches to inform a Q study has been carried out previously by others looking at sensitive subjects (Denning et al., 2013; Hill et al., 2017). Collecting and comparing two types of data provides depth, highlighting findings which corroborate, but also present findings which have little or no synergy, enabling identification of future areas for research (Creswell and Plano Clark, 2011). This comparison is known as triangulation, furthering understanding of the different dimensions within a topic (Moran-Ellis et al., 2006).

**Table 9 Overview of the multi methods design**

Study	Methodology	Method
<b>Pre-study</b>	Literature review of current evidence	Systematic search of electronic databases and grey literature. (Chapter 2)
<b>1a. Ref group</b>	Co-Production	Interviews and PPI strategy (Section 3.4 and Chapter 4)
<b>1b. Participants</b>	Qualitative methodology	Semi-structured interviews (Chapter 4)
<b>2.</b>	Q methodology	Q-sort Qualitative data from booklets (Chapter 5)
<b>3.</b>	Evaluation	Combined discussion of the Interview and Q studies (Chapter 6)

### 3.12 Plan of research

As is often the case in research using multiple methods, one aspect of the data collection informed the next (Creswell and Plano Clark, 2011). In this instance the qualitative interviews informed the Q-sort, as justified in section 3.11. Figure 3 provided an overview of the process of the research, including the input of the reference group throughout the research process.

After reference group members had been interviewed initially they provided feedback regarding recruitment and data collection methods. Alterations were made to the study design based on their feedback. Qualitative interviews then took place, generating data to be used in statements for the Q-sort. The Q-sort process was piloted by the reference group and two others, before being rolled out to participants. Once all data had been collected, analysis of the interview data was undertaken followed by analysis of the Q-sort. After findings had been generated for both the interview data and Q-sort, they were integrated. The reference group were asked for their feedback again after integration of findings. Changes were made based on

their feedback and a combined evaluation of the study as a whole was conducted. This is presented as a discussion in Chapter 6.

### **3.13 Ethical approval**

Ethical approval for the study was sought from the School of Healthcare Research Ethics Committee. Approval was gained in two stages. Firstly approval was granted for working with a reference group (SHREC/RP445/09.06.14). Approval for the main study was sought separately, inclusive of both studies (SHREC/RP/492/27.02.15). Approval letters are contained with Appendix B. Risk assessments were carried out as part of this process. In accordance with the ethical approval given, only participants with capacity to consent were included in the study.

## Chapter 4 Interview phase

### 4.1 Introduction

This chapter describes the interview phase in greater detail than was provided in the previous chapter. The interview phase builds upon the work of Getliffe et al. (2007) in seeking to understand women's experience of using absorbent products for urinary incontinence in contemporary British society. Getliffe et al. (2007), whilst focusing on the impact of absorbent products, found that the data drew out themes which related specifically to the psychological and social impact of urinary incontinence. Moreover, the themes which related specifically to absorbent product use contained data which related to social impact of incontinence, for example, the need for discretion. Therefore in this study it was important to recognise that the experience of urinary incontinence was fundamental to gaining a better understanding of women's use of products. Whilst the experience of urinary incontinence and product use have been considered separately in previous studies, it was important based on the literature search to gain a better understanding of these aspects of incontinence together by developing an integrated question that addressed both aspects. The question developed for the interview study addressed the overall aim of the research by considering the first two research objectives. The research question for the interview study was "what are women's experiences of urinary incontinence and absorbent products?"

Several recent qualitative studies undertaken in the UK regarding urinary incontinence have tended to focus on aspects of intervention or management strategy efficacy (Basu and Duckett, 2009; Booth et al., 2009; Farrington et al., 2016). While these are important areas of concern for clinicians and other stakeholders, there is less evidence for understanding what women living in the UK think about incontinence independently of healthcare intervention. There are studies conducted outside of the UK which focus on body image; culture; stigma; and management strategies for example (Lowder et al., 2012; Siddiqui et al., 2012; Pakgohar et al., 2015b;

Southall et al., 2015). Although this evidence may be pertinent to British women, transferability is unclear due to lack of evidence which could substantiate how cultural differences impact women's experience of urinary incontinence. Those researchers who have considered culture as an important aspect of incontinence experience in the UK have focused on South Asian populations (Sange et al., 2008; Doshani et al., 2009b). The UK evidence base requires strengthening through additional qualitative studies, so that health services can be better prepared to meet the needs of these women, particularly those who do not actively engage with healthcare (Shaw et al., 2008; Doshani et al., 2009a).

The chapter begins by giving an account of the methods used, including an in-depth explanation of the analysis approach. Following on from this, findings resulting from the analysis will be presented, before a discussion of the findings will explore them in relation to the literature. Reporting within this chapter follows the relevant standards for reporting qualitative research (O'Brien et al., 2014). The chapter will end with a summary.

## **4.2 Methods**

### **4.2.1 Qualitative approaches**

As explained in Section 3.7 a number of qualitative approaches were considered prior to method selection. From a philosophical view it could be argued that ethnography might be the most appropriate qualitative methodology to answer the research question as lived-experience is central to ethnographic research (Koro-Ljungberg and Greckhamer, 2005). Despite theoretical synergy with the aims of the research, ethnography uses data collection methods not feasible in this study, requiring sustained contact with participants in their daily lives (O'Reilly, 2008).

Other in-depth methods were also considered, including phenomenology and participatory action research. Classic phenomenology requires the researcher to bracket their experience to fully engage with the data, and is at odds with the objectivist approach of socio-technical theory (Belousov, 2016). Whilst there are methodologists who have adapted the methods to

take into account the difficulties associated with Husserl's early approach to phenomenology, it remained incongruent with the objectives of the study because of the philosophical position required to undertake such research (Groenewald, 2004; Wagstaff et al., 2014).

Participatory action research provides opportunity for participants and the researcher to reflect on current practice or circumstances to enable change (Schneider, 2012). Power sharing between participants and the researcher is common in this type of research; participants are involved in the whole process of research including data collection and analysis (Baum et al., 2006). As an exploratory study without an aim of facilitating change, participatory action research was not a suitable approach for the study.

Instead, the approach taken used the work of Cunliffe (2011) as a foundation to select the most appropriate methods for this study. Cunliffe (2011) challenges the perception of binary approaches to methods and the paradigmatic divide by highlighting 'grey areas' which may be ignored by researchers. Taking a progressive approach to method selection was particularly pertinent to this research because of the topic of interest. Engagement with a hard to reach population to explore a sensitive subject required careful consideration. The decisions made with regards to method selection ensured the yield from the research was appropriate to population under investigation. Within this research a 'grey area' was highlighted that suggested that the study could not be conducted reflexively because of the philosophical basis required to answer the research question (Cunliffe, 2014). Reflexivity is not researcher-focused but based on the research process and data (Alvesson, 2011). It seeks to open possibilities rather than explain 'truth' (Alvesson and Sköldböck, 2000). Reflexivity can only be fully engaged when it is bidirectional (Engward and Davis, 2015). This was not possible because of the fixed nature of some aspects of the study. Therefore a reflective approach was taken which facilitated critical on-going learning and development of the project. Reflection in healthcare enables the practitioner, in this case the researcher, to learn from their experience and to improve their practice by making links between theory and real-world experience (Jasper, 2003). Using a retrospective approach to understanding action and events, it was envisaged that subsequent analysis of the study



would uncover areas for future development (Burns and Bulman, 2000). Using Cunliffe (2011) as a guide, it was ascertained that the qualitative study should be conducted from a subjectivist stance, recognising the appropriateness of an interpretative ontology within the pragmatic epistemology required for the topic. From this basis, methods were selected for the project, these will be explained in the following sections to ensure replicability.

#### **4.2.2 Semi-structured interviews**

Semi structured interviews, also known as semistandardized interviews, are used in qualitative research to elicit in-depth information from participants (Turner, 2010). Interviews enable the subjectivity of the participant to be explored thoroughly. Opportunity for ongoing dialogue between the interviewer and researcher allows additional information to be requested and clarification to be gained, capturing subtleties (Rossman, 1992; Stokes and Bergin, 2006; Berg and Lune, 2014).

Semi-structured interviews provide a moderate level of standardisation for interviews. Rather than use set questions, a topic guide is used to direct the interviews (Yin, 2015). This level of standardisation facilitates analysis between data from different participants. Unlike structured interviews which do not deviate from predefined questions, questions are developed and adapted during data collection (Berg and Lune, 2014).

Allowing some deviation within broad topics ensures that aspects which may not have been previously considered by the researcher to be explored through the interviews, and may be considered a form of early analysis (Yin, 2015). Themes which are illuminated in one interview can be taken forward into future interviews, testing the transferability of the themes prior to full analysis taking place. The process of undertaking the interviews is described further in section 4.3.

### **4.2.3 Thematic analysis**

Thematic analysis is the process of analysing data to examine similarities, differences and relationships between data sets (Gibson and Brown, 2009). Categorisation is conducted through coding of the data and collation into themes. Unlike other forms of analysis, thematic analysis is a tool which is not constrained by theoretical underpinning, making it applicable across a range of methodologies (Clarke and Braun, 2017).

Thematic analysis was considered appropriate to this study because of its previous application to inductive and deductive approaches (Selvam and Collicutt, 2013). This made thematic analysis suitable for use with the nodes of socio-technical design model which provided a priori codes, whilst also giving freedom to explore other types of categorisation through development of inductive codes (Braun and Clarke, 2006; Guest et al., 2012).

Thematic analysis can be successfully used on small or large data sets, due to the flexibility in its application. As recruitment to the study was recognised as a potential challenge, thematic analysis was a suitable method regardless of number of participants engaged in the project (Cedervall and Åberg, 2010). Due to its enduring relevance across epistemologies and research methodologies, there is little consensus about application of thematic analysis (Nowell et al., 2017). Guidance from a number of sources was sought to develop the process of analysis which was used in this study (Alvesson and Sköldberg, 2000; Silverman, 2004; Alvesson, 2011; Gibson et al., 2012; Clarke and Braun, 2017). Despite the lack of consensus it was important to have a clear process of analysis to aid replicability. The process of analysis used within this study is explained further in section 4.4

## **4.3 Undertaking interviews**

The integrated research question underpinning the qualitative study was “what are women’s experiences of urinary incontinence and absorbent products?”. Appropriate methods were selected to answer the research question. The use of qualitative interviews was appropriate to provide in-depth understanding of women’s experiences of urinary incontinence and

absorbent products prior to the Q study. The purpose of the qualitative study was twofold. Firstly it was able to meet the first two objectives of the research, by answering the research question noted previously. Secondly it was a source of information for the subsequent Q study. Data gained in the interview phase was used to guide statement development for the Q-sort. After statements for the Q-sort had been devised, the interview data was analysed in full and the findings compared with the findings of the Q-sort.

Women were invited to speak about their experience of leakage rather than incontinence. Leakage was perceived by reference group members to be more widely understood and more socially acceptable than the term incontinence. Due to the lack of evidence regarding women's attitudes to urinary incontinence from a social perspective rather than a healthcare perspective, it was important to gain as much depth of understanding on the topic prior to the Q-sort being carried out. Using a method which allowed women to express their views on the subject was imperative. Interviews provide authenticity by enabling participants to describe their thoughts, behaviours and experiences within a confidential setting (DiCicco-Bloom and Crabtree, 2006). The depth of understanding provided by interviewing participants individually may not have been as easily gained through other qualitative methods, for example focus groups, due to the sensitive nature of the research topic. However, employing qualitative interviews to explore sensitive subjects also creates challenges. Speaking openly to a researcher can be difficult for some, and steps were taken to overcome some of these potential problems. The following list highlights some of the actions taken to mitigate for some potential participants' perceived concerns and to ensure an ethically sound study.

- Use of appropriate, but non-ICS standard terminology
- Overt promotion of confidentiality assurances
- Opt-in recruitment strategy
- Opportunity to withdraw data after data-collection had concluded
- Use of telephone interviews for those who did not want to meet face-to-face

Interviews with reference group members were conducted in August 2014. Interviews with study participants were conducted between April and May 2015. Nine interviews were conducted face to face and two were conducted by telephone.

#### **4.3.1.1 Topic guide**

Topic guides are useful aides-mémoires to help guide the interviewer. Using a topic guide to direct interviews enables clear, open-ended questions to be used, rather than using a more ad-hoc question format. The guide helps the interviewer to devise a logical structure for the interviews, so that a comfortable interaction with the participant can occur (Doody and Noonan, 2013).

The interviews were semi-structured using a topic guide created using the nodes of the sociotechnical design model (Appendix D.1). Standardised open-ended questions were created, with example prompts for additional questioning (Turner, 2010). Prompts were also directed by reviewing the literature and by responses given by previous participants. Including additional prompts iteratively allowed themes to be explored which had not been identified during the literature search (Price, 2002). The topic guide was piloted by the reference group. Amendments to prompts were made, as well as consideration given to interviewing style in response to their interview data and to feedback they provided about the interview process.

King (2010) suggests that interviews should be commenced with a question that provides an easy introduction for the participant, with more sensitive questions later on. However, due to the nature of the subject there was no obvious 'starter' question. Instead, interviews commenced by ensuring that participants were happy to begin; then they were asked "please could you tell me a little about your experience?", as an introduction (Qu and Dumay, 2011). This enabled participants to set the tone and direction for the interview. Their response enabled a better understanding of their experience to be gained. Avoiding incontinence related language in initial questioning took into account the sensitivities women may have about addressing the subject directly (as identified through an analysis of initial emails from

potential participants), giving participants opportunity to begin their narrative wherever it felt most appropriate. This is particularly important when interviewing on sensitive subjects, as participants may feel anxious and conscious of power imbalances with the researcher (Elmir et al., 2011).

### **4.3.2 Inclusion criteria**

Inclusion criteria for the interview participants were the same for both stages of the main study. Participants were required to be –

- Female
- Aged 18 or over
- Experiencing urine leakage
- Residing in the Yorkshire and Humber region

### **4.3.3 Exclusion criteria**

Women who met the study inclusion criteria, but who were unable or unwilling to provide informed consent were excluded from the study. Women who were unable to understand spoken and written English were also excluded, as no resources for translation were available.

### **4.3.4 Consent process**

An informed consent process is essential to ensure that research participants understand what they are undertaking and the risks involved (Hardicre, 2014). Clear and appropriate information was provided which outlined the purpose of the research. The participant information sheet gave details of the researchers involved in the study, what participants would be expected to do, what would happen to the data they provided and what to do if they chose to no longer be part of the research. Women were provided with participant information sheets via email or by post. They were given opportunity to reread (or have read aloud to them) the participant information at the beginning of the interview. After this, participant questions related to the study were answered, prior to informed consent being gained.

#### **4.3.4.1 Face-to-face Interviews**

When participants were satisfied with the information given, they were asked to read the consent form and sign their initials after each clause. Participants provided a full signature and date at the end of the document. The consent form was also signed and dated by the researcher.

In addition to standard consent approvals to take part in the research, consent was also requested for anonymised data to be used again by the lead researcher and shared with others during future academic work. As the evidence base for this population is small, there may be opportunity to conduct secondary analysis on the data provided during this study. The School of Healthcare Research Committee did not approve a request to allow the data to be used by other researchers in future due to concerns about maintaining confidentiality.

#### **4.3.4.2 Telephone Interviews**

When telephone interviews were conducted a second protocol for gaining informed consent was used. This protocol was approved by the School of Healthcare Research Ethics Committee. Each clause of the consent form was read to the participant and they were asked to state whether they agreed with it. Every clause was initialled by the researcher to indicate the verbal consent provided. Unlike participants of face-to-face interviews, participants undertaking telephone interviews were given the option to remain anonymous to the interviewer by not providing their name. None of the telephone participants chose to remain anonymous to the researcher, instead preferring study anonymity, as assured to all participants.

The consent procedures conducted over the telephone were not recorded, as participants had not consented to audio recording at the start of the telephone call. Audio recording did not start until the start of data collection as per the consent provided.

#### **4.3.5 Consideration of quantitative measures**

Consideration was given to use of a quantitative tool alongside the interviews, to provide further information regarding the leakage experienced

by participants. One such measure has been developed by the International Consultation on Incontinence (ICI), covering a range of symptoms. The ICIQ-UI short form questionnaire, measures symptoms, quality of life and treatment outcomes (Avery et al., 2004). This tool, originally designed for clinicians is also favoured by researchers; using only four items it can be completed quickly and in conjunction with other data collection methods and tools (Rotar et al., 2009; Svihra et al., 2012).

Permission was sought and gained from the International Consultation on Incontinence Modular Questionnaire (ICIQ) Advisory Board to use the ICIQ-UI SF questionnaire, on the understanding that feedback would be provided to the Advisory Board about its use within the study in due course (Appendix D). Using the ICIQ-UI SF within this small study would not have produced any statistically significant data due to the number of women expected to participate. Its use may also have inhibited the qualitative data collection, by immediately connecting urine leakage with urinary incontinence. Early hypothesising with the reference group suggested that such associations may not be made by women who have not sought help.

The reference group piloted the use of the ICIQ-UI SF. Having completed the questionnaire, they felt that some of the items were unclear and did not fully represent their leakage experience. In particular the options of frequency were not perceived to be continuous as ordinal statements had possible answers missing. The lack of a 'twice a day' option in relation to frequency was noted by one reference group member. One reference group member raised the concern that answers to the questionnaire may be 'idealised' by some participants. Certain types of incontinence (and associated connotations) may be more acceptable to some women, leading to the possibility that data provided in the questionnaire might not be congruent with lived-experience. With this in mind, the use of the questionnaire was removed from the study and feedback was provided to the questionnaire authors.

### **4.3.6 Sample characteristics**

Including interviews conducted with the reference group, the sample consisted of eleven women. All lived in their own homes and were considered to be living independently.

### **4.3.7 Demographic data**

Demographic information about participants was collected, which was unrelated to their experience of leakage. This was a four-measure tool identifying

- ethnicity
- age bracket
- household income
- employment status

These measures were considered important in helping to analyse the data collected. Categories of ethnicity were taken from the 2011 Census, as this was perceived to contain a comprehensive list (ONS, 2011). To maintain participant's right not to answer, every question provided a 'prefer not to say' option. The demographic data of the interview participants are collated in Table 10. The details of the two reference group members who participated in interviews are also included in this table. Demographic options which were not selected by any participant (for example particular ethnicities) have been removed from the table for clarity, but other options were available for participants to select from during data collection.

#### **4.3.7.1 Understanding the demographic data**

All interview participants described themselves as white and from the United Kingdom. The majority of participants willing to answer the question about household income also had above average household income, based on data from the Office of National Statistics (Stoyanova, 2016).



Despite participants reflecting a wide age range, interview data from these participants is only able to reflect a small sub-population of women within the geographical area from which they are recruited.

Some participants felt that their occupational status could not be adequately defined by one descriptor, therefore the number of occupations undertaken by participants was greater than the number of participants.

**Table 10 Demographic data of interview participants (including reference group members)**

Measures	Participants
<b>Ethnicity – White</b>	
<b>British/ English/ Welsh/ Scottish/ N. Irish</b>	11
<b>Age</b>	
<b>30-39</b>	2
<b>40-49</b>	2
<b>50-59</b>	1
<b>60-69</b>	1
<b>70-79</b>	4
<b>80+</b>	1
<b>Employment Status</b>	
<b>Employed full-time</b>	2
<b>Employed part-time</b>	2
<b>Student</b>	1
<b>Self-employed</b>	1
<b>Voluntary</b>	1
<b>Home-maker</b>	3
<b>Retired</b>	6
<b>Household income (£)</b>	
<b>0-10,000</b>	1
<b>10,001-20,000</b>	1
<b>20,001-30,000</b>	2
<b>30,001-40,000</b>	0
<b>40,001-60,001</b>	2
<b>60,001-100,000</b>	3
<b>Prefer not to say</b>	2

Appreciating that women did not want to be defined by one occupational description was useful in understanding more about the participants' narratives. Whilst the data may appear to be unclear, having permitted participants to select all that they felt applied to them, in its raw form the data provides a better understanding of motivations and temporal meanings of the interview data. Demakakos et al. (2008) showed that subjective social status in older age is an important correlate of health in ageing. The

participants who chose to tick more than one box may have done so to highlight their social utility, increasing their subjective social status and therefore maintaining continuity of narrative. Continuity of narrative and its importance to women experiencing urinary incontinence will be considered further in section 4.6.

#### **4.3.8 Data management**

Data was managed in line with University of Leeds policy and following the Data Protection Act (1998). Electronic data was stored on a secure, password protected University of Leeds server. Data in paper-format was stored in a locked cabinet on university premises. Personal details were kept separately from other data.

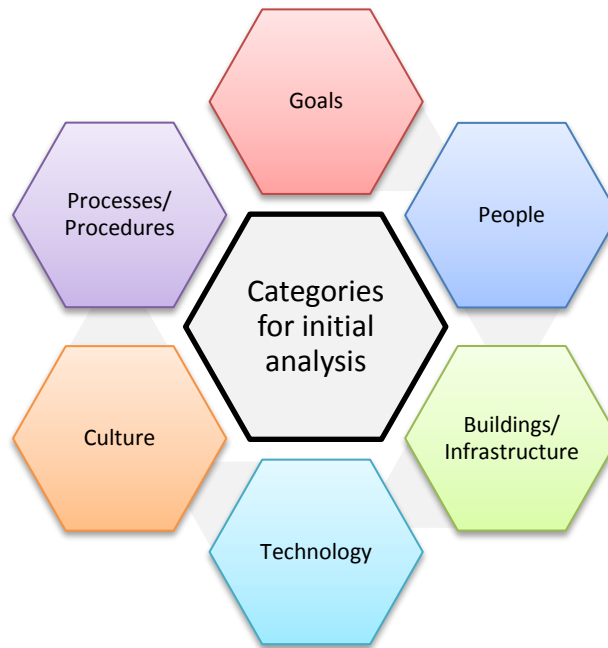
Digital recordings of interviews were made. Recordings were downloaded on to the secure server and transcribed verbatim by the researcher, providing additional opportunity to increase understanding of the data collected. After transcription all audio files were deleted.

### **4.4 Analysis**

Transcribed data was analysed thematically using NVivo 10 software (QSR International, 2013). Initially two analyses were undertaken, one that considered data relating to the experience of urinary incontinence and one that considered data relating to absorbent products. This ensured that should there be a distinction between experience of urinary incontinence and experience of absorbent product use it would become evident. Inductive codes were assigned to the raw data. Codes and early analysis were sense-checked by the PhD supervision team. Codes were iteratively developed through a process of categorisation which led to themes being generated. Further to these analyses, key findings from both analyses were then reanalysed to bring increased clarity to the themes. After each stage of analysis discussions with the supervision team ensured that findings were

corroborated by the raw data. The final thematic analysis which combined data relating to experience and product use is presented within this thesis.

In addition to thematic analysis a deductive analysis was also undertaken on data relating to absorbent products. Using the nodes of the sociotechnical design model data was stratified into six categories (3.10). The categories corresponded with the titles of each node (Figure 5).



**Figure 5 Categories for analysis taken from nodes of the sociotechnical system model**

The majority of data required categorisation within several nodes. This is in line with the use of the sociotechnical design model which recognises that social, organisational and technical processes impact one another (Challenger and Clegg, 2011). Data within each of the sociotechnical categories was then analysed using the socio technical design model as a framework to describe the experience. The findings from a sociotechnical perspective is presented in section 4.9.

## 4.5 Findings

After analysis, three main themes were identified which contained a number of subthemes, covering both the experience of urinary incontinence and the use of absorbent products. Together, the themes were able to meet the aim of the study, by describing women's experience of urinary incontinence and their use or non-use of absorbent products.

At a superficial level, there were distinctions that could be made between the data relating to experience and data relating to absorbent product use, but further analysis suggested that at a deeper level, there were themes which bound much of the data together. Experience of urine leakage and use of products were inextricably linked.

Table 11 shows the themes and subthemes of the data after analysis with a brief overview of each. The themes will be described in depth through the rest of this chapter. In addition to the three main themes, a further sociotechnical exploration of particular subthemes relating to product use was conducted. This is described in section 4.9.

To improve the clarity of the data presented and to protect anonymity some idioms and all identifiers have been removed from quotes. Table 12 explains the coding used for quotations.

**Table 11 Short descriptions of the integrated experience and product use themes**

<b>Major theme</b>	<b>Overview</b>	<b>Subtheme</b>	<b>Overview</b>
<b>Maintaining identity (4.6)</b>	Perceived threat from leakage determined how women chose to cope with symptoms, enabling continuation of an accepted narrative.	Cover Stories (4.6.1)	Aspects of life which enabled positive personal attributes to be promoted, despite leakage experience.
		Ageing and Gender (4.6.2)	Belief that leakage was due to the ageing process, a female-specific concern usually considered through a social lens.
		Challenges to identity (4.6.3)	Challenges to identity comprised negative connotations of leakage and absorbent product use, which was predominantly discussed in relation to others.
		Clothing (4.6.4)	Clothing was an often-compromised expression of identity, used as a coping strategy to hide leakage & absorbent products.
<b>Communication (4.7)</b>	Verbal and non-verbal strategies were used to cope with leakage and absorbent product use.	Terminology (4.7.1)	An important aspect of understanding experience, women often did not consider themselves 'incontinent' preferring other terms to express symptoms.
		Communication with others (4.7.2)	Communication styles differed depending on audience; participants used existing relationships to develop support networks.
		Non-verbal communication (4.7.3)	Non-verbal communication was used as a means of negotiating socially-challenging situations, in particular the emblematic value of absorbent products was context specific.
<b>Seeking help and information (4.8)</b>	Uncertainty about symptoms and professional support caused variation in help- and information-seeking by participants.		

**Table 12 Key to codes used for quotes**

Code	Explanation of use
<b>RF</b> <i>number</i>	Reference group member plus identification number
<b>P</b> <i>number</i>	Participant plus identification number
[ ] <i>square brackets</i>	Word added or changed to improve clarity of meaning or to remove an identifier.
( ) <i>round brackets</i>	Non-verbal information that provides additional depth to the quote
... <i>dots</i>	Indicates other communication occurring within the utterance but which would not have aided clarity of quote had it been included.

#### 4.6 Theme 1 - Maintaining identity

Maintaining identity was the first theme because of its importance to all participants. Despite differences between lived experiences of each participant, maintenance of identity overarched several aspects of these women's views in terms of understanding their experience and also how they coped with symptoms. This theme most clearly met the research objectives of describing and understanding women's experiences of urinary incontinence and understanding the use/ non-use of absorbent products to contain urine. It also provided congruence with the work of Getliffe et al. (2007).

Attempting to maintain identity was based on perceived threats from leakage. Efforts to maintain one's identity may account for the delay in help-seeking by many women (Minassian et al., 2012). Having an 'incontinent' narrative may be challenging for women, who may seek to normalise their experience and continue with their lives using coping strategies (Shaw, 2001). Coping recognises that changes are made when leakage is experienced, whether that is practical or psychological adaptation. Coping was employed with the aim of maintaining a recognisable self and social identity. This theme provided understanding of strategies used by women, including absorbent products, to maintain identity.

*“But you know, I think, you just have to, or I have this, not being a perfectionist any more, but just being barely adequate and you can’t be the perfect [partner], mother, [professional], friend, daughter, you can’t do it all...And it’s part of the expectations of what you’ve got and at least I’m healthy, a bit of wetting myself, that’s normal.” P02*

Coping can be defined as a *“person’s cognitive and behavioural efforts to manage the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the resources of the person”* (Folkman et al., 1986, pp.572)

Coping is not defined by the successful management of the stressful situation (Stroebe, 2011). Therefore what might be considered maladaptive coping strategies, are coping strategies nonetheless. Although participants spoke about a range of coping strategies, it was clear that strategies were multifaceted, and that not all coping strategies were recognised as such by some participants. Participants found coping strategies which were perceived to be least disruptive to their identity or routine.

Participants knew they weren’t alone in experiencing urine leakage but would sometimes seek reassurance. Paradoxically, the feeling of being alone was sometimes expressed alongside the assumption that they were one of a number of women in the same situation. Despite this, there did not appear to be an obvious collective identity that women sought to be part of.

*“...before I had children I didn’t have any problems (laughs), I’m sure that’s not, I’m not the only one with that...” P11*

Although not all participants knew someone else with the same experience, many sought to normalise it by attributing meaning, often through assigning causality or by generalising symptoms beyond themselves. Some suggested that perceptions of the issue by people in wider society might not be the same as their own. Finding reassurance by attributing meaning was important to all participants and was integral to maintaining identity.

Participants expressed beliefs about their understanding of symptoms, which were not necessarily congruent with the evidence-base on the subject. Even those participants who had knowledge of biological factors affecting symptoms sought to normalise and minimise their experience. Despite the normalisation expressed, some participants did question symptom frequency, but not cause.

*"... I'm not embarrassed...it's normal thing that a lot of people suffer from..."*

P14

*"...Some days actually it's worse than others and I can't, I can't really understand why." P07*

Coping strategies were employed to deal with the uncertainty caused by leakage. In addition to normalisation of symptoms, some participants expressed normalisation of absorbent product use. Their use was considered a way of exerting control of their chosen identity in a situation which may not always feel under control. Participants indicated that using absorbent products impacted on what they believed about themselves and what others may believe about them too. Even women who chose not to use absorbent products expressed views which suggested non-use was a negotiated process of maintaining control and continuing identity. When absorbent products were used, consideration was given to the type of product which would least challenge identity.

*"I mean if somebody knew I had a pad, I don't think I'd be that bothered really. It's more the embarrassment of 'oh, look, you've wet yourself', you knew you would and you still hadn't prepared, how stupid is that. It's a bit like not wearing a tampon, it's the same kind of, 'you expected it, why haven't you planned for it', sort of thing. I've stopped [carrying a spare pad] now actually. I did have one in my handbag for a long time um, but I've stopped doing it now and I just accept that. You know, my pants are going to have a small spot of wee on them most of the time." P02*

*"...It hasn't made me want to wear protection because I just, I hate it and it's sweaty and horrible and the thought of that makes, you know, is worse than*



*[a drop of urine in underwear], I suppose it's like insurance isn't it, sanitary protection [for urine leakage], I kind of don't want to take the insurance out yet (laughs)."* P09

*So I buy, I would buy night time sanitary wear if I was going [to exercise] because it's a little bit thicker, and it's got the wings usually, which kind of hold it in place....they're longer I think.... But I wouldn't buy something for incontinence because it just doesn't, it doesn't feel right and I don't, I suppose I don't, I don't want to go there, do you know what I mean? (laughs)"* P09

As illustrated by the quotes from P09 above, there were occasions that participants expressed conflicting views about products, making a distinction between products for menstruation and products for urine. The ways that the women chose products was related to the maintenance of their identity, and the minimisation of symptoms.

*"I decided I would start wearing ordinary liners... you know the day-to-day keep you fresh liners...so I wore them for a couple of years and then it was actually they're not enough anymore so then I got into the, you know, into the very thin [incontinence brand] ones... I started on them and yeah, sort of, you could probably wear one of them a day, where now it's probably you have to sort of like, three, four times a day, you have to go change it... But it's, I'm not into the fat ones, I'm still into the reasonably thin ones"* P08

*"You know, it was a few drips and I was on a very small pad. Afterwards it got worse ... Um, I've gone onto (sucks in breath) Do you know the drip system?... (laughs) right. I used to have, I used to get the [brand] one and a half, no, two and a half drips... and then I thought 'ooh these aren't so clever'....so now I'm on the four drip."* P07

A smaller, less absorbent product was sometimes prioritised over a larger one, particularly those products specifically designed for incontinence.

*“...but I’m choosing to wear a really thin pad...but I guess there is only so much absorbency that they can take cos I choose not to use the really thick [incontinence] pads” P03*

However sometimes women ‘experimented’ with a larger absorbent product and then used smaller ones as they became more familiar with their leakage experience; what caused symptoms to occur, severity and frequency.

*“I guess when it was bad I used proper incontinence pads... the [incontinence] type things, but not the massive great big ones, like the slim ones....Not the sort of thing you want visible in your shopping basket...But I did use those and then I just use the standard panty liners, cos you know it probably doesn’t happen very often...” P11*

Using a smaller product, particularly a product not even designed for urine, appeared to provide a sense that the leakage was minimal. Even if the leakage was not always contained by the product, the need for a smaller absorbent product was prioritised.

*“...I feel, well the sanitary towels that I use at the moment, I think they could be um, maybe more absorbent because even though they are very thin and I use the one with wings, the odd occasion, and it has been the odd occasion, they, it has leaked.” P03*

When severity of symptoms increased, larger (or incontinence-specific) absorbent products were used, with the anticipation that it was a short term measure.

*“So I suppose it’s improved and I don’t wear um [incontinence] pads.... And I’ve got some [incontinence] pads still in the cupboard but I won’t wear them on a regular basis.” P02*

Absorbent products enabled social control, however fear of visible signs of leakage were not fully eliminated through the use of absorbent products.

*“You know, it’s embarrassing sometimes if you’re out and you know that you’ve coughed and it feels a bit wet behind and you think” (looks behind shoulder to imitate checking whether anyone has seen) P07*

The need for secrecy was self-perpetuating. Use of absorbent products enabled the women not to have to confront dealing with the leakage in a way

which may involve others. Absorbent products allowed a socially continent narrative to be maintained.

*“...I went out.... And I put those [reusable absorbent products] on...and I thought ‘well, I am OK for the day’, you know, that’ll cope with any problem that I might have during, during, you know, five hours out [away from home]...”* P14

Although participants stated coping strategies which allowed them to maintain their identity, some women recognised a conflict between the identity they wanted and the identity they associated themselves with.

*“...because you kind of think in your head that you’re still like 21year old, you know, lovely, fluffy woman who’s capable...”* P02

Others gave accounts which appeared contradictory, possibly not recognising the apparent inconsistencies in their narrative.

*“well interestingly and thinking about it [...], I would have to say I don’t experience leakage at the moment.....”* P01 (continent identity)

*“Like last week (laughs) [...] I actually weed”* P01 (incontinent identity)

*“Yes, yes they are [comfortable – absorbent products]”* P13

*“I can’t bear to have them on longer cos [they’re] very uncomfortable”* P13

When asked about what the ideal outcome would be in terms of their leakage experience women did not always hope for improvement. In some cases maintenance of the symptoms was desired. Increased severity of symptoms was seen as a potential threat which might have to be dealt with by other coping strategies.

*“Maintain the situation, yes, I would be very happy about that. I wouldn’t want it to get any worse.”* P13

*“Just continue, until I suppose it got really where it was continual running and then it’s a different thing.”* P07

Very few participants believed that there would be possibility of regaining continence. Their understandings of leakage, or their experience of healthcare, had meant that continence was perceived to be not very likely.

*“well I’m probably gonna experience urine leakage for the rest of my life I think, unless I have an operation.” P03*

Although some participants had already sought healthcare and been discharged from services, they were unlikely to return for help (at least in the near future), believing that improvement of symptoms was now their responsibility.

*“I guess I would go back to my GP if it was kind of causing me a, an issue but at the moment I guess I think if I, I should probably just be doing my exercises a bit more frequently than I am” P11*

By reducing or having unrealistic expectations of cure, responsibility was negated. Women who did not seek improvement of symptoms were never going to be disappointed and their identity could remain unchallenged by engagement with healthcare. These women sought to maintain control of the situation, and therefore the direction of the narrative.

*“I want it to be instant. I want to go in somewhere, get all embarrassment out of the way cos you know, legs akimbo and whatever else...get all that sorted and then go ‘yeah we’re going to do this [curative treatment]’ Bumph...even if it hurts... It’s worked, it’s done, it’s sorted.” P08*

*“I can live with this, I just don’t think it’s worth it [accessing healthcare]...After going through what I’ve been through [with other health issues], it just isn’t worth it.” P07*

There was some ambivalence shown towards symptoms once an assumed cause, be that biological or social, had been adopted. Maintaining identity appreciated the need to have a standard ‘story’ by which women could attribute meaning to their experience. The following sub themes help to explore this further.

#### 4.6.1 Cover stories

Cover stories were used by many of the participants. In many cases cover stories were not untruthful, rather they highlighted a particular aspect of the narrative which participants felt most comfortable discussing. They provided opportunity for women to discuss the characteristics which they most wanted to be displayed in spite of, and because of, the leakage they experienced.

Other health issues were used as cover stories. Sometimes other health issues were perceived to be more acceptable and therefore would be used as a means to hide the urine leakage from others.

*"I'll say 'can you look after this [task]' you know, 'I need to go [to the toilet]; because the [employers] know that I've, um, I'm [having other health issues]...they think it's that...usually it isn't, it's usually that I need a wee"*

P08

Giving birth was often given as a cause for urine leakage and as a reason for its continuation, irrespective of whether help had been sought, or length of time since giving birth. Being a mother was a cover story which provided meaning.

*"I had very bad births. It went on for about two years after each of the births and ....it almost stopped.... And then I would say it started, probably, when I was [much older]"* RF1

In addition to cover stories which provided positive framing of leakage experience, participants also sought to show positive personal characteristics in view of their leakage experience. The behaviour of women had to be rationalised when they had behaved in a way which was not fully consistent with social norms. This did not mean that the behaviour was socially unacceptable; often in fact it would have not drawn attention to the women. However, participants who divulged these protective behaviours were very aware that if others' knew the motivation for their actions, they may not necessarily be perceived as acceptable. Often behaviour was characterised by the need for embarrassment to be avoided.

*"we'd been out for dinner and I went to the toilet...the whole thing [pad] collapsed and it was tiny little beads inside and it was all over the floor....so I*

*picked up as much as I could...and it was about the only time I wouldn't say what had gone on" P07*

Some women were able to admit they were embarrassed, others suggested they were not, but irrespective of how participants felt in any specific situation, the avoidance of negative feelings about self because of leakage was paramount. On occasion women wanted to maintain a continent-identity in social situations, which could be challenged by a number of factors including absorbent product use.

*"...I've got to be honest, it's a good job I'm thick skinned cos once one [absorbent product] fell out when I was wearing a skirt. And I was getting on to the bus. I just picked it up and got it. But if I was somebody who was really s (pauses), I mean, that would have been death to some people. Um, and that's it really. If I'm. If. They can improve the design [of products] but you know .....I had no choice when it was really bad [other than to wear pads]."*

RF1

Where as in other situations, women wanted to maintain social control of the incontinent-identity.

*"I actually bought (makes snoring noise) some [pelvic floor training] weights ... I didn't even use them. I gave them to a friend. I thought 'ooh gawd, I really can't be bothered'. No. Have you ever seen them? They sort of get bigger and bigger and I thought 'ohh'. I said 'do you want these?', she said 'have you used them?', I said 'no of course I've not used them!' (laughs) In fact we had a dinner party once and I brought them down, you see I'm just, I'm just not bothered. It's a good job. But I am just really am not, I just don't get phased at all" P07*

In addition to the cover stories, rationalising behaviour was a defence that women used within the interviews. Rationalising behaviour highlighted the most positive characteristics that women displayed in socially difficult situations. In some instances it was more important to avoid certain behaviours altogether, in particular modification of activities was discussed as a mode of protecting the socially-continent identity. Some participants didn't immediately recognise when they had modified activity to prevent leakage, particularly when it was perceived as minor modification.

*“No [modifications] (with great emphasis)...I actually, you’ve just, the only thing I wouldn’t, I don’t do star jumps any more, that’s the only thing I kind of...um, well, I can probably do a couple, then I have to stop, so you know that is adapting my activity levels, I can’t do that kind of bounce without worrying about things.” P11*

Others were very aware of modifications they had made to prevent symptoms occurring, but exhibited a level of defiance, ensuring that the narrative was not disrupted by leakage.

*“...I haven’t let it stop me [...] but it has meant that I’ve had to modify my behaviour, my choices” P09*

#### **4.6.2 Ageing and gender**

Previous research has shown women to understand urinary incontinence as a natural occurrence with age (Róin and Nord, 2015; Basu and Duckett, 2009). Participants in this study often viewed leakage as a female-specific problem related to various life-stages particularly child-birth and later life, and but suggested it was also influenced by lifestyle, for example weight or exercise.

*“..I think I kind of thought it was to do with old age, but I think that’s because now it’s very easy to think everything’s to do with old age.... But I suspect not...cos in my mind I am clear that it’s about having had children that that’s, you know bugged up my pelvic floor a bit” P01*

Despite attributing meanings to why leakage may occur, didn’t mean symptoms or managing symptoms were viewed positively.

*“My [older relative] had [UI] and I used to go to the clinic and get these pads for her...and I though ‘humph, I’ll never be like that’. Mmm, yes” (said ironically.) P07*

Although older participants were aware that some men might experience continence problems, male experience was viewed as a consequence of other health concerns, (a diagnosable medical condition) rather than as an

issue viewed through a social lens, which participants applied to their own experience.

*"...because they're saying about men's prostate problems...don't men dribble as well?"* RF1

Participants suggested there was some expectation that lots of women experience urinary incontinence, but that it wasn't inevitable.

*"In fact I, when I did the [run], think to myself, any women running this that's had a baby, it's quite likely that we are weeing our way around [the location]! (laughs) you know there's probably a lot of us in the same boat so um, but it isn't really talked about."* P09

Despite assuming that lots of women experienced leakage, participants did not consider it a shared experience between women. The reasons for this may be explained in the following subsection.

### **4.6.3 Challenges to identity**

In addition to attributing meaning with regards to themselves, women were also aware of challenges to identity because of negative connotations of leakage and absorbent products. Often these were not spoken about in relation to self, but 'others' using hypothetical situations, or situations that were not so socially challenging. Efforts were made to highlight the positive aspects of the identity, even when the situations being described might be socially problematic or challenge moral norms.

*"You're sort of like, it's like being a sniper and you're going into combat [looking for toilets in public].... You're sort of subconsciously, you're doing that 'where's the next ones?...' "* P08

The primary negative connotations were odour; shame; blame; and uncleanliness. Several participants spoke about how much worse it must be for other women, particularly in regard to the embarrassment and shame others must feel. Whilst participants recognised specific instances where they may have felt embarrassment, participants only generalised negative feelings when talking about others. The all-encompassing shame which



might be attributed to women experiencing urinary incontinence, particularly those who have not sought help, wasn't necessarily applied to themselves.

*"I think they're (pauses), embarrassment. People feel, they think it's just me, or there's something wrong with me. And also it just, even if they know that other people have it, there's just (pauses). I can't quite work it out ....but I know that, that people do the same sort of thing as if people can't write, um or read... its shame, somehow shame..."* RF1

Whilst shame may have been problematic for some, the most prominent of the negative connotations, unsurprisingly, was odour which has also been noted in other studies (Brittain and Shaw, 2007; Getliffe et al., 2007).

Although none of the participants felt that odour from urine was a problem for them currently, the concern that it might be in future was never far away.

*"It's also linked to smell of course. That's why it's such a taboo....I mean it is a very, there is no pretending...there[s] nothing nice about it about weeing and then drying and that, that's not nice and will turn people off you very quickly, so that's, that's why I think you'll always have an element of taboo about it because it's associated with smell...."* P01

In addition to odour from urine, the odour from absorbent products was also a problem for some women.

*"I hate the smell, I really hate the smell. ... I'm sure different brands smell differently anyway, but it's just the smell of the, it's just disgusting and even though it's meant to be hiding something, I dunno, that, that's part of the, I can smell it and I can smell it on myself, instead of my normal smell I've got this artificial smell...."* P02

Despite absorbent products being used as a coping strategy, participants were not always happy with their use. In addition to the problems women faced in relation to maintaining identity through use of products, there were also problems with the functionality and usability of products. Participants were keen to see the design of products change to prevent that challenges to their identity. The need for innovation was driven strongly by social needs, in addition to physical needs.

*“... there’s scope for redesign isn’t there and younger women...because if childbearing aged women say, women in their 30s and 40s are experiencing [leakage].... There’s more and more running and sport and sports activities... I mean seeing people in lycra now, is just completely common place....And is [having to wear a pad] putting people off...?” P01*

*“They should be discreet, small but maximally absorbent, not stink, um you know, different colours, so black would be good (laughs) not white that if, you know, you’ve got a, clothing that you can see through it catches ultraviolet, cos often they’re bleached aren’t they...they feel horrible and a bit rough, if they were smoother...if there was something that was slim and black and felt smooth in your pants like silk, kind of underwear type thing, you might be more inclined to use it.” P02*

As well as consideration to redesign, participants spoke of difficulties using current products.

*“It used to be awkward, you know, they’d catch on your pubic hair” RF2*

There were problems not just when absorbent products were in place, but even getting them into situ could cause issues.

*“...And then there’s the sticky back and you’ve always got to, somewhere to put that sti, it always sticks to your fingers cos it’s static-y and you go (shakes fingers as if to remove static backing paper), you have to touch the bin, it’s a faff and it’s just annoying isn’t it” P02*

*“You don’t get them on properly and then you can’t stick them [when you try to place them for a second time in your underwear] and you think I’m not getting another one out because that’s however much [money wasted]...” P02*

Absorbent product use created problems of its own; odour remained a concern, as did feeling unclean.

*“The liners they’re not designed, they’re not designed to keep you fresh if you’re leaking....if you try to use it....to sort of cover up any leakage you are*

*having then they, you know, got, you've probably got about an hour, two hours in there. Er, the [brand] that I tend to find are about sort of three hours, you have to be changing them...and I think that's where I, sort of, with most products now it's, I don't tend to go more than three hours, four at a push."*

P07

Disposal of absorbent products was a problem for all the participants. All had developed routines which enabled them to dispose of products as discretely as possible.

*"I roll them back in their little cover and if there aren't any bins, in all honesty I sort of fold them in such a way that I make a little parcel and you shove them in your pocket til I find a bin, w, it's, you [are] then really conscious of the fact you've got it in your pocket and you're really conscious that you're trying to find a bin (getting louder) so as soon as you get a bin you're sort of, straight in it and you think 'OK, I can settle again now'."* P08

Disposal was a problem not only in terms of ease, but also how participants felt about the environmental impact that product disposal had.

*"I do think well this is a shame, that I'm having to use this and cos it's going to landfill"* P09

However, despite the concerns of participants, it was really important to them that product functioning, particularly absorbency, was not compromised by improvements to environmental credentials.

*"If [reusable absorbent products] had the same [properties as disposable], I guess I've had issues, I've had it with nappies and they don't work the same."* P11

Participants were keen to see developments which would make disposal easier, quicker and have less environmental impact.

*"...Disposing of them isn't very easy. At home in your own bins um, you know, you end up kind of wrapping them up in, or just leave, you can't leave them, where do you put them... you need a nappy bag don't you really, because there's the same amount of urine as a nappy but ... you know it's funny I saw in [a shop] these like special dog poo bags that were all flowery*

*and I thought that's what people need for their...pads or whatever, so I think they ought to come with some kind of disposal thing..." P02*

As women's coping strategies were largely created through a process of trial and error, any new products would have to meet the standards of functioning currently expected, plus have additional social benefits. Many of the participants had different criteria for the types of absorbent product they wanted.

*"I don't think I'd like them coloured. Yeah cos I think if you've got some kind of dye in it then, I don't think it's particularly clever." P07*

*"They've got a waist through the middle [of the pad], but actually that bit in the mid, that thin bit is exactly (taps table) where (taps table) you (taps table) need (taps table) the (taps table) most absorption. So when you're left with the bit that shows, actually not the front usually, but at the front and the back you think that's just there for stickability, it's not because I need it up there, and yet that's the bit that's showing, so I, I'm kind of thinking I want something that's more that shaped (draws elliptical shape with finger)." P01*

When women spoke about the use of absorbent products, they spoke about their use as a process, rather than as an item. They considered buying products, trialling different products, product use and disposal. The participants wanted the whole process of absorbent product use to be better to enable them to maintain a socially-continent identity.

*"I find that the incontinence pads and the sanitary towels are too close together [on the supermarket shelf] because people who don't know what they're looking for, and me as well sometimes, I'm not sure which I've picked up. You know because like um, is it [brand] they do sanitary towels and [pads for incontinence]...well I find that quite annoying... because I'm stood there looking when I'm not sure what to get and thinking 'which is which?' yeah...because they don't work the same." P07*

Considering product use as a system lends itself well to analysis using a sociotechnical perspective, which will be discussed in section 4.9. Leakage occurring for the first time in public, or early in the women's experience

before coping strategies had been adopted was considered embarrassing. Some participants would state that they had forgotten about an instance where they were embarrassed until the interview prompted the memory.

*“You’ve just reminded me of another....I remember...It’s interesting cos actually I’m harking back to an era [several years ago]. And yet, I mean, this, it’s interesting, it’s just triggered another.... I was wearing a grey suit....and suddenly realising I had a mark the size of a dinner plate and I kind of had to do all sorts of embarrassing things like take my jacket off and sort of holding it in front of me and leaving very quickly....” P01*

The blame expressed by women, was directed in two ways. Firstly, towards themselves. As aspects of the leakage experience were negotiated, resentment was expressed at the inability to change particular aspects of themselves or their experience.

*“It’s the assumption pretty much every woman bleeds so you don’t kind of, you don’t carry sense of sort of blame or self-beating-up about that, it’s like that’s what happens to women, whereas I think there is that [with urine leakage], much easier to go, I’m, I mean that adds to the taboo...I’m leaking, I’ve done something wrong or I’ve got a body that’s not working well, you know, in all sorts of subtle ways without even putting it into words you’re carrying more self-blame.” P01*

Secondly, where healthcare professionals or healthcare systems were perceived to have had negative impact on a participant’s experience, resentment or blame was expressed towards them.

*“Had I known [the risks of medical procedure] I think it would have made, maybe made it easier psychologically to accept, but I feel quite angry...I was vulnerable...” P03*

Even when participants were quite positive about healthcare professionals, they still had very negative feelings about the treatment or investigations they were subjected to, affecting how they felt about themselves.

*“it’s quite degrading...you feel dirty even though there, it’s not anything you’ve done...” P03*

Whilst, these challenges were caused by internal and external factors, some of the challenges, particularly use of absorbent products, could be overcome by use of clothing as an additional coping strategy. This will be discussed further in the next section.

#### 4.6.4 Clothing

Clothing is important as a method of expressing identity. One's status is expressed through garments worn (Keenan, 2001). Participants talked about the clothing they wore to help cope with the social consequences of potential leakage and absorbent product use. Clothing choices were made to hide leakage and absorbent products. Preparation was made well in advance of potential leakage occurring (as was consideration about whether an absorbent product would be necessary). Other strategies were sometimes also employed to offset clothing choices that had been made. Women were not always able to wear the clothes they would have liked to, to ensure a better disguise.

*"I love wearing [a particular style of] dresses and you [are] suppose to wear them just like that, especially sort of in the nice summer but you sort of think 'nah, we'll put some leggings on with this'... and you think 'no actually all I want to do is put a pair of sandals on but it's no, we can't do that'" P08*

Important to several women was finding clothing that would hide the appearance of absorbent products. In many instances visible leakage was less problematic than wearing absorbent products that might be seen.

*"So I wear [track suit bottoms] you know, with my big pants on and a [pad]....I thought this is not a good look, [a pad] showing through with the [track suit bottoms], no it's not a good look." P02*

*"I'm not self-conscious about walking round in lycra. I really don't care what people think. But actually, so I don't care if they think I look weird or eccentric but I would care if they could see I was wearing a pad. I really would care. Really care. In fact, a deal breaker. Isn't that interesting? So how awful is that." P01*

In addition to changes to outer clothing, experiencing leakage limited women's underwear choices. All participants wanted to be able to maintain the style of underwear that they were most comfortable wearing (physically and psychologically), but use of absorbent products meant this was not always possible. Some participants did make modifications to the types of underwear they wore to prevent potential problems with the absorbent products occurring. In some instances participants wore two pairs of knickers; a preferred pair and a pair that kept the absorbent product in place, on top.

*"Because I actually, I wear a panty thing as well, er like a spanx thing, so that sort of keeps it in place as well."* P07

Others had found reusable products enabled them to maintain discretion.

*"I've got some [reusable absorbent underwear] ... I mean I don't think... you [can] tell I've got anything other than normal knickers on.."* P14

Problems with absorbent product performance because of the style of knickers worn were noted by participants. Gusset size was a common issue. Absorbent products were not perceived to be designed in the same shape as underwear, meaning that participants found that absorbent products bunched and rippled, minimising effectiveness.

*"The problem is that there's not many pretty wide gusseted pants. And (laughs) it's quite funny actually, we did have a discussion about this cos we were out somewhere....and I was looking for some new pants and they were all, they were shouting 'these have got wide gussets', because yes, sometimes it's not, it's not too wide [the pad] and it, but you, you've got to have it wide though haven't you."* P07

Poorly placed seams also meant that there might be 'run off' from the absorbent products which didn't sit evenly within the knickers.

*"..I've got make sure I place them [pads] because sometimes I put them just over my seam on my pants but then I find it's only the top bit that's wet and the rest of it is completely dry so I really ought to move them up a bit, but*

*then if I move them up a bit and I cough or sneeze it could have consequences that way.” P07*

Women invested considerable time shopping for underwear and absorbent products which they liked and which would not prevent the products from being effective.

*“...[The pad is] tapered so that you’re not, it doesn’t overlap on thin panties. You know, you can wear the bikini kind of pants, stuff like that... I think they’ve only been in a few years the tapered ones.” RF2*

Wearing a different style of knickers was not only a problem in terms of product performance, it also created difficulty for maintaining identity. Underwear choices were highly personal, an embodiment of womanhood.

*“If I were willing to wear the sort of old fashioned proper knickers, but I don’t wear those, I wear the sort of...not exactly G-strings but you know the normal...” RF1*

Some participants suggested there was also scope for change to clothing design to enhance absorbent product use.

*“Not so much the pads [that need to change] but pretty pants that have got wider gussets.” P07*

*“I think they’d be better off designing nice glamorous pants and having Velcro in it... [the pad] wouldn’t move, you’d only need a tiny bit of Velcro at each end... but sticky doesn’t work...I go, millions of women do, to Marks and Sparks, um they have the nice combination [of underwear]...you know, bit prettier sort of.” RF1*

Underwear allowed women a form of expression that was highly personal and which may have not be seen or noticed by anyone other than the woman herself. Whilst comfort was important, it appears that when considering underwear and use of absorbent products, there was a balance between product performance and underwear design to maintain identity.

Clothing had communicative value which impacted upon identity.

Communication will be explored further in the next theme.



## 4.7 Theme 2 - Communication

Communication in a variety of forms was extremely important to women. The ways in which women presented themselves to others was varied. This theme further illuminated the first two research objectives. In addition to understanding communication in relation to identity, it also provided information which highlighted views regarding product use and healthcare practice.

### 4.7.1 Terminology

The ways in which women chose to describe their urinary incontinence was important, as had been previously suggested by the reference group. Many women did not want to be associated with 'incontinence' and chose other terms to describe the issue that they were experiencing. Some did not recognise their leakage experience as incontinence.

*"No, absolutely not [incontinence]. No that makes me think of old people...And not just wee, yeah. No. There is no way that I would think about it like that! (laughs)" P09*

Some women thought incontinence represented a loss of control and made reference to children and older people. One participant also made a direct comparison with dementia, in terms of loss of control and the social understanding that people have between lay- and medical terminology that comes with diagnosis.

*"...Incontinence is one of those incontinence pads, old people's homes, um, people who are controlled, people who are demented, once you're in that category you've lost it...where as a bit of leakage is just a 'oh you haven't bothered to do your pelvic floor, you're a mum, you're busy, you know, not quite looking after yourself, it's, that's, everybody leaks don't they', whereas not everybody's incontinent. You know I think it's that, it's that kind of medical word, it's quite, you know 'ooh, my, I've got, I'm a bit confused, I can't remember things that well', [versus] 'oh well you're demented' It's kind of an official term and a diagnosis isn't it, rather than a symptom" P02*

Others accepted that they were experiencing urinary incontinence, sometimes reluctantly, but would choose carefully the terminology they used depending on audience.

*“If I were talking to a friend in a joking kind of way, I’d call it, refer to it as my, as pelvic floor issues, but, uh, I’d guess, that’s probably how I would refer to it... I did [describe it as incontinence] at the beginning when it was bad...”*

P11

Interestingly, leakage was not perceived as a problem for all participants. There were some women who made it clear that it was not a problem. They had negotiated its place in their lives, and whilst some modifications to behaviour, choices and activities may have been made, the leakage was not considered to be a problem in itself. The language they used to describe their experience reflected this. Whilst incontinence was associated with lack of control, negativity and diagnosis of a severe medical problem, leakage was considered far more socially acceptable and easier to discuss.

*“...The odd drop is leakage...the full nappy is incontinence.”* P01

Whilst some women could accept that their leakage would constitute incontinence, only one participant (P03) referred to herself as incontinent, when expressing the severity of her experience. This participant had different circumstances to every other participant and approached the subject from a different viewpoint. Labelling herself as incontinent showed ‘medical’ severity but she was clear that was not how she considered herself usually.

*“I mean I don’t mind the word leakage...for example I don’t think that I’m incontinent I guess, but, but when I’ve had the urodynamics and I, I face the facts I do experience, I think mine was a plus-plus so it’s quite severe, um so I am, I am incontinent but I guess yeah, if I explain it to friends I’ll minimise it and so I’ve got a bit of urine leakage.”* P03

#### **4.7.2 Communication with others**

Other women were often the greatest source of support to the participants. Even those who had very supportive partners often had disclosed their

urinary incontinence to other women. Participants found reassurance in talking to other women experiencing the same issue.

*“..well I mean I don't talk about it but, except my [female relative]...I presume she's got more of a problem than I have... but, she's the only person ...I talk to.”* RF2

But attitudes to leakage and to discussing it with others were varied in the participants' experience. Some women were not aware of anyone else with the same issue. Despite this they had supportive female friends or family members, who helped to normalise the situation. These supportive friends became confidantes and on occasion would act as helpers in 'emergency' situations where public identification of incontinence was a threat.

*“I talk about it all the time because sometimes when I sneeze when I'm out with the [friends] and they'll go 'oh here we go, don't get up, the chair will be wet' and I say 'no it won't because I've got my four drips on today’”.*  
(reference to absorbency of pad) P07

Whilst all participants who had a partner knew that their partner was aware of the leakage, not all of them discussed it with that person directly. All participants who discussed their relationship within the interviews were in heterosexual relationships. Some woman had not only confided in their partners but the partners took on the role of supporter, much like female friends did for others.

*“My [partner]'s really good if we're going out and I'm all dressed up he, and I, you don't have pockets, [he] will put the liners in his pockets....we sort of do it quite discreetly”* P08

Other partners weren't as supportive but participants were able to find positives, often in the level of communication within the relationship, rather than with the partner's attitude.

*“Like, he's very accepting, he's like 'oh whatever' because that, you know we are quite [laid back]....but I can imagine some women would just not even go there.”* P02

There were certain elements of the leakage experience that were more easily approached with male partners. This appeared to be the practical

elements of coping; partners often provided practical support but not emotional support, which was gained elsewhere. The ways that women described their communication with partners was often coded, avoiding directly referring to the leakage, rather only mentioning its effects or behaviours enacted to prevent leakage occurring.

*“you know when you’re a kid and your mum goes ‘go for a wee before we set off [on a journey], we do that....my [partner] will say sort of ‘right, we can go for an hour and a half, two hours and then we’ll stop’ and the first place we go when we stop is the toilet” P08*

Participants didn’t directly tell members of their family in many cases. With the exception of male partners, female relatives were seen as the most likely person to discuss leakage with, even if discussions had not taken place previously. Choosing not to communicate with particular relatives, was as often for the relative’s perceived protection, rather than the participant’s privacy.

*“...The only reason I wouldn’t say something to my [male relative] is that, I think he gets a bit freaked by it. I mean he’s been very good...but you know there’s information he would chose not to, not to know...” P01*

Disclosure to other relatives tended not to occur unless it was to an individual with whom there was shared experience or when the individual was perceived as someone who could give help or advice. Even when women did have opportunity to tell others who may have provided support, they often chose not to.

*“I wouldn’t be shy of discussing it with them [friends], but I don’t” P13*

Participants did not speak of embarrassment being a reason for non-communication with those in their social circles. Despite this many participants had other rationales for not disclosing symptoms.

### **4.7.3 Non-Verbal communication**

In addition to verbal communication, non-verbal communication was highlighted by participants as a means of negotiating situations. When participants lived in a household containing several members,

communication about the issue was via behaviours and visibility of objects, rather than by verbal means.

*“Obviously the immediate family does [know], obviously my [partner] and my, my [family at home] do cos they sort of are more involved than my [relative, who] is away living somewhere else. Um, they all know that the sort of... they know and they don't know...we've never covered up sanitary towels or anything like that...they think I wear a liner...it's that, we, they don't really talk about it...”* P08

Products in particular had emblematic qualities which the women judged themselves and others by.

*“I hadn't thought about actually having pants that were absorbent, but that again, I would be reluctant to buy them because I'd know that the packaging would arrive and it would be like 'leakage pants for all your' and like having spanx underwear, it's like wearing clothes because my body's, it's like a reminder when you put it on, I need to wear my padded pants because I'm going to piss myself like an old lady.”* P02

The following quote from P01 illustrates the emblematic qualities of absorbent product use.

*“I'm very, very acutely aware of how I position [the absorbent product]. Like, it's here to catch wee not poo, so you don't need it, you know (indicates back of gusset), you know, I really am spending a lot of time when I put it into my pants...I mean you can hear what I'm saying. I don't want anyone... behind me going 'Oh she's wearing a pad' so that's a massive taboo. What's wrong with wearing a pad? And what should be wrong. And yet. And having seen someone else and thinking 'oh so embarrassing' on their behalf, which is a horrible thing to admit, but it is the case.”* P01

Women who use absorbent products may still judge others in similar situations for the use of absorbent products, reiterating the importance of avoiding social stigmatisation. Participant P01 recognised the double standard, but still wanted to ensure that she was not like the woman who allowed an absorbent product to be visible through clothing.

Communication allowed women to negotiate their social experiences, but there were instances when communication did not work in the women's favour. These circumstances could be difficult to overcome, increasing perceived threat. In the next section communication in relation to healthcare will be considered.

#### **4.8 Theme 3 – Seeking help and information**

The way in which women wanted to approach healthcare and their assumptions about (and experience of) healthcare professionals was varied. Talking to a healthcare professional depended very much on how severe the 'problem' was perceived to be, however women were not always sure of the best source for advice. This theme met the objective of understanding women's experience of urinary incontinence, by describing their use and familiarity with healthcare interventions.

*"ohhh, it would have to get a lot worse....But if it did, I, um, yes I would do something about it... I'd first, probably contact the helpline [seen advertised on TV] because they, they, so, a GP is only a general practitioner, whereas presumably you get experts so I'd contact the helpline. And then if I didn't find that was satisfactory then I'd go to my GP cos I've got a really good GP." RF1*

Women communicated differently with health professionals compared to others when discussing their continence. When discussing the priorities for their lives, women had a social understanding of leakage. However, when considering the information they would share with health professionals, especially in the first instance, they would highlight the physical problem only.

*"..but how can you yourself judge when it gets to the stage that it's a medical problem, probably when it becomes a social problem...like if it's really, really inconvenient, you think 'oh I want to get something done about this. See if I can have some treatment', you know an operation or something." P14*

Some would even use healthcare-related terminology, for example incontinence, because it was perceived that is what the professional would understand.

*“...Yes, I mean, I, even if I went to a doctor I might say I’m finding I’m leaking more often, I’d use that word you know. I might say I want to talk to you about incontinence, I might start by saying I want to talk to you about urinary incontinence and then I’d talk about how much I’m leaking.” P01*

In instances where women had gained knowledge of incontinence through means other than health professionals, understanding symptoms could be affected. Some participants had informed the doctor of what they believed the medical diagnosis was, without actually explaining the symptoms they were experiencing. Stress incontinence was spoken about far more regularly by participants that recognised their leakage as incontinence. However the leakage they described did not necessarily correlate with the ‘diagnosis’ they had assigned.

*“when you’re in the doctors there are posters all over the place and it goes ‘do you have to go to the toilet more ... is there an urgency?’ ‘yes, I have urgency of going and yes I leak’ and it, the, it was on a poster it sort of says oh ‘you might have, er stress incontinence, or you could have bladder cancer’... I think I’ve got stress incontinence because I don’t possibly admit the fact you know, possibly could have been bladder cancer... but you know it’s never gone any further or we’ll do any other investigations, it’s always been ‘yeah you’ve got stress incontinence’ because that’s what I told [the GP] I had.” P08*

Trusting a healthcare professional was important. Not only in terms of individual relationships, but also the system within which professionals worked. In some instances participants didn’t return to healthcare providers when symptoms persisted because of the barriers that they perceived.

*“I’d want to go and talk to my GP rather than a random locum GP” P11*

*“... the follow up from the hospital was a phone call and I didn't pick up the phone because I was busy ..., you know what it's like and you can't ring them back and they say 'oh if you need to be followed up again then go and see your GP' and I thought well I can't get into see my GP, it's a nightmare....it's too many barriers in the way of getting followed up.” P02*

Professionalism and confidentiality were not enough for some women to feel safe to discuss symptoms of urine leakage. In addition to patient-professional relationships that promoted trust, there were also encounters which did not promote trust.

*“...so I was obviously feeling um, you know, ..., embarrassed about the situation.... a bit scared and anxious and then the consultant was very um, yeah, very abrasive, very unsympathetic, quite uncaring...I was really, you know, upset by that...” P03*

The availability of services was also seen as a limitation to approaching professionals for help. The amount of money that was perceived to be spent on services was sometimes considered inadequate, affecting women's attitudes towards care and the trust they had in treatment options.

*“And it's never going to attract a lot of money because it's not life and death. You know, so it's lifestyle. It's making people's lives miserable.... It'll stop people going out so it's actually massively significant because that has all sorts of health consequences.” P01*

*“I don't want it to take years to sort out [referring to length of time needed for pelvic floor exercises to work] just cos it's cheap” P08*

At postnatal screening, although some participants were experiencing leakage, it wasn't considered a problem and therefore they didn't mention it. Even when leakage was experienced it took time for women to understand it as a 'regular' occurrence, rather than a short term problem or one-off instance. The issue for participants who experienced leakage after childbirth came when normal activities were affected (a social problem), not from the experience of leakage itself (physical problem).



*“Thing is I’m not entirely sure at that stage of having a routine check-up if I’d have known it was an issue, because that might have been about six weeks after having the baby and at that point I wouldn’t have been [undertaking usual activities] so it would need to be later than that [when health professionals ask about leakage], but I don’t know when the opportunity would be there.” P09*

Participants suggested that information about pelvic floor required previous knowledge. There were instances when health professionals expected women to know how to perform the exercises effectively. Whilst all participants had some understanding of pelvic floor exercises, their experience of performing the exercises was varied, affecting the ways in which they coped and how they felt about seeking additional help.

*“In the hospital they were like, ‘oh there’s the leaflet, off you go’ but not really checking whether I was doing it properly or not” P02*

The sources of information used by participants to gather information about pelvic floor exercises were diverse. Some had previously undergone specialist intervention with physiotherapists or specialist nurses. Others had been given information when pregnant or postnatally. Even those who were post-menopausal referred to information that they may (or may not) have been given when they had their children decades earlier.

*“When I had my children there was much less information either before you had your child or afterwards” P14*

The level of knowledge women had about pelvic floor exercises was related to the information they had received over a number of years, often prior to urinary incontinence occurring. This meant that women’s knowledge about pelvic floor exercises was not necessarily research-based or current best practice, particularly those women whose experience of childbirth was many years before.

*“...Cos I know you’re not, I read that you’re not supposed to do it - which is the old idea - that when you’re urinating you had to stop, and then I read in*

*fact that was a bad idea. And having done that for years, so then I do it, normally if I'm sitting and I remember, I'll do it" RF1*

*"[Information] was a bit mixed really... I mean the [second hospital attended] they were good, um and they gave, the physiotherapist talked me, taught me through how to do it and then I was given a leaflet but it's very difficult to do them" P03*

Women who were receiving antenatal care, or who had children in the recent past, were unable to recall whether pelvic floor exercises had been mentioned to them, despite recognising it as an important subject.

*"Its maybe been mentioned to me, you know 'Don't forget your pelvic floor' but actually that might have been on websites that you look at, so, I don't think they [midwives] do tend to talk about it and um, if they do, I mean I know what the pelvic floor is and how to do it but it is quite a strange concept so (laughs) it's not really been mentioned" P09*

*"I mean I didn't know that um, that you had to do um, pelvic floor exercises when you were pregnant so I guess; a friend advised me about it and I'd already given birth but she said 'oh did you do your pelvic floor exercises when you were expecting?'...but I never did any pelvic floor exercises until actually, you know, until I guess I went to um, the doctor [regarding UI]...but it was only after speaking to friends they said oh yeah if you do your pelvic floor exercises before [giving birth] that helps as well" P03*

The majority of women had not been shown how to do pelvic floor exercises.

*"I think you just sort of contract your muscles don't you? And I don't remember how I ever, if anybody ever told me, I mean you just vaguely know these things. I may have read it in a magazine or something" P14*

Participants felt that there was an assumption by professionals that they had lots of time to invest in undertaking exercises and other intervention strategies. In fact, most of the participants who had sought help were of working age and had caring responsibilities.

*“The first time I went to hospital they were on about the cones..... It was really sort of ‘what planet are you on?’. I think I managed about two weeks with them.....it’s just unreal, yeah it is unrealistic...” P08*

*“...especially the first lot [of physiotherapists] that treated me. I was like, you know, you couldn’t really do [the exercises] with a baby, you had to be kind of lying on the floor in a, in a quiet room so you, so they were a bit tricky...” P11*

*“I think also there was a lack of realism ... because you know, when, I had a young toddler, I was working... I didn’t have a support network but when I went to physio some of them, you know and my friends have said this as well, that they’re not realistic ....” P03*

There was also a certain amount of guilt because lack of time and the need to prioritise other daily activities meant that pelvic floor exercises were not always given the time required. Some women compensated for not doing the pelvic floor exercises with other interventions that they thought might help.

*“(Sad voice) It can be fixed for most people. (Normal voice) but if I do my pelvic floors it probably will get gradually better and it’s like everything else, I’m not going to eat chocolate, I’m going to do my pelvic floors, it’s on the list. And I know it’s probably in my hands” P02*

*“I do try to remember to do my pelvic floor exercises. I’m not quite as good as I should. But I do a lot of exercise now... I think that really does help” P11*

Whilst women’s attitudes to undertaking pelvic floor exercises may have differed, motivation to continue to do the exercises reduced over time, irrespective of whether their use had been perceived positively or negatively. Information about the benefits and methods of undertaking pelvic floor exercises was inconsistent in these participants’ experience. The women did not actively seek information about pelvic floor exercises, despite having

understanding that they may be useful in reducing symptoms. Even when information was given to the women it was often perceived as very basic. Many of the women had ideas about when they would have liked information to be available, to learn about urinary incontinence, how to deal with it effectively and to overcome stigma. Some participants wanted to have known about the likelihood of experiencing incontinence well before the eventuality.

*“Do you know it sounds funny but I think it ought to be incorporated into sex education in schools. Which is probably rubbish still..... I mean I have ...[younger relatives], they’d probably die of embarrassment if I sort of mentioned anything you know. Um, but, so build it in... those kind of things should be, it’s an important thing... so that it doesn’t, they don’t have chance to become embarrassed... because it’s just important as sex. Because not everybody has a partner, not everybody...gets married, whatever...we all go to the toilet”. RF1*

When women attributed urine leakage with having children, they highlighted the importance of antenatal information. Although the NICE pathway for routine antenatal care recommends that pelvic floor information is given during the initial booking appointment, some women didn’t feel this had been given the priority it deserved (NICE, 2016).

*“They have an awful lot .....of individual differences between the women that they have to cater for and obviously you don’t have that long with your midwife um, but it would be good if perhaps it was, yes if it was mentioned early on um and if there was an information sheet or leaflet that they could hand out about it because, the, you don’t really hear about why it’s important and if somebody says to you ‘don’t forget to do your pelvic floor’ but they don’t say ‘so that you don’t wee yourself every time you sneeze afterwards’ (laughs) then you know people aren’t going to do it.” P09*

The priority for most was to learn how to cope with leakage, rather than find out why they might be experiencing leakage. Most had already assigned a cause, often ageing or childbirth, irrespective of any healthcare intervention received. Many of the participants spoke about “the operation”, only two of

whom had been offered surgical intervention. Views about surgery were mixed and often not informed by good quality evidence.

*“...but what do you do? I don’t want to have, um, I don’t know what you call it, is it a hitch and stitch or something?” P07*

*“when I win the lottery....I’m going to have...me bladder done (laughs).” P08*

*“why did I bother having that surgery...I’m not sure how much benefit I’ve really got, cos I’m still leaking...” P02*

*“...If I wanted I could go to the doctor, although they would probably say ‘you need an operation and we’re not going to do that to you quite yet [based on current circumstances]’.” P09*

Having information about cause was considered less important than preventing symptoms occurring and coping strategies for when they did occur. Several participants mentioned the use of the internet when looking for information about leakage. Although not all participants had previously used the internet, most would consider it if they wanted more information. Reputation of websites was important; some participants were cautious about the websites that they would choose to gather information from.

*“I’d probably Google it and try and find something fairly reputable like the NHS.” P11*

*“Um, you can go online and look at these things but going online can be a bit dangerous sometimes cos you get so much weird stuff.” P09*

Participants were aware that the terms they used in search engines could bring up unwanted or unhelpful websites.

*“I mean I know there’s a lot of rubbish that you get through Google, you’ve got to be selective of what you er...and you might get some rude stuff... depends how you put your words in.” P14*

In terms of finding out about other’s experience of treatments, some women found others’ opinions helpful in identifying benefits and risks, prior to making their own decisions about intervention.

*“... she really highly recommended to have the TVT operation and she said ‘oh I’ve had this and um, it was really successful for me” but when I’ve looked into it on the internet there’s really mixed reports about it...there’s forums have been written...and there’s a lot of, I find, negative.... you know, negativity.” P03*

#### **4.9 Analysis from a sociotechnical perspective**

Using the sociotechnical design model, use of products can be considered integral to systems and subsystems in which women operate. Products enable women to continue with a life that is largely representative of their continent-selves, particularly in social situations. Table 13 shows the overview of the following section. Each of the sociotechnical design nodes was used to understand the interview data and provided a broad overview. Whilst some categories of data did fit ‘neatly’ into a single node, in many cases there was overlap between the nodes. For example, the importance of improvements to ecological benefits of absorbent products over-arches environmental considerations, but also goals, people and technology.

For this reason it was more complex to analyse the data using the sociotechnical model than had been anticipated. As the entire system was not analysed, only a small sub-system was considered, conclusions could not be drawn. However, what follows is an attempt to consider various aspects of product development and use, from a sociotechnical perspective, with the objective of describing how findings may influence future absorbent product design.

**Table 13 Overview of the sociotechnical analysis**

<b>Analysis from a sociotechnical perspective 4.9</b>	Goals	4.9.1.1
	Processes	4.9.1.2
	Culture	4.9.1.3
	People	4.9.1.4
	Buildings and infrastructure	4.9.1.5
	Technology	4.9.1.6

The following ideas for absorbent product design are based on the participant's data only. Within the design process, other stakeholders would be involved (as shown in the full sociotechnical design model). Therefore, whilst these ideas as formal design concepts are incomplete, they are able to draw out some of the most pertinent concerns for those wearing absorbent products. It is worth noting again that all participants were independent, living in their own homes and most bought absorbent products from the supermarket. Therefore, these ideas may not be representative of the majority of women using absorbent products.

#### **4.9.1.1 Sociotechnical node - Goals**

Participants had several goals for product development. Firstly absorbent products should not be visible through clothing. One of the ways that this could be negotiated is to provide absorbent products in a variety of colours. Other ways suggested by participants included an integrated underwear system which hides an absorbent core within the gusset of underwear.

*"....Most pants actually do have a kind of double layer, don't they, around the crotch and if you could slot that [insertable pad] into the double layer and you had a stack of those ...inserts and you could just take those out and you had a special place to put them, or they could go down the loo or whatever...that would be good actually." P02*

New products should allow women to maintain their usual style of underwear. As noted previously underwear is particularly important to the participants.

*“So I would like development of a pad or a, that is, that is still, can be worn with my underwear.” P08*

The absorbency to thinness ratio should be increased in products. Thinness of product was so important to many participants, that they were prepared to use less absorbent products than required, rather than use a bulky product.

*“What they’re stressing nowadays is um, thinness and comfort aren’t they? They’re the two things but if it doesn’t do its job, it’s no good.” RF1*

Odour was a concern, and for the majority of participants they would prefer a neutralising product, rather than a fragranced product. There is opportunity to explore more ‘natural’ alternatives; participants were not keen on additional chemicals near their genitals.

*“...You then get really paranoid about it but then you do the ‘well am I [smelly], or is it just me thinking I am?’ and you sort of just go change [the pad] anyway, it’s easier.” P08*

Natural alternatives would also meet the environmental concerns of participants, however, product performance cannot be sacrificed (or even perceived to be sacrificed) as a consequence of improved environmental credentials.

Physical comfort should also be considered by manufacturers. The edges of products were particularly criticised.

*“I do find some of the pads chafe, they do um, you know, they rub on your leg, the top of your legs a bit, cut in, the edges of the plastic....” P14*

Absorbent products enabled participants to delay taking further action in regards to their leakage experience.



*“I do feel that I just put [the pad] on and just completely forget about it and then I don’t have to think about it, so it’s almost as if I’m not incontinent really.... Which does help, cos it, it’s delaying me thinking, you know, about the operation and the side effects and things and I, I’m managing it better by, you know, being able to wear a very slim, er, um, sanitary towel.” P03*

#### **4.9.1.2 Sociotechnical node - Processes**

Participants had a need for haste in their use of products. They didn’t want to be slowed down when shopping for; using products; or disposing for them.

*“and I suppose you know, women are going to be looking at the sanitary aisle whatever, so it’s less obvious...that’s where I anticipate [products for UI] would be, you know, that’s where I would look first.” P09*

Ways in which time efficiency could be achieved included clear information on packaging, easier disposal and better attachment to underwear. The process of absorbent product use starts with advertising (prior to buying products) through to disposal, as explained in the following quotes.

*“...You don’t have somebody pouring a whole of, cupful of water on the advert, it’s just like for a little, and there’s like a drip isn’t there? For the drip coding on the [branded products], its like ‘how much dripping are you doing?’.” P02*

*“So I got some... little black liner things, little bags...because I think to throw [pads away] in someone else’s house is awful.” P07*

The need for haste was largely driven by the need for secrecy, and maintaining the social processes that would ordinarily be undertaken and removing the ones that would not.

*“But how lovely to reduce some of those, those, so you’re not carrying used products around in a bag, or a pocket, or up a sleeve or something [by creating a product that can be easily disposed of].” P01*

There is a process of building trust between the product user and the product. Elimination of perceived product failure could be increased through clear information, better understanding of appropriate product use and a greater degree of meeting social needs.

*"...I'm quite happy with mine. I've been buying them in [budget retailer] of all places...and they're just, don't seem any worse than the, um, [branded products]. The worst ones I got were some from [a supermarket] (laughs)."*

P07

*"[The pads] get ridged...the ridge is sort of formed to the shape of your body and you think 'actually can you not do that, can you just flatten out and stay flat, cos this is now irritating', so you change because you've ridged it, rather than actually you need to change it...you change it and stick a new one cos that's more flat, more covered sort of, an even cover, rather than ridged it."*

P08

#### **4.9.1.3 Sociotechnical node - Culture**

The participants were clear that one size does not fit all. Currently product manufacturers are producing products that are very physical-function focussed, then may attempt to 'feminise' with branding or advertising. Participants were disparaging about this approach and felt there was more that could be done, through product design and in advertising.

*"It's just naff isn't it? It's really naff [TV advertising], sanitary wear is, you know, it's women who are ...younger than me, usually doing handstands, which I didn't do when I was ....younger, usually wearing white trousers, you know, having the times of their lives, all patronising. Um, and then I suppose at the other end of the spectrum you've got the incontinence stuff which is an old women in it, she could be advertising dentures you know so, neither particularly appeals... you know she can still have a glamorous life, even though she wees in her pants (laughs)."* P09

The cultural understanding of urinary incontinence, as described by participants, was not one that they could recognise of themselves. This in itself is an opportunity to further develop products to meet additional needs of these women. Participants did not feel they themselves were stigmatised (although they sought to avoid it), therefore the approach taken by commercial companies should recognise this nuanced understanding.

Absorbent products were either viewed as essential items or hated items, depending on how leakage experienced is understood. Older participants were more likely to be grateful that products now were better than the sanitary towels available during the twentieth century.

*"...I very deliberately look for the very flattest ones...and I come from the generation that actually did sanitary towels and you know, and so I'd have loads of memories of just how horrible those are."* P01

The participants all had low expectations of what might be achieved in a new product.

*"That's the issue. I mean what feels safe about a pad is that it's got the plastic. The bottom line is that it's plastic... there is plastic between you and, you know, your clo, your outside clothes..."* P01

Most women wanted to spend as little money on absorbent products as possible and would look for products that were on offer. The money spent on products was seen as necessary and participants didn't begrudge paying for the products.

*"Do you know, it sounds awful but I don't know how much they are because for essential things I just buy them (laughs), you know, like bread or milk, whatever. And um, I don't take notice of the price but I think, probably one, but I do look for cheaper ones ... there is a price range, but I just get the... cheapest, thinnest at the moment."* RF2

The less money they had to pay, the better, providing that the products had the qualities of the more expensive brands. If a product 'failed', participants would not use the product again.

*“Like at [supermarket 3] it says ‘women’s something or other’ and I think actually they’re one of the worst ones, actually [supermarket 4] is similar...”*

P07

#### **4.9.1.4 Sociotechnical node - People**

The participants’ main concerns about people were that no one should know that they were wearing an absorbent product. Design of the absorbent products, and the associated items, should allow women to maintain as much secrecy as possible. Participants were more concerned with what other people might think about the product in situ, rather than personal concerns about products.

*“They’re [manufacturers] obviously trying to appeal to younger women who don’t want to feel like they’re wearing some cumbersome thing. I mean even if you had a kind of little pouch at each end [of the knicker crotch] that [the pad] slotted in, you’re going to make it, as they would think, more visible in tight trousers or something. Um, but which is worse? Having a damp patch on your nice white tight trousers or (laughs)...I know which I would prefer I think.”* RF1

They believed that more could be done by retailers to make buying products easier, and that products designed for specific circumstances should be available at specialist retailers.

*“...probably online...or a sports shop, you’d expect, if it’s sports [induced UI]....”* P09

Buying products when using a staffed checkout could also be problematic. Women often looked for a staff member who they believed would be sympathetic to their product use, before selecting which checkout to use.

*“...I do actually feel sorry for, if there’s a boy on the till, um, you know, but it’s a fact of life isn’t it?”* P07

Although some participants had family members who would buy products on their behalf in some situations, procuring products was usually the responsibility of the participant.

*“Obviously we go shopping together and [he] will say ‘do you need some things?’ as we’re going past but then I’ll pick them up, but I never send them to go buy.” P08*

*“...I wasn’t allowed to drive [for a period of time], [my partner] used to go and get [the pads] for me and I thought that was above and beyond the call of duty.” P07*

#### **4.9.1.5 Sociotechnical node - Buildings and infrastructure**

Disposal was a major issue and participants wanted new designs which considered the process of use, in public spaces particularly. Participants would often look specifically for toilet locations when in public. This technique was used alongside absorbent product use, for either timed voiding, or dealing with ‘emergencies’.

*“Oh, do I like to know where the toilets are? You are not kidding. Yes...” P07*

Problems were noted in the merchandising of products by retailers. Products were not necessarily easy to find for those women who don’t know where to look.

*“...Is it a medical problem, or it is just, you know, a cos, not exactly cosmetic, but clen, hygiene...just cleanliness... problem, issue, like where you buy your shampoo and your soap, or is it where you buy your aspirins and your er, er, and such like, that’s quite an issue isn’t it?” P14*

#### **4.9.1.6 Sociotechnical node - Technology**

Participants had low expectations of what could be achieved from a new product. When given prompts, some women were particularly enthusiastic about absorbent products which could have a diagnostic element. They liked the idea that a urinary tract infection could be identified, prior to making a GP appointment.

*“That would be brilliant cos I don’t, I’m [asymptomatic with urinary tract infections]...so for me that would be perfect, it would be sort of ‘alright, tootle off to the doctor’ you know.” P08*

Others liked the idea of a range of products, for example ones that could be used whilst exercising, or which had characteristics which made them more appropriate for a specific circumstance.

*“... if it’s [a] piece of sportswear then you look in a sports shop...if I was buying that kind of thing it would be specifically for [exercising].” P09*

Participants were also keen to see technologies for additional items. As mentioned previously bags for disposal and underwear were particularly important. However, there were also opportunities for other types of clothing which would hide an absorbent product.

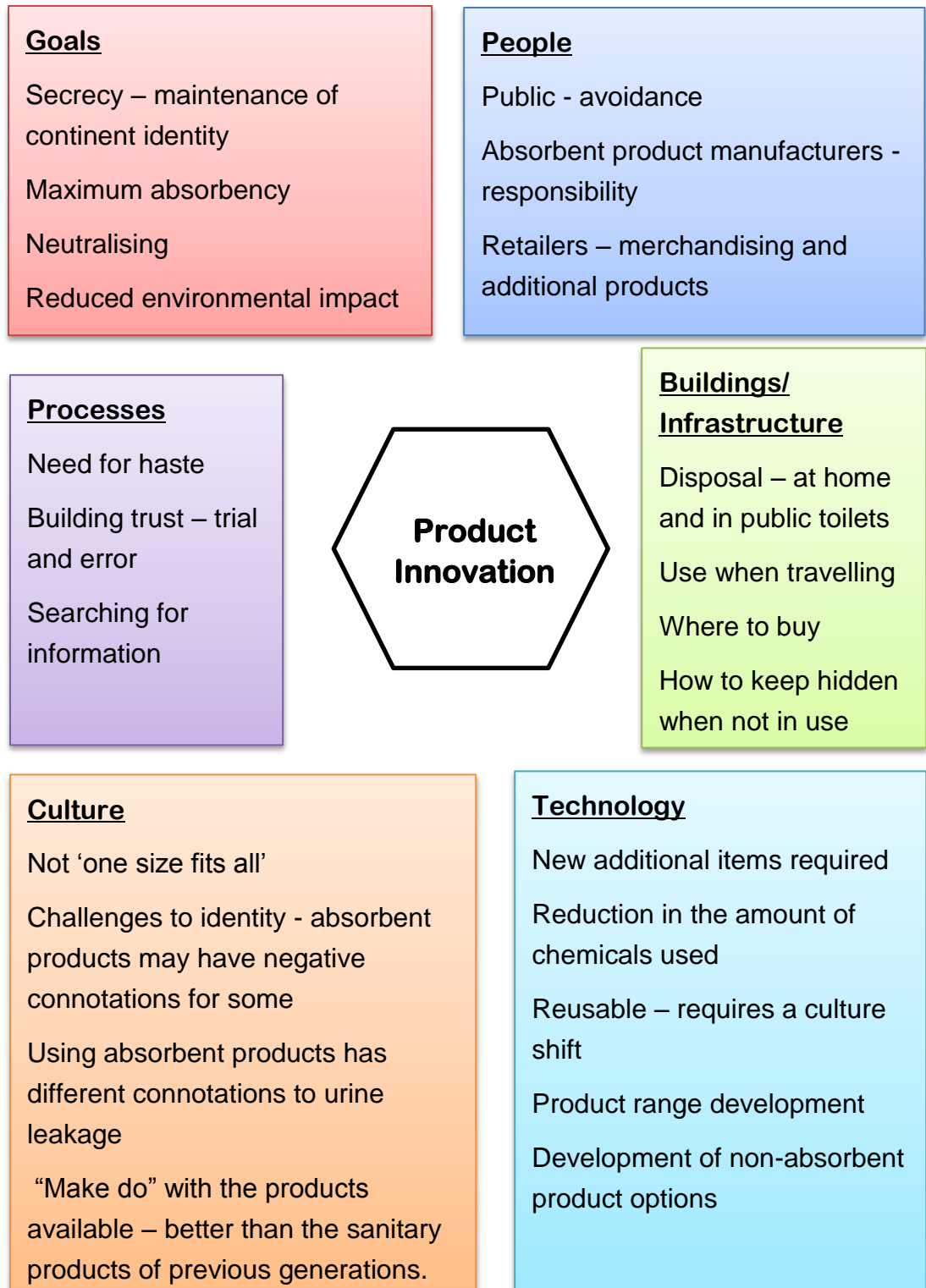
*“As I’m speaking I wonder whether there is a link there....mmmm because it’s a funny thing to do, to wear a skirt [for exercising] isn’t it? ...Some people just wear that and I’ve always assumed, I mean either you are very girly and like, just really like skirts, or you think you carry weight that you’d like to hide....I would assume it’s about you’re not happy with a part of your body but actually how interesting that may be, just some of those, because it hadn’t occurred to me that actually that [leakage] would be a massive, that would really get in the way of my [activities], so you know what’s to be done about that?” P01*

Neutralising products were favoured over fragranced products, as they were perceived to be less stigmatising.

*“Some of them are scented which actually is almost worse so (laughs) yeah, they’re just really horrible.” P09*

Products that would biodegrade over time, or that could be flushed down the toilet were also spoken about with enthusiasm by some.

*“That would be an amazing thing for all sorts of reasons. I mean, A) anything that’s flushable, it really was green-flushable...as in didn’t have implications for the oceans...that would be amazing.” P01*



**Figure 6 Women's priorities for absorbent product innovation**

## **4.10 Discussion of interview study**

The interview study aimed to investigate women's experience of urine leakage and the use of absorbent products. The integrated question guiding the interview study was "what are women's experiences of urinary incontinence and absorbent products?". This question was developed to meet the first two research objectives and was established as a result of the literature review.

The literature review had identified that whilst many women do use absorbent products, their use is often complex with many psychosocial implications. The work of Getliffe et al. (2007) was identified as the best source of evidence to build upon. From the results of the literature review and in conjunction with reference group opinion, research objectives for the study were developed. The first two objectives were met through the interview study; to describe and understand experiences of women with urinary incontinence; and to understand the use or non-use of absorbent products for containing urine. The interviews were conducted either face-to-face (n=9) or by telephone (n=2) using semi-structured questioning. The interview data was analysed using thematic analysis and the resultant themes identified aspects of commonality between participants. A second analysis was conducted using the socio-technical design model, which used a priori themes taken from the nodes of the model to stratify and explain data relating to absorbent product use.

This section discusses whether the study aims and objectives were met, the conclusions that can be drawn from the study and the strengths and limitations of the study.

### **4.10.1 Main findings of the interview study**

A gap noted in the evidence base described in Chapter 2 concerned the distinction often drawn between experience of urinary incontinence and use of absorbent products. Findings from previous literature on absorbent product use suggested that product use was closely linked to experience of urinary incontinence and therefore a decision was made to investigate both



phenomena using an integrated question to frame the study. Use of terminology which was better suited to potential participants' understanding of their symptoms was made after discussion with the reference group, removing all reference to incontinence from the study. Instead, symptoms were referred to as urine leakage to minimise the negative connotations associated with other terminology. Potential participants were invited to opt-in to the study through a range of advertising materials. Recruitment was designed to reduce the likelihood of public identification of women who may be eligible for the study. Interviews took place by telephone or face-to-face. Women who were unable to travel to the university were offered opportunity to be interviewed in their homes. The interview study findings provided empirical evidence for considering experience of urine leakage and absorbent product use collectively. This complements and reinforces the work of Getliffe et al. (2007) who recognised the experience of living with urinary incontinence affected psychosocial outcomes for women using absorbent products.

Eleven women were interviewed for the study, including two reference group members. Analysis of the interview transcripts identified three themes, which sought to describe important aspects of women's experience, taking into account their decisions about whether or not to use absorbent products as a coping strategy. Whilst three over-arching themes were generated, not all participants had similar experiences of urine leakage, nor did all women feel similarly about the use of absorbent products. This will be discussed further in the following sections.

#### **4.10.1.1 Maintaining Identity**

All participants spoke about the need to maintain an identity with which they felt comfortable. For some, this meant a continuation of their previous continent identity, for others it meant accepting leakage as part of their identity. To maintain identity, the women appeared to undergo negotiation processes which enabled them to adapt, thereby understanding and coping with symptoms. This was not only apparent in learning to manage symptoms, but also in the decisions to use absorbent products. Importantly,

the findings suggested that adaptation was undertaken practically, through changes in behaviour, and psychologically, through changes in expectations and beliefs. Both types of adaptation appeared to affect functioning in the social world to a greater or lesser degree. However, these changes were not absolute, nor were they exact. There appeared to be some fluidity in the behaviours and beliefs of women towards their experience to ensure that maintenance of identity could be maintained. This was particularly evident in the quotes which exemplified conflicting thoughts of participants on the same subject.

It was apparent that participants were attempting to make meaning out of their experience, either through assigning cause or rationalising behaviours. Meaning-making is thought to be associated with mental well-being following adverse events and may support adaptation (Klinger, 1998; Bonanno, 2013). The findings of this research suggest that meaning-making was a process of maintaining identity which enabled women to understand symptoms and facilitated coping. However, there is also evidence to show that meaning making may be linked with poorer mental health outcomes (Park, 2010). Urinary incontinence is thought to be associated with reduced mental well-being for some, being linked to symptoms of depression and anxiety for example (Bogner et al., 2011; Felde et al., 2012). Waters et al. (2013) found the association between meaning-making and distress was linked to whether the adversity in question was considered part of an individuals' identity. Therefore attitudes towards experience of urine leakage may impact on ability to cope depending on how maintaining identity is achieved.

There were a number of reasons why participants thought they experienced leakage. Amongst these reasons were female-specific biological changes after childbirth or as a result of ageing. There appeared to be a gendered approach to understanding the experience of leakage, which has also been found in other qualitative research on the subject (Horrocks et al., 2004; Esparza et al., 2018). Whilst some participants noted the possibility of men experiencing urine leakage, examples were explained in relation to other health conditions, rather than as an effect of a life process which was more common when discussing female experience. The assumption that symptoms might be expected at various stages of life may affect attitudes to

help-seeking. Previously Teunissen and Lagro-Janssen (2004) found older adults expressed similar attitudes about expectation of symptoms as those seen in this study, their results also showed that women waited until their symptoms were far more severe than men before seeking help. Attributing cause to the ordinary life course rather than to an underlying pathophysiology may normalise symptoms and in turn affect coping strategies.

Participants noted a range of coping strategies, one of these being the use of absorbent products. Products were selected depending on a number of factors related to maintenance of identity. Some women mentioned a trial and error approach to product use, or the need for a range of products dependent upon activity, which is consistent with other literature (Hayder and Schnepf, 2010; Fader et al., 2014). Use of absorbent products facilitated the need for a continent social identity, but use of products also affected the clothing that women were able to wear. Adaptation of clothing choices was sometimes necessary to ensure that products would be hidden and be effective. Twigg (2007, pp.290) suggests that clothing is used to “*display, underwrite and express social and cultural meanings*”; clothing has the ability to reflect or reject bodily changes. Participants of this research provided examples of the use or non-use of absorbent products in relation to clothing choices, illustrating both rejection and reflection of the changes encountered as a result of leakage. Clothing has long been recognised as a form of communication to negotiate identity and there is potential for this aspect of research to be developed further, to facilitate improvement of clothing which satisfies women’s desire to maintain identity despite experiencing leakage.

#### **4.10.1.2 Communication**

Several participants when talking about their experience would alternate between referring to their experience in the first person, using the pronoun ‘I’, to the second person pronoun ‘you’. This can be identified through the quotes from a number of participants in this chapter. Distancing in this way has the potential for positive and negative psychological effects, but is used

as a defence in situations where there is a perceived threat to something which is considered valuable but vulnerable (Davy and Cross, 2004). The use of 'you' as a defence is illustrated very clearly by the quote by P08 describing "you" as a combatant. *"You're sort of like, it's like being a sniper and you're going into combat [looking for toilets in public].... You're sort of subconsciously, you're doing that 'where's the next ones?..."*. The participant was able to convey meaning through shared understanding of a sniper, using war imagery to highlight the challenges of locating toilets. Whilst the phraseology of 'you' may suggest defence, the imagery portrays attack, control and an elevated sense of situational-awareness. This quote is able to highlight positive aspects of the participant's character, for example the ability to not raise concern amongst others and operating on a level which is unrecognised by those in the vicinity. It illustrates the communication between researcher and participant has a level of distancing, but it suggests that the participant makes choices about how to communicate with others around her through concealment and by maintaining anonymity. Whether consciously or subconsciously, participants demonstrated their vulnerability and defences against it using carefully selected phraseology. Although perhaps unrecognised as such, similar communicative strategies are evident in other qualitative studies with similar populations (Andersson et al., 2008; Getliffe et al., 2007).

In addition to defence, using "you" to describe a personal situation facilitates espousal of a rule (Sacks and Jefferson, 1992). By identifying a problem and satisfying conditions to enable a particular outcome, the speaker is able to communicate effectiveness and also the moral correctness of the action. Describing actions in this way provides group affiliation (Sacks and Jefferson, 1992). For women experiencing urine leakage, this may be particularly important; their understanding of the issue may be limited, in addition to uncertainty about other's behaviour in similar situations. By linguistically providing generalised rules of behaviours, and thereby creating a 'group' to which "you" belong, women were able to provide a stable narrative platform by which to explore their own actions. Róin and Nord (2015) suggested that when women in their study used "you" it gave opportunity for the interviewer to provide their own personal opinion, allowing

the participant to make judgement on the interviewer's group affiliation. Recognising the similarities between this study and research conducted in other European settings may suggest that communicative strategies may be similar across a number of cultures or sub-cultures. There is currently little evidence to support the idea of language as a coping strategy for incontinence, although it has been noted that discussing symptoms may influence coping (Jackson et al., 2012). However, cross-disciplinary literature outlines the importance of narrative and language use in relation to other potentially stigmatised health concerns (Raoul, 2007; László et al., 2013). Using language as a coping style may be indicative of hardiness. Israfil-Bayli et al. (2015) hypothesise that women with urinary incontinence who exhibit control by viewing their circumstances as challenge rather than a threat and who show positive engagement with their lives may have better ability to cope with symptoms. The use of certain terminology may be an example of this. Some participants had strong views on the appropriateness of the word 'incontinence' and preferred other terms which were less socially problematic, recounting examples of how they may approach mentioning symptoms with others, with examples given which avoided having to mention anything about incontinence or urine. The participants indicated that there was some shared understanding with the receivers of the information. Anatomical explanations were sometimes mentioned by participants, for example expressed as issues with the bladder or pelvic floor. The use of analogy has been noted elsewhere, organs may be considered containers (Faure, 2016). The structures noted within this study are internal and therefore may be perceived to have far less societal threat than urine which may have connotations of dirt and danger (Douglas, 2002).

Discussing symptoms was generally avoided, although female friends and relatives were likely confidantes. Despite many suggesting that embarrassment was not a problem when discussing symptoms it was still avoided by most, which suggests that other factors influence the decisions of whether to disclose. Urinary incontinence may be perceived as a private problem and therefore the benefits of communicating with others are outweighed by the threat of identification, which could affect identity. Previous research has suggested that there may be some cultural

dependence on the perceived importance of disclosure to others, which may affect help-seeking behaviour (Jackson et al., 2012).

#### **4.10.1.3 Seeking help and information**

Uncertainty about symptoms and healthcare intervention created uncertainty about the appropriateness of help-seeking. This ambiguity caused challenges for participants whether they had sought help previously or not. Tolerance of ambiguity is the ability to adapt based on probability rather than certainty (cognitive rigidity), and may enable more effective coping (Yakhnich and Ben-Zur, 2008). It might be suggested that participants expressed both tolerance of ambiguity and cognitive rigidity depending on the experiences they were discussing. Notably, there appeared to be more cognitive rigidity when discussing healthcare professionals and systems. Participants suggested there were expected and optimal outcomes to seeking help, so when these expectations were not met the impact was perceived negatively. In the opinions expressed by participants, there appeared to be disparity between expectations of professionals and the reality of intervention, which is congruent with the findings of Róin and Nord (2015). Valpas et al. (2015) found that patient satisfaction of surgical intervention for urinary incontinence did not necessarily correlate with success from a healthcare perspective, which suggests that expectations of healthcare from patient and professional perspectives may be dissimilar for a number of people seeking treatment for urinary incontinence. As the participants who had previously sought treatment had not returned for additional help when symptoms reoccurred, it would be reasonable for the services they accessed to presume the problem had been successfully treated, despite this not being the case. Previous research by Basu and Duckett (2009) found reasons for not returning to care despite ongoing symptoms were situated within a social prioritisation process. This study found the overriding factors in not returning when symptoms persisted were based on social and environmental considerations, for example, the way healthcare services had to be accessed, including time considerations.

Most participants understood the leakage they experienced to be a social or hygiene issue rather than one of health, which may inhibit help-seeking behaviours. Frank (2014) hypothesises that experiences become part of a personal narrative through retelling. Often experiences of urine leakage are not retold because of the moral challenges incontinence can create and as a result bypass the opportunity of becoming recognised as a part of oneself. These memories may be hidden from conscious memory, as indicated by the participants who did not remember times when leakage had caused them embarrassment until they were prompted through other discussion. Therefore the ability to disclose urinary incontinence to healthcare professionals may be impeded by the fact memories are not easily recounted or are not associated with a health narrative (Frank, 2016).

The knowledge and information women have access to regarding incontinence may also inhibit help-seeking behaviours. A number of participants talked about use of the internet to find information. Concerns were raised about the quality of information available and the caution that some participants had about trying to search for it. Quality of information relating to incontinence on the internet is known to be variable, and it has been suggested by a number of authors that better evidence-based information is required (Dueñas-Garcia et al., 2015; Larouche et al., 2016; Saraswat et al., 2016). Publicly available information on internet blogsites, written by women experiencing urinary incontinence suggests that women present themselves as fit and healthy despite incontinence (Saiki and Cloyes, 2014). Jokes and casual references to incontinence were made by the bloggers which may influence those looking for information, by strengthening cultural understanding of symptoms. Knowledge about urinary incontinence and other pelvic floor disorders has been shown to be generally poor, even by those with high literacy levels (Anger et al., 2012; Mandimika et al., 2014). Societal influences affecting understanding of symptoms appeared to be very strong, however as health literacy was not assessed firm conclusions cannot be drawn in this regard, other than to note that even those participants who had accessed healthcare still expressed opinions which were rooted in lay-understanding.

#### **4.10.2 Findings using the Sociotechnical design model**

The use of the sociotechnical design model was useful in considering the elements which are essential to system design. The topic under investigation can be considered an interconnected set of systems within which women operate, however in terms of usefulness to the research aim, the model was best suited to the second objective relating to product use. According to Clegg (2000) the principles relating to sociotechnical systems are subdivided into those relating to process, content and overarching meta-principles. Upon completion of the interview study it was clear that whilst the data met many of these principles, there was an underlying assumption by the authors of the model that the needs of the end-users within the system would be congruent, or at least negotiable, with others in the system. In this instance, considering a sensitive subject and a largely hidden population, those assumptions could not be made. In addition, whilst some women may have felt comfortable to talk about their experience, many others may not and so open dialogue within the system (and sub-systems) may not be established as might be expected in other systems. Therefore, the model was useful for developing a better understanding of product use, but not for understanding women's experience as a sociotechnical system. The relevance of the findings of this study will be considered in greater detail in Chapter 6.

#### **4.10.3 Strengths and limitations of the study**

The interview study met the aim of the research by addressing the first two research objectives. These objectives were to describe and understand experiences of women with urinary incontinence; and to understand the use or non-use of absorbent products for containing urine. An integrative research question to guide the study was developed based on the findings of the literature review. The question guiding the interview study was "what are women's experiences of urinary incontinence and absorbent products?". Experience of urinary incontinence and the use of absorbent products were explored with participants through semi-structured interviews. Interview data



was transcribed and thematically analysed. After separate analyses of data relating to lived experience and product use had been considered, a combined thematic analysis was undertaken to ensure that data relating to both aspects was described and explained in context. The data was grouped within three themes, maintaining identity; communication; and seeking help and information. An analysis of absorbent product use using the sociotechnical design model was also undertaken to further consider aspects of product use. This analysis used the nodes of the sociotechnical model as deductive themes. Taking such a systematic and thorough approach to analysis ensured that findings were representative of the data set and met the research aim and objectives.

A particular strength of this study was the incorporation of the reference group to help design the study. Patient and public involvement is a well-recognised method of ensuring that research is appropriately focussed and can address the needs of the populations it seeks to investigate. The reference group were able to identify potential challenges that might have been encountered during the study. They helped to overcome these challenges through changes to recruitment materials, including changes to terminology describing urinary incontinence.

By recognising that women may not understand their symptoms as a health matter, as explained by the reference group, the social and moral aspects of experience could be investigated. Whilst it might be considered that asking women to speak about their experience without overtly acknowledging the health implications may minimise the study's relevance to the wider literature base, it could also be argued that by taking such an approach it enabled participants to frame their experience in a way that made sense to them. This ensured that the findings of the study are relevant to those who wish to understand the daily lives of women who experience urinary incontinence. As it is believed that many women do not seek help for symptoms, qualitative research which explains experience from a social perspective is highly relevant to healthcare professionals and providers who wish to better engage with women on this subject matter.

Qualitative interviews were a suitable method of data collection to ensure rich data could be obtained. The interviews enabled participants to speak at length about their experiences to facilitate a good depth of understanding. A semi-structured approach, using a topic guide, rather than pre-defined questions allowed for a level of variation in the questions asked of each participant, ensuring that each topic discussed could be elaborated upon. The data generated by the interview ensured that the research objectives of describing and understanding experience of urinary incontinence and understand the use or non-use of absorbent products could be adequately met.

No efforts were made to define symptoms. Despite considering the use of a questionnaire to indicate symptom type and severity, it was decided that this may be inappropriate and challenge women's understanding of their experience. Since this research was undertaken, the quantitative tool considered for use in this study, the ICIQ-UI-SF, has been updated to reflect some of the challenges of use noted by the reference group. Understanding more about symptom type may have enabled stratification of findings by type and severity of symptoms.

Although some demographic data was collected, collection of additional information may have benefitted analysis. In particular collecting data relating to pregnancies and levels of education may have revealed additional insight into women's experiences. The need to further understand women's experiences of urinary incontinence and the use of absorbent products might be considered to outweigh this limitation as no previous research exists which considers women in the chosen geographic area. Therefore, whilst the analysis may have been strengthened by collecting additional data, the findings remain important to understanding the population under investigation.

The themes generated in this study like much qualitative research are not generalizable, but may be transferrable to similar populations (Pope and Mays, 2006). As the study sought to understand the experiences of women within a small geographical area, the findings should be considered within that context. It is important to consider the cultural aspects affecting

participants, particularly as others have suggested cultural differences in how women may understand and cope with urinary incontinence (Bradway et al., 2010; Apostolidis et al., 2012).

#### **4.11 Conclusion**

This qualitative study aimed to understand women's experience of urine leakage and their use of absorbent products, by building on the work of Getliffe et al. (2007). The research was informed by a reference group who helped design the study and provided feedback on recruitment. The interview study was able to meet two of the research objectives; to describe and understand women's experience of urine leakage; and to describe use or non-use of absorbent products for containing leaked urine. It was able to do this through use of semi-structured interviews with women who self-reported urine leakage. Eleven interviews were conducted in total, including two with reference group members. Interview data was analysed thematically and using a sociotechnical design model. Three themes were generated from the thematic analysis; these were Maintaining identity; Communication; and Finding help and information. The sociotechnical design analysis considered experience as a social system and described a range of factors which were important to absorbent product use and design. Both sets of findings highlighted the importance of social factors to understand how women live and cope with urinary incontinence. Participants aimed to live with symptoms by maintaining a sense of stability. This was facilitated by a range of coping strategies, including absorbent product use.

#### **4.12 Chapter summary**

Semi-structured interviews were undertaken to elicit responses from participants with regard to their own experience of urine leakage and use of absorbent products. Eleven interviews took place either face-to-face or by telephone.

Three themes were generated by analysis; Maintaining identity, Communication, and Seeking help and information. A sociotechnical design model was used to consider participant views about absorbent products, using six deductive themes taken from the nodes of the model.

Findings suggested that the need to maintain an accepted identity with was important, but the experiences of urine leakage meant this was sometimes challenged. Absorbent products were one coping strategy used to help maintain a continent social-identity, but decisions on their use or non-use were made based on a need to maintain identity. The ways in which women communicated with others, verbally and non-verbally, was a method of coping. Careful communication helped women navigate some of the challenges that urine leakage and absorbent product use caused. Some participants suggested symptoms would have to become more severe or more frequent if help were to be sought. Trust of professionals was noted as a facilitator to help-seeking, but several factors were identified as barriers to help-seeking, including knowledge of symptoms and social circumstances. The information that women wanted about symptoms and intervention was not always presented in ways that facilitated them to be able to self-care. Healthcare systems and professionals were judged on how supportive they were perceived to be.

The sociotechnical analysis suggested that there were a number of goals when using absorbent products, ultimately women wanted products that would provide social continence by providing absorbency, comfort and discretion. The use of absorbent products includes the whole life-cycle from purchase through to disposal. There was a requirement for each stage of use that may increase vulnerability of identification by others, to be hastened. Suggestions were made for product development and marketing, taking cultural considerations into account.

Data from this study informed the Q study, which will be discussed in the next chapter.

## **Chapter 5 Q study**

### **5.1 Introduction**

This chapter will describe the second empirical study undertaken during this research. Q methodology was employed to expound the findings of the qualitative study; furthering the understanding of women's attitudes to urine leakage and the use of absorbent products. The process of designing and implementing a Q study will be explained throughout this chapter. The chapter begins with a rationale for the study, and justifies the use of Q methodology to answer the research objectives. It then explains how interview data was used to inform development of the Q-set. Ethical and governance issues are addressed, before pilot testing and recruitment are considered. The process of data collection is explained, followed by an explanation of data analysis. The chapter will culminate in the findings obtained from this study and discuss implications for future care and product development.

### **5.2 Rationale for the research**

The interview study found that participants were keen to maintain an identity which allowed them control of their lives, this included communicating about leakage in ways which facilitated coping in a variety of circumstances. Not all participants wanted to access professional help for their symptoms. Decisions regarding help-seeking were affected by previous experience of healthcare and how they understood the symptoms. Often leakage was perceived as a social issue, rather than a health problem. Absorbent product use was idiosyncratic, not all participants were happy to use absorbent products. There were products deemed to be more acceptable by some, and active decisions were made about when product use was appropriate. A number of functionality issues were noted by participants who had used absorbent products. These findings were congruent with that of the literature

review which showed that decisions regarding absorbent product use were multi-factorial. Using absorbent products to cope with urine leakage was not a simple decision-making process. Whilst a continent social identity was the participants aim when using absorbent products, there remained social and physical difficulties resulting from their use.

The Q study was designed to continue exploration of the research aim by meeting the research objective of characterising women's attitudes towards their experience of urine leakage and absorbent product use. Q methodology was deemed to be appropriate for understanding women's experience of urine leakage and use of absorbent products because it is designed to assess individual perspectives (Dziopa and Ahern, 2011).

The study was designed to take into account two closely related concepts. Firstly to examine women's attitudes to their experience of urine leakage, and secondly to examine women's attitudes to use of absorbent products for urine leakage in relation to this. Characterisation of these concepts further illuminates the findings presented in Chapter 4.

The literature review lead to the proposition that understanding of women's experience of leakage symptoms and use of absorbent products should not be considered in isolation from one another, as they may not be mutually exclusive. A literature review by Siddiqui et al. (2014) previously found that experience of urinary incontinence and management of symptoms by women were overlapping concepts when considered in the context of different cultures. By considering only one aspect within the Q study, characterisation of attitudes may not have been wholly representative of participants' attitudes. Whilst it could be argued this would constitute two topics under investigation, taking this exploratory approach to the multi-faceted subject enabled further awareness of attitudes of women towards this phenomenon.

The aim of the Q study was to systematically characterise the attitudes of women to their experience of urine leakage and the use of absorbent products.

### 5.3 Q methodology

Q Methodology “*combines the richness of interviews with the standardization of a survey*” (Donner, 2001, pp.24). As explained in chapter 3, Q Methodology was designed by Stephenson to measure subjectivity; that is, participants’ views and opinions about a particular topic. It is based on the foundation that subjective points of view are communicable and established from a position of self-reference (Niemi, 2013). Q methodology is a well-established method of conducting research in psychology and has been increasingly used in other areas of research including healthcare (Holt, 2006; Honey et al., 2013; Alderson et al., 2018). Q methodology is able to systematically characterise attitudes about a topic. It seeks to find correlation between people’s points of view, creating factors which are the basis for classification (Stephenson, 1955). Factors will be explained in more detail in 5.13.1.

Self-referent attitudes form a behaviour which can be objectified, defined and studied. Whilst subjective attitudes expressed by participants may not form the basis of experience, they are important to understanding how people think about experience (Stephenson, 1955; McKeown and Thomas, 2013). Q methodology is used to find correlation between attitudes within a sample by using by-variable analysis. In Q methodology, by-variable analysis seeks to find correlation between people, rather than correlation between variables measured within the population (Watts and Stenner, 2012). The result of this is a holistic approach to identifying types of people, or views across contexts, resulting in factors which are “*numerous and broad*” (Burt and Stephenson, 1939, pp.274). To ensure that factors are representative of real viewpoints, factor rotation is also necessary. To produce the most relevant factors, rotation ensures that Q-sorts are as closely aligned to factors as possible. This is explained further in section 5.12.

Some terminology used by Q methodological researchers is specific to the methodology. Therefore a table of common terminology, as defined by Bryant (2003, pp.81) is provided (Table 14).

Term	Description
<b>Concourse</b>	The discourse or 'flow of communicability' about the topic of interest i.e. what is said about urine leakage – in this instance taken from interview data
<b>Exemplar</b>	A Q-sort that loads significantly only onto one factor and thus exemplifies the view represented by that factor
<b>Factor</b>	A factor represents one understanding of the topic of interest. The viewpoint is operationalised by merging exemplar Q-sorts for each factor to produce a synthetic composite called a factor array
<b>Factor array</b>	A synthetic Q-sort used as the physical representation of a particular understanding or factor
<b>Item</b>	A statement of proposition relating to the topic under enquiry.
<b>P-Set</b>	The 'person set' of study participants
<b>Q-Sample</b>	The sample of items selected to represent the whole concourse
<b>Q-Set</b>	The Q-sample transcribed onto a set of cards used in the Q-sorting process
<b>Q-Sort</b>	The results of the ranking procedure whereby each item is allocated a score. The Q-sort represents the pattern of beliefs of the individual sorter
<b>Q-Sorting</b>	The process by which items are ranked or sorted.

**Table 14 Definitions of Q methodological terms** (Bryant, 2003)

Q methodology aims to measure subjectivity; it's application comprises five stages as described by Holt (2006, pp.93); "*definition of the concourse; development of the Q sample; selection of the P set; performing the Q-sort; and analysis and interpretation*". These stages will be clarified throughout the following sections. This study followed the methods described by Watts and Stenner (2012).

Q methodological data is collected via a method known as Q-sorting. Before Q-sorting can take place, items for ranking within the Q-sort need to be developed. Through a process of refinement these items, usually



statements, become the Q set. The first stage of this process is defining the concourse, a large collection of statements about the topic under investigation.

#### **5.4 Development of the concourse**

The concourse describes the information which provides a foundation for item development (the Q set). The concourse is made up of a large number of opinion statements about the topic under investigation (Paige and Morin, 2014). The statements which form the concourse can be collected from a range of sources including conversation, literature, pre-existing data and hypotheses (Bartlett II and DeWeese, 2014). As opinions on any given subject are potentially infinite, the concourse aims to be representative of a broad range of views (Stephenson, 1986). The concourse contains more information than can be used within the Q set itself but is the basis from which the researcher can gain insights into behaviour (Stephenson, 1986). Development of a concourse is necessary in Q Methodology to ensure that the resulting Q-sort results may be representative (Simons, 2013).

The concourse for use in this study was developed using data that had been collected through the interview phase. Using interviews to inform the concourse is the traditional form of gathering data for use within Q Methodology (Brown, 1996). Whilst other forms of data could have been used to inform this study, the decision to only include interview data was made. The understanding of and coping with urinary incontinence may be culturally-specific and therefore developing concourse statements generated from culturally-specific data was justified (Cross et al., 2014). By using a concourse that was contextually appropriate, the Q-sort results could provide more insight into this population and be more representative of the views of the women it sought to understand (Horsfall et al., 2009).

Raw interview data from the interview phase was tabulated using Microsoft Excel. In total, 179 statements were included within the concourse. Each statement was categorised, using seven inductive themes which were generated through an iterative system of thematic coding (Fereday and Muir-

Cochrane, 2006). Similar to thematic coding for qualitative analysis, concourse statements were assigned a code which helped to condense the information into a summary format, establish links between statements and provide a framework (Thomas, 2006). Those statements with the same or similar codes were grouped together. Codes were then developed to better fit the statements that they represented until clear themes emerged. The themes used at the first stage of refinement are shown in Table 15.

Theme	Number of statements	
	Original Concourse	Final Q Set
Education	16	4
Help-seeking	24	6
Health Beliefs	24	5
Coping Strategies	35	8
Feelings associated with leakage	31	6
Managing a secret	14	3
Using absorbent products	35	11

**Table 15 Themes used during concourse refinement**

## 5.5 Developing the Q sample

Items for the Q sample can be developed in a structured manner, using pre-defined theories, or in an unstructured manner (Paige and Morin, 2016). The Q sample should be indicative of the larger concourse which it represents (Brown, 1993).

In this study, statements were initially developed in an unstructured way, based on the data from the interview phase, a process which has documented by Sæbjørnsen et al. (2016). They were then validated and revised using a structured approach, considering literature from the evidence base and using the six interconnected nodes of the sociotechnical model; people; culture; goals; processes; technology; and environment. Using the

sociotechnical design model (section 3.10) in this way ensured consideration was given to the material and human aspects of the topic whilst developing the Q sample. The process of using inductive and deductive coding of raw qualitative data has been used successfully by others, and was also appropriate to this study to ensure rigor by providing a alternative methods of interpretation (Fereday and Muir-Cochrane, 2006)

Q sample items should be clear and contain only one concept where possible. Statements which contained similar ideas were either integrated into one item, or one of the items was removed, to prevent duplication and ambiguity (Perz et al., 2013). Four rounds of refinement were undertaken prior to pilot testing (section 5.7). The first two stages of refinement considered the concepts contained within the items, the second two considered the statement wording, ensuring that half the statements were positive and half were negative.

At the end of this refinement, forty-three items were grouped by the themes originally attributed to them during the first stage of development. They were also assigned to a node of the sociotechnical design model to ensure items represented each of the nodes in the final Q set.

<b>Sociotechnical Node</b>	<b>Number of items</b>
Culture	13
Environment	4
Goals	8
People	5
Processes	7
Technology	6

**Table 16 Sociotechnical nodes represented by items in Q sample**

Items relating to culture were more numerous (n=13) than items representing any other sociotechnical node (Table 16). Due to the relationships between nodes, although statements were categorised by one

node, many also contained views that were characterised by additional nodes. A decision to use a larger number of cultural items was made to ensure that the Q sample was representative of the discourse and reflect the data that had been collected in the interview study. Face validity was provided at each stage of development by a second researcher with Q Methodology expertise. A content validity check was undertaken by a reference group member to provide subject expertise (Akhtar-Danesh et al., 2008).

A minority of the items were developed in such a way that the ideas which they represented, were modified from the data which had influenced them. The decision to include statement six; "*Nurses understand more about leakage than doctors*", was made based on data which spoke about experience of healthcare professional attitudes, rather than any participant explicitly expressing this view. Statement twenty-one "*Leakage does not affect my life decisions*" was influenced by the literature, although interview participants had expressed that leakage could affect some decision-making. The inclusion of statement thirteen: "*Leakage and incontinence are not the same thing*", may appear to contradict a fact. However data from the reference group and interviews had already clearly shown that the concepts were unrelated in the understanding of many women. From a social perspective, leakage and incontinence are discrete concepts which often describe different phenomena (section 4.7.1).

#### **5.5.1.1 Q-set**

Q sample items are printed onto individual cards, so that they can be assigned appropriately during the sorting process. These cards form the Q-set. Items were printed onto laminated cards (6x4cm), each with an identification number at the bottom right corner (Baker et al., 2006). The final statements used in the Q-sort statements, with corresponding inductive themes and sociotechnical nodes are shown in Table 17.

**Table 17 Final Q-set**

	<b>Theme</b>	<b>Node</b>	<b>Statement</b>
1	Education	Culture	Education about leakage should start in school
2		Technology	I wouldn't use the internet to find information about leakage
3		Environment	There isn't enough information about how to manage leakage
4		Processes	Leakage should be covered in routine check-ups
5	Help-seeking	Environment	Pharmacies should offer information about ways to manage leakage
6		People	Nurses understand more about leakage than doctors
7		Processes	It isn't possible to get help for leakage without making a GP appointment
8		People	It is important to trust a health professional before talking about leakage
9		Culture	I don't think leakage is a medical problem
10		Processes	It is difficult to admit experiencing leakage
11	Health beliefs	Culture	Leakage is a warning sign for another issue
12		Culture	Leakage is inevitable
13		Culture	Leakage and incontinence are not the same thing
14		Culture	I don't worry about leakage
15		Culture	There is no cure for leakage
16	Management strategies	Processes	I feel responsible for the leakage I experience
17		Goals	Pelvic floor exercises do not prevent leakage
18		Goals	Absorbent pads are the easiest way to manage leakage
19		Goals	Maintaining secrecy is a priority when experiencing leakage
20		Environment	Knowing where the nearest toilet is important
21		Goals	Leakage does not affect my life choices
22		Goals	Improving lifestyle does not improve leakage

	Theme	Node	Statement
23		Processes	It is possible to successfully plan for leakage
24	Social factors	People	The leakage I experience is not as bad as other people's
25		Goals	I try to forget the times leakage caused me embarrassment
26		Processes	Leakage does not reduce enjoyment of activities
27		Culture	Leakage is a sign of a naturally aging body
28		Culture	There is a stereotype for someone that experiences leakage
29		Culture	Attitudes towards leakage are negative
30	A managed secret	People	It is easier to talk to someone who has similar issues
31		Culture	I don't worry about the odour from leakage
32		People	Leakage does not affect personal relationships
33	Absorbent products	Culture	Using an absorbent product is a last resort
34		Culture	Absorbent products don't meet my lifestyle needs
35		Goals	A premium product that guaranteed discreetness would be worth paying for
36		Goals	Cost of absorbent product is as important as performance
37		Environment	The environmental impact of absorbent products is not acceptable
38		Technology	Products should be designed to last for several hours before they are changed
39		Technology	Absorbent products are not comfortable to wear
40		Technology	Absorbent products should not be fragranced
41		Processes	There should be products designed for different situations
42		Technology	Absorbent products for leakage and sanitary towels are the same
43		Technology	A reusable product would be better than a disposable one

### **5.5.2 The sorting distribution**

After the Q-set had been designed, the manner by which distribution would be arranged was considered. Q-set cards are placed on a distribution grid during the sorting process, so that items can be ranked, usually by strength of agreement (Brown, 1996). Stevenson advocated the use of a quasi-normal distribution, however non-symmetrical grids can be used if desired. Distribution effects have been shown to be negligible; the pattern of statements in relation to one another is of much higher importance (Watts and Stenner, 2012). The distribution is designed in such a way that positively rated items are placed at one end, and negatively rated items at the other. Statements placed in the middle are not necessary neutral, but elicit weaker responses than those placed at the extremities.

A nine-point distribution grid was used within this study. It was sized to accommodate the Q-set cards (Figure 7). Brown recommends that nine-point distributions are used for Q sets of 40 statements or less and eleven point distributions for those between 40-60 statements (Brown, 1980). However, he also suggests that a steeper distribution curve requires fewer decisions, as there is more option to place several statements in the same column. Therefore a nine-point distribution curve with a steep curve was used in this study (Brown, 1980).

By enabling participants to place three statements at the extremities of the grid, any conflicting priorities would be evident. However using this distribution also meant that determining a single 'top priority' should there be one, would not be gained. Due to the nature of the population under investigation and the research question posed, it was more important to understand the range of priorities, rather than a single top-priority.

+4	+3	+2	+1	0	-1	-2	-3	-4

**Figure 7 Sorting distribution as used within the study**

### 5.5.3 Qualitative data collection

Collecting qualitative data when undertaking Q-sorts is not imperative, but greatly aids analysis. Several methods of qualitative data collection exist. These include -

- Audio-recording whilst the Q-sort is undertaken; verbal data is collected in much the same way as an interview.
- Questions asked about statement placement and field notes taken upon completion of the Q-sort (Cai et al., 2016).
- Materials provided for participants to make notes about statement placement (Stenner and Rogers, 1998).

In this study, a booklet was compiled providing space for participants to write anything they thought was pertinent about the items. As qualitative data is not essential to Q methodology participants who wanted to maintain a greater level of privacy did not have to provide any information in the booklet. In addition to space for note making within the booklet, a demographic tool and closed-questions relating to experience of leakage were printed at the back of the booklet. Using a booklet to collect qualitative data collection enabled women to provide data without having to discuss anything verbally, allowing women to engage with the study and maintain



some privacy. Field notes were also taken, when appropriate; for instance when participants did not want to write anything themselves, but wanted their opinions to be included in the data analysis.

## **5.6 Ethics and governance**

Ethical approval for this phase of the research was gained at the same time as for the first phase of the study (section 3.13).

### **5.6.1 Pre-consent information**

Women who expressed interest were provided with a participant information sheet in response to initial contact with the researcher. After reading the participant information, participants were invited to ask further questions or arrange a meeting to undertake the Q-sort.

### **5.6.2 Consent process**

The consent process followed the same procedure as face-to-face interviews (section 4.3.4). A consent form designed specifically for this phase of the study was employed.

Before informed consent was gained, participants were verbally informed of what they would be expected to do. The materials to be used during data collection were displayed and explained (booklet, Q-set cards and distribution grid). A printed participant information sheet was also made available to all participants. Participants were given opportunity to ask questions. When satisfied with the information provided, they were asked to read and sign the consent form.

### **5.6.3 Ensuring capacity**

In instances where there were concerns about a participant's ability to provide informed consent, a process of ensuring capacity was undertaken. On two occasions during the Q study capacity was assessed, due to

information which was shared by potential participants prior to consenting to participate. Using guidance from the Health Research Authority (2016) and following the Mental Capacity Act (2005), a protocol was devised in conjunction with the supervision team, one of whom has particular expertise in this field.

The protocol was designed to ensure that the participant was able to:

- understand all the relevant material required to make decision
- retain the information provided, prior to making a decision
- use and/ or assess the information provided
- communicate the decision to participate (or not)

(Health Research Authority, 2016)

Participants were made aware that this process would be undertaken prior to the consent procedure, and was framed as a safeguarding measure for both parties. A checklist was used, to ensure that potential participants were able to meet all the criteria necessary for providing informed consent to the research.

#### **5.6.4 Data management**

Data from this phase was stored in-line with the ethical approval granted. All booklet data, including statement distribution, was transposed into a matrix using Microsoft Excel and saved securely on the university server, prior to analysis. Booklets were filed with any corresponding field notes, in a locked filing cabinet on University of Leeds premises.

### **5.7 Pilot testing**

Pilot testing is required to provide an additional level of content and Q-sorting validity (Ha, 2014). The pilot testers for the Q-sort comprised of two reference group members and two members of the public (n=4), who had previously expressed an interest in the study and who agreed to take part in pilot testing. One pilot tester had sought help for their leakage and was

receiving treatment. Three had not sought help. Pilot testers were provided with participant information and provided written, informed consent, and undertook the Q-sort as participants in October 2015. In addition to providing data, they also gave feedback on the process of data collection, the statements and the qualitative data collection tools.

One reference group member also gained the opinions of others she knew that could be eligible to participate in the study, after she had participated in the pilot test. They felt that the additional data to be collected was too invasive. Whilst it was important to collect additional data to aid interpretation, the unsolicited feedback gained through the reference group member was useful in terms of understanding how women may feel about providing different types of information relating to their experience of urinary incontinence. Although participants were under no obligation to answer the questions, the posing of the questions may have been perceived to be a barrier to participation by some.

### **5.7.1 Amendments resulting from pilot testing**

Based on the feedback from the pilot testers, a fifth stage of statement refinement was undertaken.

Statements were reworded to improve clarity and to avoid confusion about the effect of double negatives; pilot testers found that disagreeing with negatively-worded statements was sometimes difficult, and caused uncertainty. An example of this was statement 11, "*Leakage is not a sign of another issue*", which was modified to "*Leakage is a warning sign for another issue*".

Changes were also made to the process of data collection. These were –

- Velcro was added to the statement cards and Q-sort grid to prevent statements being knocked off the grid during data collection.
- Additional closed questions were included within the booklet to formalise the way in which data relating to symptoms and healthcare experience were collected.

### **5.7.2 Further amendments**

In addition to changes made after piloting, other changes were made and subsequently received ethical approval (SHREC/RP/492/27.02.15 – Amendment 1; SHREC/RP/492/27.02.15 – Amendment 2; SHREC RP/492.27.02.15 - Notice of change. See Appendix B.4). These were –

- To advertise the study more widely using additional forms of media
- To increase the time period in which data could be collected
- To be able to include a potential participant who had already been participated in the interview phase.
- To be able to undertake two Q-sorts simultaneously, after potential participants requested to take part with their friends.

## **5.8 Population recruitment – the P set**

The population from which participants, known in Q methodology as the P set, were recruited, was the same as the interview phase of the study. Advertising using a range of media was distributed throughout Yorkshire. Women from Yorkshire and Humber who met the sample criteria (section 4.3.2) could participate.

### **5.8.1 P set size**

Q methodology can be used with a sample size of one, although between 40-60 participants is the norm (Stainton Rogers, 1995). Some Q methodologists suggest that participant numbers should ideally not exceed the number of statements and therefore fewer than 43 participants were required for this study (Watts and Stenner, 2012). Due to the sensitive nature of the topic under investigation it was perceived that the P set might be smaller, however methodologically this was not considered problematic. Many Q studies have successfully used small P sets in the past (Baltrinic et al., 2013; Gough et al., 2014; Brown, 2016; Kvalsund et al., 2016). Thirty-one women formally expressed an interest in undertaking the Q-sort. Of those, 20 participated in the study which was within the accepted limits for a

Q study (Butler et al., 2014). A number of recruitment techniques had been used to advertise the study to the hidden population (section 3.6 and 5.7.2) with only moderate success. Others have found similar lack of engagement with urinary incontinence-focussed studies (Barr et al., 2000; Moore and Talley, 2015). Further recruitment was deemed unlikely to increase participation given the timeline associated with PhD data collection, analysis, write up and submission.

Of the twenty participants, six women had never sought help for their leakage, and fourteen had sought help (including services offered by private practitioners and alternative therapists). Of those who had sought help, only six were receiving any intervention at the time of participation.

**Table 18 Demographic data of the P Set**

Measures	Participants
<b>Ethnicity</b>	
British/ English/ Welsh/ Scottish/ N. Irish	19
British & Asian	1
<b>Age</b>	
30-39	2
40-49	5
50-59	5
60-69	3
70-79	5
80+	0
<b>Employment Status</b>	
Employed full-time	4
Employed part-time	6
Student	0
Self-employed	2
Voluntary	0
Unemployed due to health	1
Retired	7
<b>Household income (£)</b>	
0-10,000	0
10,001-20,000	5
20,001-30,000	3
30,001-40,000	1
40,001-60,001	2
60,001-100,000	6
Over 100,000	1
Unknown	1
Prefer not to say	1

## **5.9 Data collection**

Data was collected over a five month period between January and May 2016. In the first three months participants were more likely to have initiated contact in response to advertising. In the latter two months, participants were more likely to have made contact after hearing about the study through word of mouth.

### **5.9.1 Process of collecting data**

Data collection was undertaken either in a private meeting room at the University of Leeds or in participant homes when they were unable to travel to university premises.

After gaining informed consent as described in section 5.6, the process of data collection was divided into several stages to simplify the sorting process. These stages will be described in the following sub-sections.

Undertaking the Q-sort took between 30-120 minutes, depending on how much information women chose to disclose. On average, Q-sort meetings lasted for 50 minutes.

### **5.9.2 Condition of instruction**

A condition of instruction was given to women at the beginning of the process, so that they understood how to sort items. Participants were asked to sort the statements by how much they agreed or disagreed with them. They were also told that there were no right or wrong answers and that it was their opinion that mattered. Despite the information provided, some participants suggested they wanted to perform well, perhaps assuming there was a test element to their participation. Participants were given a pen and booklet and told they could write in the booklet at any time during the meeting.

### 5.9.3 Performing the Q-sort

Participants were given the Q-set cards and asked to sort them into three piles as shown in Figure 8.

<u>Based on your experience...</u>		
Agree	Unsure/ Neutral	Disagree
<input type="text"/>	<input type="text"/>	<input type="text"/>

**Figure 8 Initial statement sorting piles**

After the cards had been sorted into three piles, participants were asked to take the cards which were in the 'Agree pile' and sort them further by strength of agreement, as shown in Figure 9.

<u>Based on your experience...</u>		
Strongly Agree	Agree	Slightly Agree
<input type="text"/>	<input type="text"/>	<input type="text"/>

**Figure 9 Example of strength-of-agreement sorting piles**

The cards which were placed in the strongly agree pile were set out in front of the participant, so that they could all be seen easily. The participant was asked to choose the three statements which she most strongly agreed with and place them in the +4 column of the grid. The participant then selected the next four statements most strongly agreed with and placed them in the

+3 column. This process continued until there were no more 'strongly agree' cards left. Once all the strongly agree cards had been placed on the grid, a green line was placed around the corresponding area on the small grid printed on the front of the booklet. The process was repeated until there were no more agree cards left.

The same process was undertaken with the cards which had been placed in the disagree pile. Once sorted by strength of disagreement, the cards which were on the 'strongly' disagree pile were placed in front of the participant. They then chose the three which they most strongly disagreed with and placed them into the -4 column of the distribution grid. This was repeated until all statements which the participant strongly disagreed with had been placed onto the distribution grid, in the most appropriate column (Figure 10).



**Figure 10 Q-sorting** (posed by model)

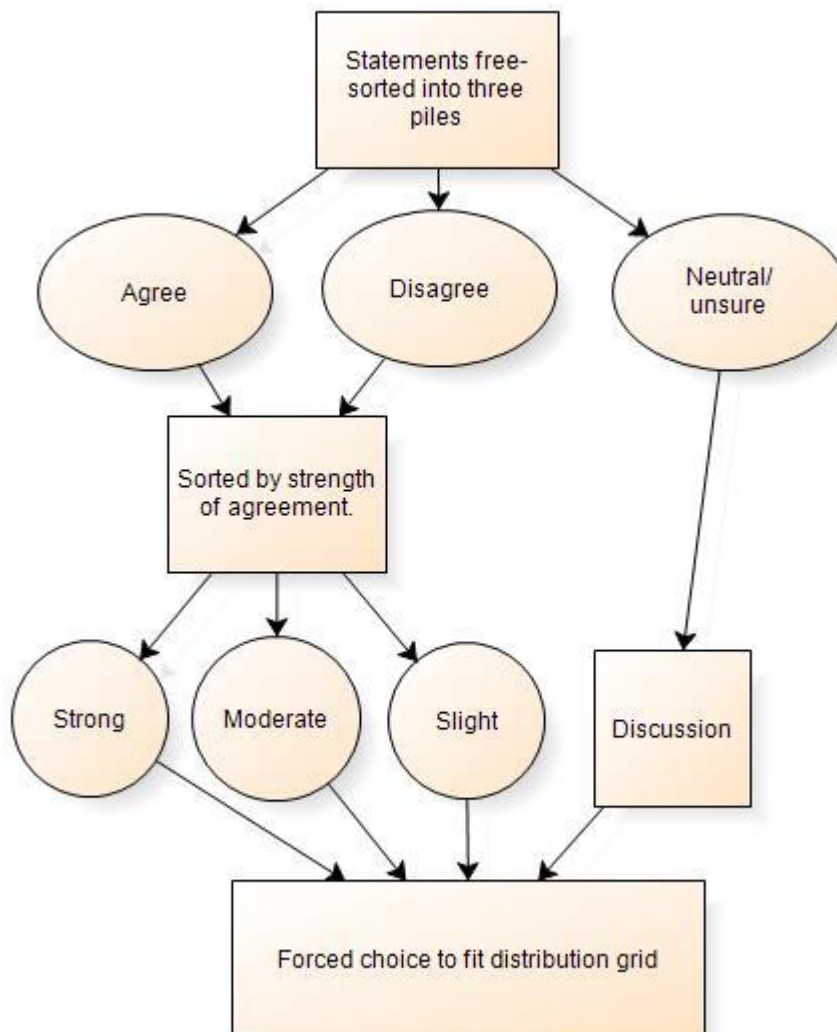
A red mark was placed around the corresponding area on the small grid on the front of the booklet. This process was repeated until all disagree cards had been placed onto the grid. Finally, the cards in the unsure/ neutral pile were sorted. In some instances the cards with which the participants had uncertainty about, could not be placed in the '0' column due to the number of



statements with which they had agreed or disagreed. In these instances, opportunity was given to the participant to talk about those statements prior to placing them. A yellow mark was made on the corresponding area on the booklet grid.

Once participants had placed all the statements cards on the distribution grid they were asked to review it and make any changes they felt were necessary, moving cards as required. After participants had clarified that they were satisfied with the placement of statements on the grid, they were asked to write the numbers displayed on each of the statement cards, in the corresponding box on the booklet grid.

Figure 11 shows the Q-sorting process diagrammatically.



**Figure 11 Q-sorting process**

#### 5.9.4 Collecting qualitative data

Participants were able to write notes in the booklet at any time throughout the Q-sorting process. Field notes were also taken during the sorting process to highlight any noteworthy comments made by participants and to generate ideas for potential questions relating to choices that had been made. Time was given to the participants at the end of Q sorting to enable them to finish writing in the booklet if they desired it.

#### 5.10 Data analysis

Analysis was performed using standard Q methodological methods and following the process outlined by Watts and Stenner (2012). There are three aspects to Q Methodological analysis; factor extraction, factor rotation and factor interpretation. Traditionally, factor analysis involved the statistical process of grouping variables to show correlation and relationship between variables (Porta and Last, 2018). Traditional factor analysis is now most often used for generating hypotheses at the start of research to identify relationships between latent and observed variables (Mulaik, 2010). As the technique of factor analysis has been advanced and expounded considerably since its origins in the late 19<sup>th</sup> century, a number of methods and tools are now available for performing factor analyses (Costello and Osborne, 2005; Mulaik, 2010). The factor analysis undertaken in Q studies is different to other factor analysis methods because the process is “*inverted*”, participants are considered the variables rather than traits they might display (Watts and Stenner, 2005). The analysis conducted in Q studies is by-person, and reflects the relationships between Q-sorts, not the relationships between individual items within the Q set (Watts and Stenner, 2005). Unlike traditional factor analysis, but in common with other contemporary forms of factor analysis, Q methodology requires that factors are rotated to provide the most appropriate solution (Watts and Stenner, 2005; Mulaik, 2010). Within this thesis only rotated factor analysis as performed in Q methodology will be considered. The process of rotation will be explained in section 5.12.

The first two aspects of analysis are undertaken using PQ Method software. Analysis of Q data requires statistical and interpretive criteria to be used, to ensure that the most appropriate solution is selected. Judgements using statistical and abductive approaches are equally valid in Q methodology (Watts and Stenner, 2012). The use of PQ Method and its usefulness to the statistical approach of solution selection will be described first.

PQ Method 2.35 software (Schmolck, 2014) was used to analyse the Q data. This simple programme enables analysis to be undertaken to the point of interpretation. PQ Method analyses numerical data rather than the statements themselves. Therefore, whilst it is useful in undertaking factor analysis and rotation, it is unable to provide interpretation for extracted factors. PQ Method provides two options for analysis, centroid factor analysis and Principal Component Analysis (PCA). The decision to use centroid factor analysis for factor interpretation was made after reading Watts and Stenner (2012) who advocate this method of analysis due to the infinite possibilities for generating a suitable rotated factor solution. They state that PCA is not factor analysis and its components are not factors. Concerns about the wide-spread use of PCA in other types of factor analysis have also been made by Costello and Osborne (2005). PCA is a multi-variate technique which seeks to extract orthogonal variables, known as principal components, from tabulated data and map similarities of variables (Abdi and Williams, 2010). Whilst a mathematically best solution will be given using PCA, it does not provide the best opportunities in Q studies to consider the data abductively as centroid factor analysis does (Watts and Stenner, 2012). Abduction is the process of extending knowledge to provide explanation based on observation by considering a number of possible outcomes (Schurz, 2008).

Data from each of the 20 Q-sorts was inputted into PQ Method for analysis. The first part of analysis was to produce a correlation matrix, which indicates the level of similarity between individual Q-sorts. Factors were generated using this matrix before being extracted. Factors are the expression of grouped participants who have similarly configured Q sort items (Watts and Stenner, 2005). The process of analysis will be described in detail in the

following three sections; Factor extraction (section 5.11); Factor rotation (5.12); and Factor interpretation (5.13).

## **5.11 Factor extraction**

Factor extraction provides an overview of variance described by the Q-sorts (Watts and Stenner, 2012). Whilst no Q-sort may be entirely typified by a factor, variance of attitudes is explained through the generation of factors. Each of the generated factors has similarities with a number of Q-sorts in relation to their statement placement. Q-sorts which are associated with a certain factor are said to be 'loading' onto it. To improve the clarity of analysis and to generate appropriate interpretation of those factors which have significance to the study population, significant loading is required. PQ Method automatically flags loadings with a p value of  $< 0.01$ . Other levels of significance can be flagged manually. After factors have been extracted, a number of statistical methods can be applied to determine the most statistically appropriate solution. Whilst these tests aid decision-making they should not be used as the only criteria for solution selection (Watts and Stenner, 2012).

### **5.11.1 Statistical analysis**

Statistical analysis is important when analysing Q data, as it enables the researcher to make decisions about the feasibility of particular solutions. Statistical considerations should be made prior to any interpretative analysis, as statistical tests are performed on unrotated as well as rotated factors, where interpretative analysis relies solely on the rotated factors. The statistical considerations that were made as part of this study follow below.

### **5.11.2 Eigenvalues using the Guttman-Kaiser criteria**

Eigenvalues provide the statistical strength of a factor and their explanatory power. The lower the Eigenvalue, the lower its explanatory power. Many Q methodologists use an Eigenvalue of 1.0 as a cut-off point, following the Guttman-Kaiser criteria (Yeomans and Golder, 1982). However, having such

an arbitrary cut-off point can remove the minority views of participants represented by factors which have less statistical significance (Brown, 1980).

The Eigenvalues of five factors were considered initially. Five factors were chosen as a starting point in this study due to the lack of explanatory value of two unrotated factors which might have otherwise have been considered. Watts and Stenner (2012) suggest that iterative decisions have to be made to select the correct number of factors in any Q methodological study. The iterative methods used will be outlined in sections 5.13.2 and 5.13.3.

**Table 19 Eigenvalues of unrotated factors**

<i>Factor</i>	<i>Eigenvalue</i>
1	4.9375
2	1.8751
3	0.8903
4	0.8793
5	0.9882

As shown in Table 19, only the Eigenvalues of factors 1 and 2 met the threshold of 1.0, as used by many researchers performing factor analysis (Costello and Osborne, 2005; Watts and Stenner, 2012). However, as the Eigenvalues of factors 3, 4 and 5 were relatively close to 1.0, they also required consideration as they may have contained information of value, highlighting minority attitudes.

The second criterion considered was that of significant loading onto factors. Using Humphrey's rule as a guide, it is suggested that factors should be retained if they have two or more significantly loading Q-sorts loading onto them.

### **5.11.3 Humphrey's rule**

Humphrey's rule is used when there is significant loading of two or more Q-sorts onto a factor. The rule suggests that a factor is only significant if the

cross-product of the two highest loading Q-sorts are more than double the standard error for the study (Brown, 1980).

Standard error =  $1/(\sqrt{\text{items in Q set}})$

=  $1/(\sqrt{43}) = 0.152499$

= 0.15

Therefore, the cross product of the two highest loadings on every factor for this study was  $>0.30$ . The outcome of Humphrey's rule for the unrotated factor solutions are outlined in Table 20. The solutions which satisfied Humphrey's rule are highlighted in bold.

**Table 20 Humphrey's rule - Values of unrotated factors**

<i>Factor</i>	<i>5 factor solution</i>	<i>4 factor solution</i>	<i>3 factor solution</i>	<i>2 factor solution</i>
1	0.41	0.43	<b>0.46</b>	<b>0.50</b>
2	0.40	0.44	<b>0.48</b>	<b>0.41</b>
3	0.42	0.42	<b>0.43</b>	
4	0.49	0.25		
5	0.23			

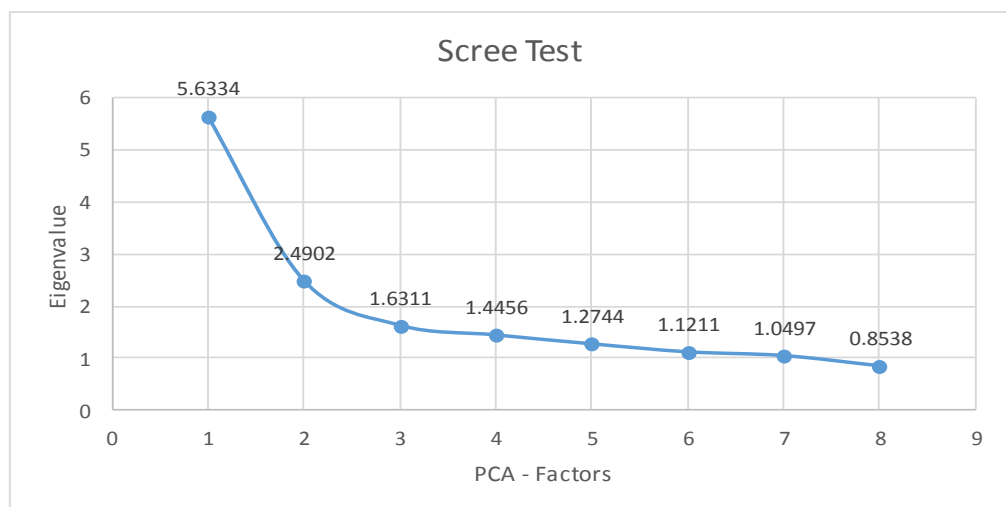
Like the Guttman-Kaiser criterion described previously, the three, four and five factor solutions show that some factors did not have statistical significance using Humphrey's rule. However, it remained important not to discount them at this stage as Q methodology relies on both statistical and theoretical reasoning to identify the most appropriate solution (Brown, 1980; McKeown and Thomas, 2013). The final statistical criterion which was applied to the Q data in this study was the scree test.

#### **5.11.4 Scree test**

The Scree test was first described by Cattell and was designed to be used with Principal Component Analysis (PCA), not with factor extraction (Raïche

et al., 2012). It was important therefore when using this test that a PCA extraction was completed through PQ Method, in addition to centroid factor extraction. During this study, PCA was only used to generate data required for Scree testing, not for other analysis purposes. The Eigenvalues that PCA generates are different to those gained through centroid factor extraction; however using the Scree test in conjunction with other statistical tests provided an additional measure by which to decide on solutions to be taken forward to analysis. Plotted on a line graph, the point at which factor extraction should stop was indicated by a change in the curve between points. However, Scree testing is known to provide a more limited answer than the other statistical tests performed (Watts and Stenner, 2012). Figure 12 shows that the Eigenvalues of seven factors in this study were greater than 1.0, but the change in curve appears after two factors when plotted on the graph. As factor one always has the highest eigenvalue, the depth of the slope between factors one and two was disregarded. Consideration was then given to the remaining factor points plotted on the graph. Interpretation of the scree test can be subjective, however in this case it appeared that factor three should definitely be considered, and there could be interpretative value to factors four to seven, given their PCA generated eigenvalues.

PCA	1	2	3	4	5	6	7	8
Eigenvalue	5.6334	2.4902	1.6311	1.4456	1.2744	1.1211	1.0497	0.8538



**Figure 12 Scree test showing the Eigenvalues of PCA factors**

### **5.11.5 Statistical value of possible solutions**

Using the statistical tests described in sections 5.11.2, 5.11.3 and 5.11.4, a two factor solution was shown to be most statistically significant to this study, based on the scree test and Eigenvalues. However, Humphrey's rule suggested that there may also be importance in a three factor solution and the PCA analysis gave Eigenvalues of above 1.0 for seven factors.

Therefore, an abductive approach to analysis was necessary, to ensure that factors which were important would not be lost because of their low statistical importance (Watts and Stenner, 2012). Based on the outcomes of these tests, five factors were selected for Varimax rotation in the first instance.

### **5.12 Factor rotation**

Factor analysis can employ a number of different types of rotation, for example geographical rotation; oblique analytic rotation and orthogonal analytic rotation (Mulaik, 2010). The factor rotation undertaken in Q methodology is similar to that used in exploratory factor analysis (Costello and Osborne, 2005). Rotation of factors is undertaken to ensure that each factor will describe a focussed view, representative of a group of Q-sorts (Watts and Stenner, 2012). Without rotation, a composite (not representing any viewpoint gained through Q-sorting) would be expressed (Watts and Stenner, 2012). Traditional factor analysis does not rely on rotation to indicate relationships and correlation between variables (Porta and Last, 2018) and therefore may be more likely to produce composite results if it were to be used. Rotation using PQ Method enables clear interpretation of Factors by allowing movement of the x and y axes in relation to the Q-sort data. The axes represent pairs of factors (e.g. factor one and factor two) which are rotated by degrees until the axes have the closest association with the groups of data. Pairs of factors can be systematically rotated to create a complete solution.



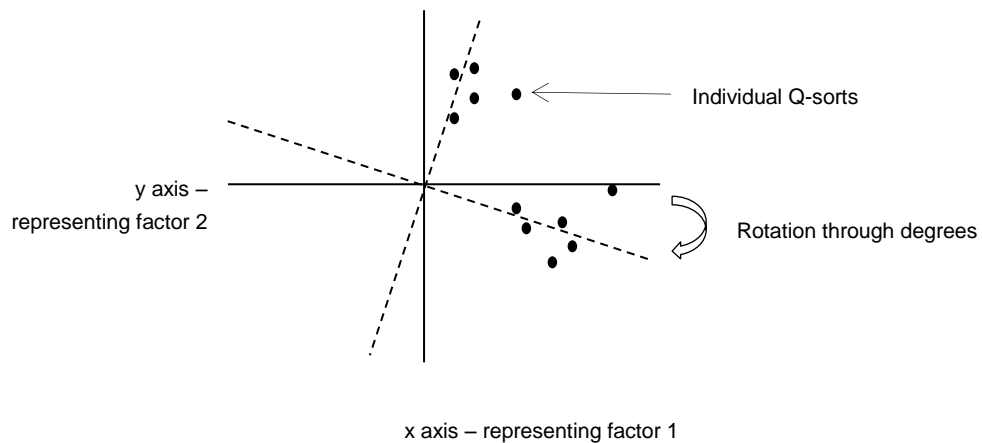


Figure adapted from Watts and Stenner (2012)

### Figure 13 Rotation of pairs of factors

PQ Method provides two options of factor rotation, hand rotation and Varimax rotation. Hand rotation, sometimes known as manual rotation, allows the researcher to rotate pairs of factors manually using diagrammatical representation of each Q-sort in relation to the factors being rotated (as shown in Figure 13). The axes are rotated by degrees to align groups of sorts more closely with the factors represented. Hand rotation is the best form of rotation when desiring a theoretically driven solution, however it is time consuming and complex (Watts and Stenner, 2005). In practice hand rotation is rarely undertaken by Q methodologist and is not recommended for researchers new to the method (Watts and Stenner, 2012). Many Q methodologists take a more pragmatic approach to rotation; Varimax rotation provides the most mathematically appropriate solution and is considered to be a simple and reliable tool to produce rotated factors (Watts and Stenner, 2005). Varimax rotation is an automatically generated process in PQ Method which provides a 'best fit' by placing Q sorts in relation to based on their mathematical significance (Watts and Stenner, 2005). Further hand rotation can be undertaken after Varimax rotation has been completed, if required. Varimax rotation was used to rotate the factors in each of the solutions generated in this study, as has been done previously by Cai et al. (2016), Perz et al. (2013) and Cross-Sudworth et al. (2011) amongst others.

### 5.12.1.1 Rotation of factor solutions

A number of factor solutions were rotated using the Varimax process described in section 5.12. Two, three, four and five factor solutions were rotated during the course of analysis. PQMethod provided rotated factor matrices for each factor solution which were used to further justify the appropriateness of each solution. Consideration was given to the number of participants whose data significantly loaded onto each factor, the number of participants whose data was confounded (that is the Q-sort loaded significantly onto more than one factor), and the number of participants whose data was not associated with any factor. The percentage of study variance explained by each of the solutions was also considered. Variance of 35-40% is considered to provide an appropriate level of explanatory value (Watts and Stenner, 2012). Table 21 shows the variance and number of participants significantly loading onto each factor within the solutions considered. Using this data it appeared that a four factor solution would account for a high level of Q-sorts and variance, and therefore may be the most appropriate solution.

**Table 21 Study variance and participant loading for four potential solutions**

	<i>Two factor solution</i>	<i>Three factor solution</i>	<i>Four factor solution</i>	<i>Five factor solution</i>
<i>Number of Q-sorts with a statistically significant loading on one factor</i>	17	18	16	16
<i>Number of confounded Q-sorts</i>	1	0	2	1
<i>Number of non-significant Q-sorts</i>	2	2	2	3
<i>Percentage of completed Q-sorts accounted for by solution</i>	85%	90%	80%	80%
<i>Percentage of study variance explained by solution</i>	34%	37%	44%	47%

### 5.12.1.2 Exemplar Q-sort selection

Once factors had been rotated, exemplar sorts were considered. These were the Q-sorts most closely associated with the views represented by a factor, and had the highest factor loadings. Exemplars were “flagged”,

**Table 22 Q-sort loading by factor**

<i>Q-sort</i>	<i>Factor 1</i>	<i>Factor 2</i>	<i>Factor 3</i>	<i>Factor 4</i>
<i>Q01</i>	0.1772	0.1840	0.6780x	0.3517
<i>Q03</i>	0.3977	0.1186	0.3114	0.5999x
<i>Q07</i>	0.1893	0.4705x	0.0192	-0.0470
<i>Q09</i>	0.5727x	-0.1133	0.1623	0.1515
<i>Q12</i>	0.0429	0.2725	0.5810x	0.2787
<i>Q13</i>	-0.2172	0.5886x	-0.0035	0.0641
<i>Q14</i>	0.5692x	-0.0510	0.2196	-0.0250
<i>Q15</i>	0.5552x	0.2503	0.2899	0.1327
<i>Q16</i>	0.4215x	0.0360	0.3786	0.1371
<i>Q18</i>	0.2684	0.0607	0.6252x	-0.1246
<i>Q19</i>	0.7477x	-0.1103	0.1074	0.1645
<i>Q20</i>	0.2551	-0.1564	0.1407	0.4133x
<i>Q22</i>	-0.0307	0.0104	0.0420	0.3263
<i>Q23</i>	0.5324c	0.2355	0.0566	0.4887c
<i>Q25</i>	0.5661x	0.2175	-0.0105	0.3280
<i>Q27</i>	0.2715	-0.0058	0.4589c	0.4096c
<i>Q28</i>	0.2550	0.0039	0.0903	0.3679
<i>Q29</i>	0.0241	0.4218x	0.1572	-0.2168
<i>Q30</i>	0.0402	0.7519x	0.3290	0.2585
<i>Q31</i>	0.2787	-0.3071	0.0348	0.4679x

enabling factor estimates and factor arrays to be created. Flagging involved marking each Q-sort within a factor, by an x to show its exemplar value.

As it had already been established that significant loading onto a factor would be 0.30 or above ( $p>0.01$ ), that was the cut off originally considered for flagging exemplar Q-sorts. Consideration was also given to factor loadings using a significance level of 0.05; however this did not produce clear results and so was discarded. Using Watts and Stenner (2012) as a guide, a higher loading cut-off point was chosen for creating the factor estimates. Therefore, Q-sorts were only considered to be significantly loading onto a factor if they had a loading of at least 0.40.

There are a number of ways to determine which Q-sorts are flagged as exemplars. Whilst PQMethod can flag factors automatically, following Watts and Stenner (2012) flagging was performed manually. The significantly loading factors for the four factor solution are shown in Table 22. All significantly loaded Q-sorts loaded positively onto the factors. Significantly loading factors are indicated with an x; confounded loadings are indicated with a c; non-significant Q-sorts are highlighted in red.

## **5.13 Factor interpretation**

Due to the small number of participants and the variability in the outcomes of statistical tests, it remained important to keep an open mind about the solution which would provide the best interpretation of data. Therefore an interpretative analysis was conducted on two, three, four and five factor solutions. To commence the interpretative phase of analysis, factor arrays were created for each of the factors within the four possible solutions. Factor arrays are single Q-sorts generated by PQMethod which represent the viewpoint of a particular factor (Watts and Stenner, 2012).

### **5.13.1 Creation of factor arrays**

PQ Method provides information about the interpretative value of statements that distinguish one factor from all other factors in a solution. The resultant Q-sort provides a 'typical' Q-sort of the participants represented by each

factor, and is known as a factor array. By considering statement placement within the factor array, characteristics of each factor can be found. An example of a factor array is shown in Figure 14.

Distinguishing statements within the factor arrays are statements which are placed significantly differently to all other factors in the solution. These statements are particularly important when interpreting the factors as they enable the researcher to pinpoint statements which may hold more value to the participants who are represented by that factor (Watts and Stenner, 2012). Consensus statements are those which are similarly placed within the arrays for each factor. The consensus statements for this study are given in section 5.15.

After creating the factor arrays, the distinguishing and consensus statements for each were highlighted to clearly indicate their positions within the arrays. These can be seen in Figure 15 to Figure 18, which outline the arrays created for the chosen solution.

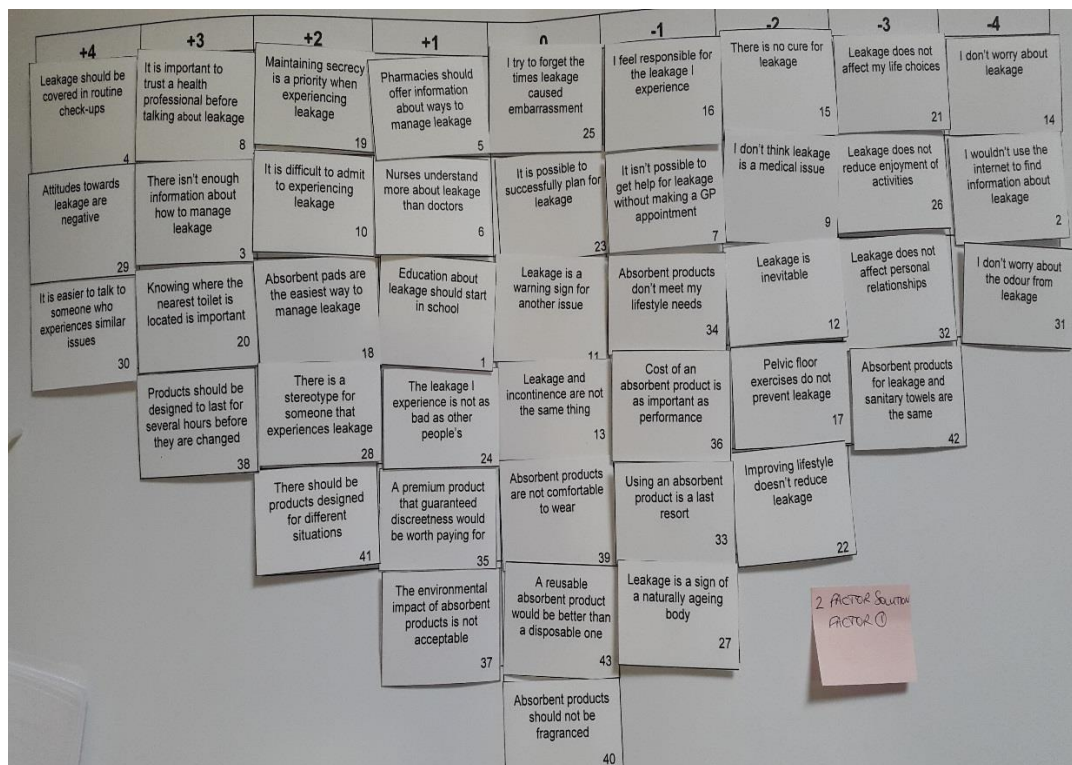


Figure 14 Example of a factor array

### **5.13.2 Interpretative analysis**

A strength of Q Methodology is that interpretation does not solely rely on statistical analysis for its findings. Whilst statistically important views can be gathered when undertaking Q Methodological research, elicitation of minority views which are less statistically significant is also possible. A benefit of this is that the researcher can gain an awareness of the fact that fewer people within the P-set characterise an attitude, and can weight the interpretation appropriately. Having the ability to recognise less statistically important views is particularly important in a healthcare system which promotes the use of individualised care. Having understanding of minority views and being able to recognise them as such, is of great potential benefit to service development.

In this study, minority views may actually represent views of women who are less likely to come forward to healthcare or to participate in research, therefore have the potential to explain views of women experiencing urinary incontinence but who remain hidden. With this in mind, it was important that statistical analysis was not undertaken in isolation. Interpretation to create narrative accounts of each factor was also required; considering each of the solutions available, framed by the supporting data.

There is no consensus between Q methodologists about how interpretative analysis should be conducted. However, Watts and Stenner (2012) note that to ensure that full interpretations are made it is important to focus on the whole factor array, not just those which have the highest or lowest rankings, or those items which define the factor array. It was important to consider all items to ensure viewpoints were accurately represented. This included consideration of relationships between items. Watts and Stenner (2012) suggest only considering a number of items when undertaking interpretation is ethically and methodologically inappropriate.

Crib sheets can aid interpretation by highlighting those statements which may hold additional interpretative value (Watts and Stenner, 2012). A crib sheet was created to show highest and lowest ranking items within each array. In addition, a second crib sheet noted those items which had a higher or lower value in comparison to the other arrays (Condensed versions in

Appendix E1.1). This tabulated information allowed comparisons to be made across factor arrays easily and aided the narrative for each factor by showing the relevant importance of less significant items within each array.

### **5.13.3 Additional data used to assist interpretation**

The qualitative data was also used to aid interpretation. Data taken from the booklets and field notes was used to make comparisons between the factor interpretations and data from participants whose Q-sorts significantly loaded onto the factor. Alterations were made to interpretations as required.

Qualitative data also enabled inter-factor comparisons to be made between participants who significantly loaded onto each factor. In this way similarities were identified. Qualitative data also helped to strengthen interpretation by eliminating aspects which were less likely to be important to attitudes towards experience and use of products.

Watts and Stenner (2012) advocate that the use of demographic data as an interpretative tool, only after an initial interpretation has concluded, to ensure that interpretation is not influenced by preconceptions. Demographic data was considered after a narrative for each factor had been developed. The demographic data was used as a backdrop to each of the factor interpretations.

### **5.13.4 Solution selection**

A process of deciding upon a single solution that met the research aim was undertaken. As previously described in this section, a range of analysis tools were used, statistical and interpretative, to process a number of solutions. Four unrotated solutions were considered in the first instance. After careful consideration, full interpretive work was carried out on the three, four and five factor solutions. Based on the interpretations of these solutions, and following additional in-depth interpretation of the five factor solution (Hunter et al., 2017), the four factor solution was found to be the most appropriate to describe the views of the participants within this study. Reasons for not selecting other solutions are shown in Table 23.

**Table 23 Reasons for exclusion of solutions**

*Factors in solution*    *Reason for exclusion of the solution*

- |          |   |
|----------|---|
| <b>2</b> | Not representative of enough of the data  |
| <b>3</b> | Factor three homogenised some very different Q-sorts. It was not representative of a distinct attitude. |
| <b>5</b> | Within this solution factor 4 did not provide clear enough explanation of views.                        |

**5.14 Four factor solution**

The factor arrays created during interpretation provided typical Q-sorts for explaining the viewpoints represented by each factor. An overview of item placement in the four factor solution is given in Table 24. The numbers within the four factor columns represent item placement on the distribution grid. Those items which were not significantly different between arrays (consensus statements) are shown in bold. The consensus statements are non-significant at  $p > 0.01$ , those marked by \* are also non-significant at  $p > 0.05$ .

The factor interpretations following are based on the factor arrays and exemplar Q-sorts generated through analysis conducted using PQMethod. The interpretations follow the format of Watts and Stenner (2012) who suggest that all factors should begin with a summary of statistical and demographic data. This is then followed by a full explanation of the factor.

Interpretation involved examination of participant Q-sorts, alongside booklet comments, field notes and demographic data associated with participants whose Q-sorts significantly loaded onto each factor. Within each factor information relating to sources of the data used for interpretation is contained within brackets. To remain consistent with Watts and Stenner (2012), information relating to statement placement within interpretations is in the format (statement number: grid reference); for example if statement 25 was placed in the +3 column during Q sorting the bracketed information relating to this placement would be indicated as (25:+3) after the relevant



explanation within the interpretation. Where participant quotes have been used to further explain statement placement, participant reference numbers have been used (Qn).

**Table 24 Summary of the four factor arrays indicating the by-factor ranking of statements**

<i>Statement</i>	<i>F1</i>	<i>F2</i>	<i>F3</i>	<i>F4</i>
1 Education about leakage should start in school	+1	0	-2	+1
2 I wouldn't use the internet to find out about leakage	-3	0	-2	-4
3 There isn't enough information about how to manage leakage	+3	+1	+2	+3
4 Leakage should be covered in routine check-ups	+4	+3	+1	+2
<b>5 Pharmacies should offer information about ways to manage leakage</b>	<b>0</b>	<b>0</b>	<b>+2</b>	<b>0</b>
6 Nurses understand more about leakage than doctors	+2	-1	+2	+2
7 It isn't possible to get help for leakage without making a GP appointment	0	-1	+1	-1
<b>8* It is important to trust a healthcare professional before talking about leakage</b>	<b>+2</b>	<b>0</b>	<b>+1</b>	<b>+1</b>
<b>9* I don't think leakage is a medical issue</b>	<b>-2</b>	<b>-2</b>	<b>-1</b>	<b>-2</b>
10 It is difficult to admit to experiencing leakage	+3	+1	+4	0
11 Leakage is a warning sign for another issue	0	-2	-1	0
12 Leakage is inevitable	-3	-2	-1	0
<b>13* Leakage and incontinence are not the same thing</b>	<b>-1</b>	<b>+1</b>	<b>+1</b>	<b>-1</b>
14 I don't worry about leakage	-3	+1	-4	-4
15 There is no cure for leakage	-4	-1	0	-2
16 I feel responsible for the leakage I experience	-1	-4	+1	+1
17 Pelvic floor exercises do not prevent leakage	-1	+2	-2	-2
18 Absorbent pads are the easiest way to manage leakage	0	+2	+4	+2
19 Maintaining secrecy is a priority when experiencing leakage	+2	-3	+3	-1
20 Knowing where the nearest toilet is located is important	+3	+2	+4	+1
21 Leakage does not affect my life choices	-3	+4	+1	-3
22 Improving lifestyles doesn't reduce leakage	-2	0	-1	-3
23 It is possible to plan for leakage	0	0	-2	0
24 The leakage I experience is not as bad as other people's	-1	+4	0	+3
25 I try to forget the times leakage caused me embarrassment	0	-3	-3	+2
26 Leakage does not reduce enjoyment of activities	-2	+3	+2	-3
27 Leakage is a sign of a naturally ageing body	-4	0	0	+3
28 There is a stereotype for someone who experiences leakage	+1	-1	-1	-1
29 Attitudes towards leakage are negative	+4	-1	0	+4
30 It is easier to talk to someone who experiences similar issues	+4	+4	+2	+2

Statement	F1	F2	F3	F4
31 I don't worry about the odour from leakage	-2	-2	-4	-4
32 Leakage does not affect personal relationships	-2	+3	-1	-1
33 Using an absorbent product is a last resort	+1	-3	-4	-2
34 Absorbent products don't meet my lifestyle needs	-1	-3	-2	+1
35 A premium product that guaranteed discreetness would be worth paying for	0	+2	+3	+4
36 Cost of an absorbent product is as important as performance	-1	+1	0	-2
37 The environmental impact of absorbent products is not acceptable	+3	-1	0	0
38 Products should be designed to last for several hours before they are changed	+1	+3	0	+4
39 Absorbent products are not comfortable to wear	+2	-4	-3	+1
40 Absorbent products should not be fragranced	+1	+1	+3	0
<b>41 There should be products designed for different situations</b>	<b>+2</b>	<b>+2</b>	<b>+3</b>	<b>+3</b>
<b>42 Absorbent products for leakage and sanitary towels are the same</b>	<b>-4</b>	<b>-2</b>	<b>-3</b>	<b>-3</b>
43 A reusable absorbent product would be better than a disposable one	+1	-4	-3	-1

#### 5.14.1 Factor 1 – Trial and Error

Factor 1 has an eigenvalue of 4.94 and accounts for 15% of the variance.

Six participants were significantly associated with the factor. The mean age of participants was 52 years (37-71 years). All but one of these participants had sought help, but none were receiving healthcare intervention at the time of data collection. All participants stated that they had symptoms associated with urge; two stated they also experienced stress-type symptoms. Symptoms occurred during the day and two participants also experienced symptoms also at night.

This viewpoint (presented in Figure 15) found that the women's attitudes were focused upon what they believed to be proactive steps for dealing with leakage alone. They were heavily influenced by the assumed perceptions of others, which was consistent with some previous interview data. The women who defined this factor were certain that the leakage they experienced was not normal and there was a cure (25:-4; 27:-4. 12:-3). Perceived negative attitudes made it difficult for them to admit experiencing leakage even to healthcare professionals (29:+4; 10:+3; 4:+4). They were searching for information about how to manage leakage more effectively, so that they could maintain secrecy and avoid being stereotyped (37:+3; 19:+2; 28:+1), with one woman describing it as "*the last taboo*" (Q14).

They were interested in finding information as it “*would be nice if there were more ways*” (Q25) to manage symptoms, believing that there wasn’t currently enough information available to them (3:+3; 1:+1). The internet had “*been one of the main sources*” (Q14) of information for these women (2:-3), however two of the older women chose to avoid internet searches “*because when you google it comes up with worst case scenarios*” (field note Q19). There is previous evidence which also suggests that people with urinary incontinence may seek information on the internet prior to seeking help from a healthcare professional (Berger et al., 2005). As already noted in the discussion of Chapter 4, quality of information available remains variable, particularly on social media (Dueñas-Garcia et al., 2015).

Although all the women within this factor had previously attempted to access professional help, attitudes of some health professionals had reinforced the idea that leakage should be dealt with primarily by the women themselves (7:0), with some starting to question their level of responsibility (16:-1). A field note taken during the Q-sort of Q14 suggests that the use of absorbent products as a coping strategy was directly linked to the negative and dismissive attitude of a healthcare professional (18:0).

“*GP was dismissive ... was told that exercises she had were following guidelines so ... keep doing them and use pads.....wouldn’t refer back to urogynae on request*” (Field note Q14).

This is consistent with other contemporary literature which has found similar themes, and may be linked to guidelines not being followed appropriately or a lack of prioritisation by general practitioners (Gerrits et al., 2008; Nguyen et al., 2013; Vethanayagam et al., 2017). When these women encountered a setback, they looked for alternatives to overcome their difficulties. They “*try and do things [to manage leakage, but] it doesn’t always help*” (Q16). Absorbent products were sometimes used “*resentfully*” (Q25) because of the negative connotations of products being associated with “*older patients*” (Q15) and because they were uncomfortable (33:+1; 39:+2). Despite looking for alternatives to absorbent products, these women had not found a “*better way*” (Q25) to deal with leakage (34:-1; 18:0).

+4	+3	+2	+1	0	-1	-2	-3	-4
Leakage should be covered in routine check-ups 4	There isn't enough information about how to manage leakage 3	Nurses understand more about leakage than doctors 6	Education about leakage should start in school 1	Pharmacies should offer information about ways to manage leakage 5	Leakage and incontinence are not the same thing 13	I don't think leakage is a medical issue 9	I wouldn't use the internet to find out information about leakage 2	There is no cure for leakage 15
Attitudes towards leakage are negative 29	It is difficult to admit experiencing leakage 10	It is important to trust a health professional before talking about leakage 8	There is a stereotype for someone that experiences leakage 28	It isn't possible to get help for leakage without making a GP appointment 7	I feel responsible for the leakage I experience 16**	Improving lifestyle does not reduce leakage 22	Leakage is inevitable 12	Leakage is a sign of a naturally ageing body 27**
It is easier to talk to someone who experiences similar issues 30	Knowing where the nearest toilet is located is important 20	Maintaining secrecy is a priority when experiencing leakage 19	Using an absorbent product is a last resort 33**	Leakage is a warning sign for another issue 11	Pelvic floor exercises do not prevent leakage 17	Leakage does not reduce enjoyment of activities 26	I don't worry about leakage 14	Absorbent pads for leakage & sanitary towels are the same 42
	The environmental impact of absorbent products is not acceptable 37**	Absorbent products are not comfortable to wear 39	Products should be designed to last for several hours before they are changed 38	Absorbent pads are the easiest way to manage leakage 18	The leakage I experience is not as bad as other people's 24	I don't worry about odour from leakage 31	Leakage does not affect my life choices 21	
		There should be products designed for different situations 41	Absorbent products should not be fragranced 40	It is possible to successfully plan for leakage 23	Absorbent products don't meet my lifestyle needs 34	Leakage does not affect personal relationships 32**		
			A reusable product would be better than a disposable one 43**	I try to forget the times that leakage caused me embarrassment 25	Cost of an absorbent product is as important as performance 36			
				A premium product that guaranteed discreetness would be worth paying for 35				

**Figure 15 Factor array for Factor 1**

Distinguishing statements  $p < 0.05$

Consensus statements

\*\* Distinguishing statements  $p < 0.01$

Defining sorts = Q09; Q14; Q15; Q16; Q19; Q25

They were acutely aware of the environmental impact of absorbent products and whilst a reusable product may be preferable for the environment (37:+3), they would be “*a pain*” (Q15) to use. There was “*scope for biodegradable products*” (Q14) (43:+1).

They had tried a number of other coping strategies, including consideration of toilet access (20:+3), undertaking pelvic floor exercises (17:-1), improving modifiable lifestyle factors (22:-2) and adapting routines (21:-3). Despite this they had uncertainty that it was possible to successfully plan for leakage (23:0). The leakage that these women experienced was problematic and concerning (14:-3; 32:-2; 21:-3). Whilst they might “*laugh about it [with friends], it’s serious really*” as noted by participant Q16 when considering statement 29. Four participants whose Q-sorts significantly loaded onto this factor were very clear in their comments that it was not true that leakage was inevitable, although there was an assumption it may be associated with age. These women had adapted their routines as they had concerns about “*the time [leakage] might happen*” (Q19) (21:-3).

There was uncertainty about how best to cope with leakage, some having found pelvic floor exercises had “*not worked*” (Q09) despite statement 17 suggesting that these women recognised potential for strengthening the pelvic floor (17:-1). Qualitative data provided at the time of sorting suggested that women had attempted pelvic floor exercises but with limited success, often without adequate knowledge of how to perform them, leading to the belief that the exercises had limited utility for them.

Due to the uncertainty the women had about leakage (11:0) they wished it was covered routinely in health check-ups (4:+4; 7:0). It was difficult to admit the experience, especially “*at first*” (Q25) (10:+3). They believed talking to someone with the same issue was easier because “*they understand more*” (Q09) (30:+4). Comments made about statement 6, suggests nurses might be better at understanding than doctors because they are “*perceived as being female*” (Q09), rather than because of professional understanding. The women didn’t want “*doctors coming in with a sledge hammer*” (Q25) because some participants were aware that interventions were not always successful. Previous experience of some of the women meant they now

prioritised a trusting relationship with a health professional (8:+2), having felt their concerns had not been adequately addressed when they had sought help in the past. Despite this, they were certain that there was a cure available if they could find it.

#### **5.14.2 Factor 2 – Carry on regardless**

Factor 2 had an eigenvalue of 1.88 and accounted for 9% of the variance. Four participants were significantly associated with the factor. The mean age of participants was 51.4 years (45-77 years). Three participants had previously sought help and one was still in receipt of treatment, one participant had not sought help. Two participants experienced symptoms both at day and night, two experienced symptoms only in the day. Three participants stated they experienced leakage associated with urge, one participant stated they experienced leakage post-void. This Factor array is presented in Figure 16.

The women that typified this factor were living lives unaffected by leakage (21:+4; 26:+3; 32:+3). They were not particularly concerned by their leakage and believed that what they experienced was minimal compared to others' symptoms (14:+1; 24:+4). They were more interested in conservative management, than possible curative measures (17:+2; 18:+2; 20+2; 15:-1).

Leakage had very little negative impact on these women's lives, and it was not "*top of things to worry about*" (Q13). They were not embarrassed by their symptoms and felt no need to maintain secrecy (19:-3; 25:-3). They had adapted their routines over time so it was "*automatic now*" (Q30). Their coping strategies ensured that they were able to enjoy activities, taking "*supplies*" if they were going out (field note Q30) (26:+3; 14:+1). The interview findings suggested that taking supplies of products and clothing when outside of the house may sometimes be as a result of fear, however this was not evident in the comments made by these women who saw it simply as a practical necessity. This is consistent with the findings of Hägglund and Ahlstrom (2007) whose study found women minimising the importance of UI by actively creating a state of readiness.

There was uncertainty “*why [other women] do not take a more active role*” in speaking about leakage or finding help (field note Q29) (16:-4). Although it could be difficult to admit experiencing leakage except to those in similar situations, these women were “*happy to talk to friends*” (field note Q29) (30:+4; 10:+1). In fact, they were confident to provide peer support to others as “*many others have the same [issue]*” (Q30). These women “*can’t understand why anyone would keep it secret*” (field note Q29) (19:-3; 25:-3). They “*suspect there is no cure*” for leakage (field note Q13) in spite of good awareness of treatments available to improve symptoms (15:-1). Having sought healthcare previously they suggested that “*doctors attitudes are not always helpful*” (field note Q29) (28:-1; 29:-1). They were not actively information-seeking but were as likely to go to their own GP as access other forms of professional help, understanding symptoms as a medical issue (3:-1; 5:0; 7:-1, 9:-2). When they found a doctor who understood the problem, they preferred to see that doctor, instead of a nurse (6:-1).

They described leakage and incontinence as two discreet concepts (13:+1). “*Incontinence is all the time*” (field note Q29), noting that “*there is more stigma associated with incontinence*” (Q13). The issue these women experienced was a consequence of a “*normal ... ageing process*” (field note Q30), and “*suspect it is*” a sign of a naturally ageing body (Q13) (11:-2; 27:0; 16:-4). They recognised other factors may have had an influence though; “*other medical issues... affected it*” (field note Q29) and “*weight made a big difference*” (Q13) (22:0; 9:-2).

The leakage experienced was considered to be minimal, knowing their symptoms are “*nowhere near as bad*” (field note Q29) as other peoples’. However odour had the potential to be a problem if the women were not able to maintain hygiene using their usual routines, including use of “*modern products*” (Q13) (18:+2; 31:-2; 33:-3). To ensure comfort they changed absorbent products “*as soon as possible*” (field note Q30), but highlighted problems with disposal, having to take “*small poly bags*” (field note Q30) with them when outside the home (39:-4; 38:+3).

Absorbent products were a “*first resort*” (Q13), meeting their lifestyle needs (34:-3). A reusable product would be a “*backward step*” (Q13) as these

women “*definitely prefer disposable products*” (field note Q29) (43:-4). They had tried a range of products in the past and suggested they had “*tried cheaper ones but [they] weren’t as absorbent, half the price but needed to use double the amount*” (field note Q30) (42:-2; 36:+1; 35:+2). All of the women had tried pelvic floor exercises but became “*disenchanted*” (field note Q13) believing that their “*muscles were not as strong*” (field note Q30) as they once had been (17:+2).



+4	+3	+2	+1	0	-1	-2	-3	-4
Leakage does not affect my life choices 21**	Leakage should be covered in routine check-ups 4	Pelvic floor exercises do not prevent leakage 17**	There isn't enough information about how to manage leakage 3	Education about leakage should start in school 1	Nurses understand more about leakage than doctors 6**	I don't think leakage is a medical issue 9	Maintaining secrecy is a priority when experiencing leakage 19	I feel responsible for the leakage I experience 16**
The leakage I experience is not as bad as other people's 24	Leakage does not reduce enjoyment of activities 26	Absorbent pads are the easiest way to manage leakage 18	It is difficult to admit experiencing leakage 10	I wouldn't use the internet to find out information about leakage 2**	It isn't possible to get help for leakage without making a GP appointment 7	Leakage is a warning sign for another issue 11	I try to forget the times that leakage caused me embarrassment 25	Absorbent products are not comfortable to wear 39
It is easier to talk to someone who experiences similar issues 30	Leakage does not affect personal relationships 32**	Knowing where the nearest toilet is located is important 20	Leakage and incontinence are not the same thing 13	Pharmacies should offer information about ways to manage leakage 5	There is no cure for leakage 15	Leakage is inevitable 12	Using an absorbent product is a last resort 33	A reusable product would be better than a disposable one 43
	Products should be designed to last for several hours before they are changed 38	A premium product that guaranteed discreetness would be worth paying for 35	I don't worry about leakage 14**	It is important to trust a health professional before talking about leakage 8	There is a stereotype for someone that experiences leakage 28	I don't worry about odour from leakage 31	Absorbent products don't meet my lifestyle needs 34	
		There should be products designed for different situations 41	Cost of an absorbent product is as important as performance 36	Improving lifestyle does not reduce leakage 22	Attitudes towards leakage are negative 29	Absorbent pads for leakage & sanitary towels are the same 42		
			Absorbent products should not be fragranced 40	It is possible to successfully plan for leakage 23	The environmental impact of absorbent products is not acceptable 37			
				Leakage is a sign of a naturally ageing body 27				

**Figure 16 Factor array for Factor 2**

- Distinguishing statements  $p < 0.05$
- Consensus statements
- \*\* Distinguishing statements  $p < 0.01$

Defining sorts = Q07; Q13; Q29; Q30

### 5.14.3 Factor 3 – Shameful secret

Factor 3 had an eigenvalue of 0.9 and explained 10% of the variance. Three participants were significantly associated with this factor. The mean age of the women was 67.6 years (57-74 years). One had previously sought help and was still receiving intervention, two had not sought help. All participants on this factor stated that they experienced urge-related symptoms. One experienced symptoms during the day and night and two experienced symptoms only during the day.

This viewpoint (presented in Figure 17) prioritised the use of absorbent products to maintain secrecy (18:+4; 10:+4; 19:+3). The women typified on this factor provided few comments within the booklet or during the Q-sorting process. The unwillingness to provide information about individual experience may be considered data in itself, as it distinguished this factor from all other factors. It is possible that these women felt the threat of stigmatisation was higher than those represented by other factors. The prominent aspects highlighted by this factor are consistent with research by Southall et al. (2015) which considered the self-perceptions of stigmatisation in women over 65 who experienced continence issues.

Women typified by this factor showed that it was very important to keep leakage a secret because of the high level of uncertainty about the symptoms they experienced (19:+3; 15:0; 24:0; 29:0). These women were not confident to approach the subject with others (10:+4). In addition to not feeling able to talk about it themselves, they also felt cautious about information sharing by other people. A booklet comment relating to education in schools by Q15 stated that she was “*unsure if pre-18 [aged children] would take it seriously*” (1:-2). There was also reticence for use of the internet as an information-gathering tool (2:-2).

The usefulness of “*going to the doctors for it*” (Q01) was questioned, and in some instances the idea was almost mocked (9:-1; 27:0). There was a belief that professional help could only be accessed through the GP, but the women would have to trust the doctor before feeling able to discuss it (7:+1; 8:+1). There was no certainty about why leakage might occur but covering it

in routine appointments might “*identify other problems*” (Q12) (15:0; 27:0; 12:-1; 4:+1).

The comments that were provided reflected some of the fears that have been highlighted in other literature regarding ageing and odour (Getliffe et al., 2007; Basu and Duckett, 2009; Nilsson et al., 2011; Southall et al., 2015). When discussing statement 28 participant Q01 noted that she “[*worried*] about becoming an old person that smells of wee” despite the Q-sort results suggesting women on this factor considered people with leakage were not stereotyped (14:-4; 28:-1). The disparity between comments and Q results may in part be due to social-response bias, further highlighting the sensitive nature of the subject for this group of women. Odour was of particular concern because “*it affects personal hygiene*” (Q12) (31:-4).

Whilst these women did not want to smell of stale urine, they also felt strongly that they did not want to mask the smell with something else, such as fragranced products (40:+3).

There was a feeling of futility in this group of women. They had a sense of responsibility for the leakage, but “*there’s nothing [they] can do about it*” (field note Q18) (16:+1; 25:-3). Whilst they might on occasion have felt embarrassed, they “*had no choice*” in the situation and therefore could not forget (field note Q18) (25:-3). They were unable to successfully plan for leakage, but relied heavily on absorbent products (33:-4; 34:-223: -2).

Previously, Hägglund and Ahlstrom (2007) explored the feelings of powerlessness that some women exhibit and suggested that the coping strategies displayed, however maladaptive they may appear, were used by women to try to regain control. Leakage did not reduce enjoyment of activities because other coping strategies such as fluid restriction were employed when activities were undertaken (26:+2), with Q18 stating “*I’d not drink anything*” when undertaking a long journey. Knowing toilet location was considered “*important*” (Q12) but it was a strategy always used alongside products (20:+4). Daily routines continued in spite of unsuccessful planning (21:+1; 23:-2).

+4	+3	+2	+1	0	-1	-2	-3	-4
It is difficult to admit experiencing leakage 10	Maintaining secrecy is a priority when experiencing leakage 19	There isn't enough information about how to manage leakage 3	Leakage should be covered in routine check-ups 4	There is no cure for leakage 15	I don't think leakage is a medical issue 9	Education about leakage should start in school 1**	I try to forget the times that leakage caused me embarrassment 25	I don't worry about leakage 14
Absorbent pads are the easiest way to manage leakage 18	A premium product that guaranteed discreetness would be worth paying for 35	Pharmacies should offer information about ways to manage leakage 5	It isn't possible to get help for leakage without making a GP appointment 7	The leakage I experience is not as bad as other people's 24	Leakage is a warning sign for another issue 11	I wouldn't use the internet to find out information about leakage 2	Absorbent products are not comfortable to wear 39	I don't worry about odour from leakage 31
Knowing where the nearest toilet is located is important 20**	Absorbent products should not be fragranced 40	Nurses understand more about leakage than doctors 6	It is important to trust a health professional before talking about leakage 8	Leakage is a sign of a naturally ageing body 27	Leakage is inevitable 12	Pelvic floor exercises do not prevent leakage 17	Absorbent pads for leakage & sanitary towels are the same 42	Using an absorbent product is a last resort 33
	There should be products designed for different situations 41	Leakage does not reduce enjoyment of activities 26	Leakage and incontinence are not the same thing 13	Attitudes towards leakage are negative 29	Improving lifestyle does not reduce leakage 22	It is possible to successfully plan for leakage 23**	A reusable product would be better than a disposable one 43	
		It is easier to talk to someone who experiences similar issues 30	I feel responsible for the leakage I experience 16	Cost of an absorbent product is as important as performance 36	There is a stereotype for someone that experiences leakage 28	Absorbent products don't meet my lifestyle needs 34		
			Leakage does not affect my life choices 21**	The environmental impact of absorbent products is not acceptable 37	Leakage does not affect personal relationships 32			
				Products should be designed to last for several hours before they are changed 38				

**Figure 17 Factor array for Factor 3**

- Distinguishing statements  $p < 0.05$
- Consensus statements
- \*\* Distinguishing statements  $p < 0.01$

Defining sorts = Q01; Q12; Q18

#### 5.14.4 Factor 4 – Wanting change

Factor 4 had an eigenvalue of 0.88 and explained 10% of the variance. Three participants were significantly associated with this factor. The mean age of the women was 49.3 years (45-57 years). All had previously sought help, but only one participant was receiving any intervention at the time of data collection. All participants on this factor stated that they experienced stress and urge-type symptoms. One experienced symptoms day and night and two experienced symptoms only during the day. The factor array for this Factor is presented in Figure 18.

The women typified on this factor believed leakage was “*definitely*” a natural sign of ageing (field note Q31) (27:+3). Due to this belief they managed symptoms palliatively, with absorbent products being their key coping strategy. These women were keen to see product innovation, prioritising statements that promoted product development (35:+4; 38:+4; 41:+3). The Q-sorts indicated that whilst the women did use absorbent products, they did not meet their needs (18:+2; 34:+1; 33:-2). The impact of leakage was significant and had caused embarrassment previously (25:+2). Unlike women represented on other factors they were willing to pay a higher financial price for absorbent products, theoretically at least, to be able to balance the effects of leakage more easily, with one stating “*money shouldn't be an issue*” (field note Q31) (36:-2).

These women were sure that leakage was age-related because “*tone decreases with age naturally*” (Q03) (27:+3). Therefore the ways that they dealt with leakage was based on the assumption that it was normal and may be “*hormone-related*” (field note Q20) (12:0). These women looked to “*identify times when [it was at its] worst*” (Q20) so they could at least try to plan for it (23:0). Whilst they did feel they had some responsibility for the leakage they experienced, the responsibility was as much for effective management as for self-blame for the symptoms (16:+1). One also expressed feelings of resentment for their symptoms when discussing the level of responsibility, rhetorically asking “*why me?*”, highlighting whilst the symptoms were assumed to be age-related they may not be inevitable (field note Q31) (12:0).

Absorbent products were important to these women and whilst cost was a consideration (even for the participant who received absorbent products through the NHS), these women wanted new products (35:+4). Fader et al. (2014) found women with higher incomes who enrolled in a shopping experiment were more willing to increase theoretical budgets to ensure that they received the products they preferred. Two of the three women associated with this factor had higher than national average household incomes, between £40-60,000 per year. This may suggest that they too would be willing to pay more for a preferred product (36:-2).

The women also had ideas about what they wanted new products to be. Discreetness would include “*no overspill, maximum absorbency and there should be no visible outline through clothes*” (field note Q20) (38:+4). These women had used, or were considering using, a range of products which they felt were necessary to deal with leaked urine (41:+3). Fader et al. (2014) also found that when the budget for buying absorbent products was reduced women opted to buy a range of products, which is perhaps consistent with the attitudes of the women associated with this factor. Despite suggesting they may be willing to pay more for the ideal product, they were conscious of the money that was already spent on less-than-ideal products, with particular problems noted by some, “*pads are no good at night.*” (field note Q31).

They didn't prioritise maintaining secrecy and sometimes could talk about their experience, despite it being “*difficult and stressful*” in some circumstances (field note Q31) (19:-1; 10:0). They did however believe that people's attitudes towards leakage were very negative (28:-1; 30:+2). This could make a difference when buying products in the supermarket. Some women sought to avoid “*young or male*” checkout assistants (field note Q03), as negative attitudes did affect choices these women made (29:+4; 21:-3).

They were aware of medical intervention, including “*an operation that could help*” (field note Q31) (15:-2). There wasn't always “*time to include the extra problem [of leakage]*” when attending GP appointments (field note Q20). Despite that, if they were asked they “*would be happy to disclose to a*

*healthcare professional*' (field note Q20) (8:+1). They thought it would be useful if the symptom was routinely covered in health check-ups (4:+2).

There were ongoing concerns about leakage and also odour (14:-4). Some of the concerns related to future possibilities, but current concerns were dealt with using a number of techniques including frequent washing and de-odourising (31:-4). Absorbent products were also used in a way to manage odour, frequent absorbent product changes were necessary to ensure that smell did not occur (38:+4). These women had made changes to their lives in the hope that it might reduce leakage, and had considered other coping strategies that they may try in future (2:-4; 22:-3).

They felt there wasn't enough information available to them about how to manage leakage (3:+3). They also thought it might be useful to educate young people so they knew what to expect in future (1:+1). The women who had attempted to find information via the internet felt very strongly about this source of information as a positive aspect of their coping strategies, however field notes also suggested the trustworthiness of the internet was sometimes questionable with Q31 stating that she "*[didn't] trust the information on there*" (2:-4).

+4	+3	+2	+1	0	-1	-2	-3	-4
Attitudes towards leakage are negative 29	There isn't enough information about how to manage leakage 3	Leakage should be covered in routine check-ups 4	Education about leakage should start in school 1	Pharmacies should offer information about ways to manage leakage 5	It isn't possible to get help for leakage without making a GP appointment 7	I don't think leakage is a medical issue 9	Leakage does not affect my life choices 21	I wouldn't use the internet to find out information about leakage 2
A premium product that guaranteed discreetness would be worth paying for 35	The leakage I experience is not as bad as other people's 24	Nurses understand more about leakage than doctors 6	It is important to trust a health professional before talking about leakage 8	It is difficult to admit experiencing leakage 10	Leakage and incontinence are not the same thing 13	There is no cure for leakage 15	Improving lifestyle does not reduce leakage 22	I don't worry about leakage 14
Products should be designed to last for several hours before they are changed 38	Leakage is a sign of a naturally ageing body 27**	Absorbent pads are the easiest way to manage leakage 18	I feel responsible for the leakage I experience 16	Leakage is a warning sign for another issue 11	Maintaining secrecy is a priority when experiencing leakage 19	Pelvic floor exercises do not prevent leakage 17	Leakage does not reduce enjoyment of activities 26	I don't worry about odour from leakage 31
	There should be products designed for different situations 41	I try to forget the times that leakage caused me embarrassment 25	Knowing where the nearest toilet is located is important 20	Leakage is inevitable 12	There is a stereotype for someone that experiences leakage 28	Using an absorbent product is a last resort 33	Absorbent pads for leakage & sanitary towels are the same 42	
		It is easier to talk to someone who experiences similar issues 30	Absorbent products don't meet my lifestyle needs 34**	It is possible to successfully plan for leakage 23	Leakage does not affect personal relationships 32	Cost of an absorbent product is as important as performance 36		
			Absorbent products are not comfortable to wear 39	The environmental impact of absorbent products is not acceptable 37	A reusable product would be better than a disposable one 43			
				Absorbent products should not be fragranced 40				

**Figure 18 Factor array for Factor 4**

- Distinguishing statements  $p < 0.05$
- Consensus statements
- \*\* Distinguishing statements  $p < 0.01$

Defining sorts = Q03; Q20; Q22; Q28



## 5.15 Shared views across factors

Despite the four factors expressing distinct attitudes towards the topic under investigation, there were some items which were placed similarly within each factor. These items are known as consensus items. Consensus items indicate where participants across all factors had shared attitudes towards a statement.

The consensus items had interpretative value in relation to other items within the factor arrays, but their placement within the arrays was non-significant at  $p < 0.01$ . In the solution chosen, there were six consensus statements. Their placement within the factor arrays are shown in Table 25.

**Table 25 Consensus statement placement in factor arrays**

Statement	Factor 1	Factor 2	Factor 3	Factor 4
5. Pharmacies should offer information about ways to manage leakage	0	0	+2	0
8. It is important to trust a health professional before talking about leakage	2	0	1	1
9. I don't think leakage is a medical problem	-2	-2	-1	-2
13. Leakage and incontinence are not the same thing	-1	1	1	-1
41. There should be products designed for different situations	2	2	3	3
42. Absorbent products for leakage and sanitary towels are the same	-4	-2	-3	-3

### 5.15.1.1 Recognising symptoms and accessing appropriate help

The first set of common viewpoints across factors included items which may have some effect on help-seeking. These were items 5, 8, 9 and 13.

Although the items may not all appear directly related to help-seeking, qualitative data suggests that participants considered them in this context.

Disagreement with statement 9, "*I don't think leakage is a medical problem*"

might suggest that participants recognised the potential implications of the symptom. However, when considered in relation to non-consensus items such as item 7 *"It isn't possible to get help for leakage without making a GP appointment"* or item 11 *"Leakage is a warning sign for another issue"* it may also illustrate a level of discrepancy between participants' attitudes about symptoms and when help-seeking might be warranted. The qualitative data relating to item 8 implied that symptoms may exacerbate before help is considered. One participant explained that *"It can be [a medical problem]...it could be better managed before it becomes a medical issue"* (field note Q23). The recognition that symptoms could be considered medically may not necessarily be indicative of help-seeking behaviour due to underlying uncertainty about symptoms and the psychosocial implications of them. The following consensus items may help to explain this further.

The participants that defined Factors 2 and 3 understood leakage and incontinence as discrete concepts. Factors 1 and 4 showed a negative ranking, indicating those participants considered the concepts as the same symptom. However the placement was not significant between Factors and therefore item 13 *"Leakage and incontinence are not the same thing"* was considered a consensus item. As Q-sorting involves forced choices, it might be that placement would have been closer to 0 given free choice. Therefore this item explained uncertainty within the sample about whether leakage can, or should, be considered as incontinence. This may further understanding of attitudes towards help-seeking, particularly when the next consensus item suggests that women prefer, if not expect, to be able to trust a health professional. The placement of item 8 *"It is important to trust a health professional before talking about leakage"* in the Factor arrays ranged from positive (+2) to neutral (0). Qualitative data suggests that placement of this item largely related to previous or ongoing relationships with a professional, rather than professional integrity. Booklet comments focussed on the ability to discuss a sensitive topic and to have it dealt with appropriately. The participants indicated a need to feel confident that their concerns would be dealt with sensitively. They noted challenge of finding a trusted professional with comments such as *"yes, but difficult to know given nature of GP surgery"* (Q12). As the Factor interpretations have shown,

concerns were not necessarily purely focussed on physical symptoms. Item 8 highlights that motivation to seek help may not be entirely related to the symptoms experienced. This may also explain the consensus of item 5. “*Pharmacies should offer information about ways to manage leakage*” was ranked at 0 in three Factors but +2 in Factor 3. The qualitative data showed a wide variety of opinions on this item. Some participants highlighted the need for discretion in a public place, raising similar concerns to those regarding item 8, with comments such as “*Difficult to manage due to privacy issues of broaching subject*” (Q27), “*You'd need to have a good relationship with a pharmacist.*” (Q03) Whereas others were less cautious, perhaps due to differing relationships with staff “*Pharmacy is brilliant. Already offer info*” (Field note Q30). This consensus may suggest that use of pharmacy-led provision may be dependant on other aspects of women’s attitudes towards incontinence, in particular caution about disclosure and public identification.

#### **5.15.1.2 Absorbent product features**

All factors provided a viewpoint that absorbent products for leakage and sanitary towels were not the same. Participants in the Q study were very clear that they were different products, with medium to strong levels of disagreement. Item 42 ranked between -2 to -4 in the Factor arrays. The implications of this will be discussed in section 6.6 in relation to absorbent product development.

All factors positively ranked item 41 “*There should be products designed for different situations*”. It was placed at +2 to +3 in the factor arrays. As not all factors shared views about whether products met lifestyle needs, this is a particularly fascinating finding, perhaps suggesting those women who suggested absorbent products were able to meet lifestyle needs, still considered there was scope for some improvement.

#### **5.15.2 Reference group opinions**

Feedback from the reference group suggested a simplified version of each factor should be written so that it could be understood clearly by anyone not familiar with the project. In addition to the simplified factor descriptions, the following table (Table 26) was created to show some of the most pertinent

themes drawn out by four factor solution. The reference group thought that there were opportunities to develop the table into a quick-reference resource which could be of benefit to other women. Creating resources was outside the scope of this project, however it could be pursued in future research. A discussion relating to the results of the Q study can be found in Chapter 6, wherein views of participants will be discussed in light of both the interview and Q studies.

	<i>Factor 1</i>	<i>Factor 2</i>	<i>Factor 3</i>	<i>Factor 4</i>
	<i>Trial and error</i>	<i>Carry on regardless</i>	<i>Shameful Secret</i>	<i>Wanting change</i>
<i>Attitude focus</i>	Leakage	Leakage	Secrecy	Products
<i>Information-seeking</i>	Yes	Not actively	Yes	Yes
<i>Natural ageing</i>	No	Uncertain	Uncertain	Yes
<i>Cure</i>	Yes	Possibly	Uncertain	Yes
<i>Maintain secrecy</i>	Yes	No	Yes	No
<i>Pad use</i>	Reluctantly	Yes	Yes	Yes
<i>Greatest concern</i>	Leakage	Odour	Leakage & Odour	Leakage & Odour
<i>Stereotyping</i>	Yes	No	No	No
<i>Embarrassment</i>	Sometimes	No	No	Yes
<i>Personal responsibility</i>	No	No	Yes	Yes
<i>Successful planning</i>	Uncertain	Uncertain	No	Uncertain

**Table 26 Overview of attitudes from four factor solution**

## 5.16 Discussion of the Q study

The Q study aimed to characterise attitudes of women towards their experience of urine leakage and use of absorbent products. Using Q methodology enabled identification of attitudes, in addition to highlighting

similarities and differences between those attitudes. The literature review had previously found that not all women used absorbent products as a coping strategy, highlighting differing views to their use. When absorbent products were used by women they created a number of practical and social challenges for women. Getliffe et al. (2007) found that in attempting to contain the problem women encountered psychological and social difficulties, which overlapped with the physical issues encountered. The interview phase of this study aimed to continue on from the work of Getliffe et al. (2007) by considering the leakage experience of women in alongside to their product use. The interview study found that the ways in which women understood their leakage symptoms may impact on their methods of self-care, including use of absorbent products. This suggested that absorbent product use and women's experience of urine leakage may be inextricably linked.

The Q study built on the literature review and interview study by systematically characterising the attitudes of women to their experience and absorbent product use. It was able to identify salient issues within four different viewpoints, demonstrating the aspects of experience and absorbent product use that were most prioritised by participants. This empirical evidence contributes to the understanding of women's attitudes towards the experience of urine leakage and the use of absorbent products.

This section discusses whether the study aim and objectives were met and presents the conclusions drawn from the Q study. The chapter will conclude with the strengths and limitations of the study.

### **5.16.1 Participant characteristics**

The participants in this study were all women living within the Yorkshire and Humber region and who experienced self-reported urine leakage.

Participants were aged between 36 years and 77 years of age (mean age 57.3). Two participants were in their late 30s (10%), five were in their 40s (25%), five were in their 50s (25%), three were in their 60s (15%) and five were in their 70s (25%). A small sample such as the one in this study may not be representative of the wider population, however a comparison of age

trends for urinary incontinence found that whilst prevalence has a positive correlation with age that the correlation may not be linear (Milsom et al., 2013). This may help to explain why fewer women in their 60s participated than might otherwise be expected.

Ten participants were in employment (50%), two were self-employed (10%), one was unable to work due to ill health (5%) and seven were retired (35%). Household income of participants ranged between £10,000 to over £100,000, however data was not provided by two participants. All but two participants over the age of 60 had a household income of between £10,000 - £20,000. Only one participant over the age of 60 was still in employment, the rest being retired.

Eighteen participants considered themselves to be White British or English; one participant was White Irish and two participants were dual heritage. The three participants who did not have White British/ English heritage were aged between 45-46 and all had household incomes of over £40,000. Two of their Q-sorts were defined on Factors 2 and 4, and one did not significantly load onto any factor (Q07 onto Factor 2; Q20 onto Factor 4; Q27 non-loading). Factors 1 & 3 therefore only contained the viewpoints of White British/ English women, culturally this may be important particularly as there is no other commonality between the demographic data or self-reported symptoms of participants loading onto any of the factors. However, as only Factor 1 had statistical significance it is important not to generalise the findings further than can be justified.

### **5.16.2 Main findings of the Q study**

The Q study was designed to meet the third research objective by characterising women's attitudes to urinary incontinence and use of absorbent products, and to deepen understanding of the findings from the literature review and the interview study. The literature review identified that daily absorbent product use was not fully explained within the evidence base. Absorbent product use was often considered in dichotomous terms, (for example used/ not used; day/ night) which did not take into account participants' differing attitudes towards the symptoms they were

experiencing. The interview study found that women aimed to maintain an identity and used a range of coping strategies to manage leakage. Participants communicated their needs using context-specific terminology. They did not necessarily consider their symptoms to be incontinence, and gave examples illustrating a range of views. The likelihood of seeking treatment was largely dependant on past experience and how symptoms were understood, which also influenced product use. The socio-technical analysis of the data found that the goals women had when considering product use had a blend of social and physical purposes. Product use considered the whole life cycle of the product, from purchase of the products (and additional items necessary for ease of use) to disposal. The participants often felt they had to 'make do' with current products as alternatives could be more challenging to their identity. The Q study therefore provided evidence of women's attitudes towards their experience of urine leakage and use of absorbent products, further developing understanding of the subject.

Q methodology was used to characterise a range of shared perspectives. Twenty Q-sorts were included within analysis which identified four separate viewpoints, representing a sample of women living within the Yorkshire and Humber region. The viewpoints were named Trial and error; Carry on Regardless; Shameful secret; and Wanting change. These views highlighted diversity in women's attitudes, indicating that attitudes towards urine leakage and product use are not homogenous. The ways in which absorbent products were prioritised was different between each viewpoint, which may be due in part to the understanding of symptoms. Each of the factor arrays provided item distributions which were congruent with the Q-sort data. The factors demonstrated the complexity of attitudes towards urine leakage and the management strategies employed. In brief, the views of women expressed through Factor 1 thought that leakage was curable and absorbent products were not a substitute for finding help. The women described by Factor 2, thought that leakage was an accepted part of life and that absorbent products were a good strategy for dealing with leakage to ensure continuity of life. Factor 3 described views which conveyed that absorbent products were essential to maintaining secrecy; voicing concerns about

leakage was challenging, particularly because of the lack of knowledge surrounding the issue. The women typified by Factor 4 expressed that leakage was concerning but associated with ageing; there was a desire for new products which would better meet the needs of the user. The findings of the Q study established that women's attitudes towards symptoms of urine leakage are varied, requiring a number of practical approaches to enhance the ability to cope.

There were a number of shared viewpoints across all factors. Two of these shared viewpoints related to accessing healthcare professionals, two related to understanding of the symptom and two to product design. Despite all the participants having access to NHS services, the Q study demonstrated that not all women may wish to access the professional help available to them. This is despite placement of consensus items suggesting that participants did recognise that incontinence and leakage may be comparable and that the issue could be considered a medical problem. It is well documented that many women delay seeking treatment for urinary incontinence (Hannestad et al., 2002; Bilgic et al., 2017; Schreiber Pedersen et al., 2018). Previous studies have shown that women will prioritise other health conditions, and will seek help for those first (Vethanayagam et al., 2016). Additionally, attitudes of health professionals can affect help-seeking behaviours (Mallett et al., 2018), which was signified in this Q study by the need for trust which was illustrated within all viewpoints.

All participants were experiencing urine leakage, and had previously (if not at the time of participation), used absorbent products. It was the aim of this study to recruit women outside of a healthcare context, to ensure there were opportunities for women who did not engage with healthcare professionals about their symptoms to have their views included in the study. As a result, women who had never sought help, women who had previously sought help and women who were currently receiving intervention for symptoms were included in the study. This heterogeneity ensured that the factors represented a range of views, independent of whether help had been sought or not.



The viewpoints derived from this study are not meant to be indicative of all women's views, nor are they entirely representative of the women who participated. Those participants whose Q-sorts were most closely associated with a Factor will be most clearly represented. Whilst Factors 1 and 2 were most statistically significant, the importance of Factors 3 and 4 should not be overlooked. These views indicated that there may be women who do not engage fully with professional help because of their understanding of symptoms and the reliance on absorbent products. The Factors may have been strengthened by additional recruitment, however, these viewpoints may represent people less likely to be willing to admit leakage, (Factor 3 in particular) and therefore additional recruitment may have made very little difference to the number of Q-sorts which informed these viewpoints.

It is possible that different views would be found if the study had been larger. The study considered women in the Yorkshire and Humber region only and therefore women living in different geographical areas may have different views. The attitudes of the participants towards urinary incontinence were affected by the cultures of which they were part (Siddiqui et al., 2016). In addition, the large majority of participants were White British or Irish and therefore the views may not be representative of people living in Yorkshire or Humber who originate from a different cultural background. However, a previous qualitative study which considered people from South-East Asian backgrounds living in the UK, has highlighted similar themes to the attitudes expressed in this study (Doshani et al., 2009b).

Xu et al. (2016) found that the relationship between Quality of Life and symptom severity is partially mediated by coping style. The factors identified in this study may hint at differing coping styles. Further research should consider whether attitudes towards urinary incontinence may help identify women who could benefit from tailored approaches to care which improve Quality of Life.

### **5.16.3 Cross factor comparison**

This section will consider pertinent differences across factors, with particular focus on the social aspects of managing urine leakage. Items relating to

social concerns provided the most contrast between factors and therefore require further consideration. The literature review and interview study already demonstrated that social concerns were influential when participants explained their experience of urine leakage and absorbent product use. In Factors 2 and 3, the views relating to life choices showed that exemplars did not make choices about their lives based on their symptoms of urine leakage. They were still able to enjoy activities in spite of the leakage. This is in stark contrast to the views in Factor 1 and 4, where exemplars modified their choices to take leakage into account, and believed leakage impacted on their enjoyment of activities. The effect on decision-making may be due in part to the understanding the participants had of leakage. The views highlighted in Factor 2 suggest that whilst there might have been some uncertainty about the cause of leakage, exemplars did not worry about the symptoms. Interestingly Factor 3, which emphasised the need for secrecy in its interpretation, shows that exemplar participants did not make changes to life choices, although with less strong agreement than the exemplars on Factor 2. This may suggest that decision-making and participation in activity remained unchanged to ensure secrecy, rather than due to lack of concern. On the other hand, Factor 1 illustrated very clearly that leakage was not inevitable, not associated with normal ageing and could be cured. Factor 4 also shows a belief in curative measures, despite understanding the symptom as a natural ageing process.

How women deal with symptoms may also be affected by how they feel about communicating with others. Factors 1,2 and 4 all provided a view of attitudes towards leakage as negative, where Factor 3 suggested uncertainty about others' attitudes. Whilst all viewpoints shared agreement that it was easier to talk to someone who experienced similar issues, and wished leakage were covered in routine appointments, there was difference of opinion about how difficult it was to admit experiencing leakage. The women typified by Factor 3 provided the strongest indication that admitting to experiencing symptoms was problematic, followed by the women typified by Factor 1. Interestingly, women typified by Factor 4 were less likely to agree with difficulties admitting leakage than those on Factor 2, who were generally more accepting of their symptoms.

Attitudes towards product use also varied between factors. Factor 4 was the only factor which suggested absorbent products did not currently meet users' needs, in contrast to Factor 2 suggesting high levels of acceptability. Despite this, the views of women on Factor 2 illustrated that changes to product design would be welcomed. Women typified by Factor 1 suggested they used pads as a last resort, unlike women on all other factors. Factor 3 highlighted that those exemplars felt very strongly that absorbent products were not a last resort, suggesting similar levels of use and comfort as those typified by Factor 2. Comfort was an issue for exemplars of Factors 1 and 4, both these viewpoints also indicated that cost of the product was not as important as its performance.

## **5.17 Methodological considerations**

### **5.17.1 Strengths of the Q study**

This original research study used Q methodology to advance knowledge gained through the literature review and interview study. Q Methodology is an appropriate method for gaining attitudes of those experiencing urinary incontinence as it allows participation without challenging the narrative of a continent-self. Participation can be carried out without detailing personal experience verbally but data can still provide depth usually expected from qualitative methods. Q Methodology is particularly useful when investigating hidden populations and sensitive subjects as its primary data collection method allows minimal engagement with the researcher. However, it also facilitates those participants who wish to discuss their choices of item placement to have opportunity to talk to researchers, alongside the data they provide in the Q-sort.

The benefit of having four distinct attitude types showing that women's attitudes are affected by a number of concerns is that personalised care and products can be targeted effectively. Understanding that differing attitudes may affect help-seeking, coping strategies and perceptions of self and others, will enable healthcare providers to start considering continence services which are designed for individualised care.

### 5.17.2 Limitations of the Q study

Despite the strengths of the study, there were also limitations. Participation in the Q study was not as high as originally hoped and whilst this did not affect the quality of the study methodologically, it did limit the statistical significance of findings particularly from Factors 3 and 4. Despite this limitation, these viewpoints do have explanatory value. The interpretations of these women's viewpoints are important as they illuminate further understanding of women who may not ordinarily choose to seek help or take part in research on such a sensitive topic.

Whilst there was no obligation for participants to sort the items used in the Q-sort in any particular way, some social response bias may have occurred due to the sensitivity of the topic. Some consideration was given to this at the research design stage, ensuring participants understood they were entitled to anonymity and confidentiality. The condition of instruction indicated that the items were to be sorted based on the participant's experience, however due to the stigma surrounding the topic it is possible this was not always the case. However, as Q methodology does not seek to understand experience, rather it enables characterization of attitudes about experience. Therefore any social response bias may provide insight into what women want to believe about their experience.

Despite efforts to refine the statements used in the Q set, there were still aspects that could have been improved which did not become fully apparent until analysis. Although it was vitally important to consider experience and product use, some statements could have been framed in a way which would have better considered products within women's daily lives. Additionally, there was difference in understanding statement 32 "*Leakage does not affect personal relationships*". This statement was meant to encompass all aspects of close relationships but some participants suggested that they understood the statement differently, either relating it to sexual relationships, or long-standing relationships. The statement was purposefully vague to account for different lifestyles, but could have perhaps been worded as "*Leakage does not affect relationships*" to ensure that all participants could make meaning of it in relation to their own experience.

Level of educational attainment was not measured, which may have been a useful parameter to consider when interpreting the factors. Level of education may affect the way in which continence is understood and managed. Health literacy is known to affect self-management of other conditions (Rowlands, 2009) and may also be important to understanding attitudes towards urinary incontinence and how women deal with leakage symptoms (Cohn et al., 2018).

## **5.18 Chapter summary**

This chapter presented the methods used to conduct and analyse a Q study, which resulted in four attitude types characterising women's experience of urine leakage and the use of absorbent products.

Statements were generated from interview data (described in chapter 4), to be used as Q-set items within the Q study. A refinement process was undertaken, culminating in a pilot test undertaken by reference group members and two other women.

Twenty women participated in the main Q study. Analysis of the Q-sorts was undertaken using PQ Method software. A variety of statistical and interpretive methods were used to help decide upon the most appropriate solution. A four factor solution was created. The four viewpoints were described narratively using booklet and field note data to help illuminate attitudes further. The viewpoints were titled Trial and error (1); Carry on regardless (2); Shameful secret (3) and Wanting change (4). Viewpoints expressed in Factors 1 to 3 were primarily concerned with the effect of leakage on daily life, the viewpoint of women on Factor 4 prioritised absorbent products as a method of coping with leakage.

The next chapter will consider findings from both the interview study and the Q study, to provide an integrative discussion. The discussion will highlight similarities and differences between the two sets of findings.

## **Chapter 6 Discussion**

### **6.1 Introduction**

The aim of this PhD thesis was to gain a deeper understanding of women's attitudes to their experience of urinary incontinence, and the use or non-use of absorbent products. A scoping literature review was conducted which identified previous research on this topic area. Work with a reference group of women focussed the research design further, before two empirical research studies were undertaken to address the overall aim of the research. Firstly, a qualitative interview study was conducted to explore a range of experiences and perceptions of women who experienced urinary incontinence. This was followed by a Q study, to characterise women's attitudes. The findings of these two studies were presented in the preceding two chapters and addressed the first three research objectives.

This chapter presents the integrated discussion and conclusions from the study, with reference to the four research objectives which were outlined in Chapter 3. Using the findings from the interview and Q studies an integrated table of findings is presented, highlighting the core themes which were evident in both studies (Table 27). The findings of both studies are combined within this chapter to address the overall research aim and further illuminate women's understanding of urine leakage and absorbent product use. This is followed by the findings' relevance to policy, practice and product development thereby meeting the fourth research objective. Key findings and conclusions of the study will then be detailed. Finally, the chapter will close with a brief reflective account of the PhD process, to give an overview of the researcher's journey throughout the study.

### **6.2 Integrated discussion**

The initial scoping literature review considering women's use of absorbent products for urinary incontinence, which found that absorbent product use

was multifactorial. Use of absorbent products to contain leaked urine was influenced by women's experience of urinary incontinence and their social circumstances. It was clear from the literature that women's experience of urinary incontinence and absorbent product use were inextricably linked. The work of Getliffe et al. (2007) was identified as providing the most holistic consideration of absorbent product use, taking psychosocial factors into account. A research aim for the PhD was developed to elaborate on the understanding generated from the Getliffe et al. (2007) study. From this four objectives were proposed which would address the gap in knowledge –

1. Describe and understand experiences of women with urinary incontinence.
2. Understand the use/ non-use of absorbent products for containing urine.
3. Characterise women's attitudes to urinary incontinence and its management.
4. Discuss how the findings may influence future absorbent product design and healthcare practice.

The first and second objectives were met by the interview study; the findings highlighted three themes which indicated a number of social and practical challenges for women when experiencing urine leakage or using absorbent products. The third objective, to characterise women's attitudes, was met by the Q study, using raw data from the interview study to develop items for the Q-sort. Four distinct viewpoints were represented by the findings of the Q study; two which prioritised statements relating to leakage experience and two which prioritised use of absorbent products. The final research objective was met by critically considering the findings of both studies independently and in conjunction with one another. Discussions of the individual studies were presented in Chapter 4 and 5. This chapter will discuss the findings in an integrated manner, thus enabling consideration of future product design and healthcare practice.

### 6.3 Cross study comparisons

The key similarities between the interview study and Q study will be considered in this section. Whilst each study produced distinct findings, some comparisons can be made between the two studies which will further meet the overall research aim, by addressing the fourth research objective. Table 27 shows the synthesis between the interview findings and the Q study findings. Each of the three themes generated in the interview study was mapped against the key features identified within the four viewpoints generated by the Q study. This synthesis strengthens the understanding of urinary incontinence and use of absorbent products within both empirical studies.

The interview study resulted in three themes, these were maintaining identity; communication; and seeking help and information. From the Q study, the first viewpoint suggested that leakage was a concern and that it negatively impacted on women's lives. Use of absorbent products was not necessarily a straight-forward choice to make. The second viewpoint showed acceptance of symptoms and a continuation of activities and routines using absorbent products as a preferred coping strategy. The third viewpoint also showed that absorbent products were a preferred coping strategy, but the stigma of leakage instigated a secretive approach to coping. The final viewpoint suggested that whilst women did have concerns about their symptoms they felt it was a natural part of ageing. Due to the problems these women encountered when using absorbent products there was enthusiasm for product development.

Whilst not all participants of the Q study prioritised the statements similarly, the attitudinal priorities of those women represented by the first two viewpoints (Factors 1-2) were most affected by feelings towards leakage on their daily lives (sections 5.14.15.14.2). These views were statistically significant. Where the interviews identified some of the very specific concerns women had in relation to maintenance of identity, the Q study findings suggested that not all women had equal concerns about the impact of urine leakage on their identity. Each viewpoint distinguished particular aspects of experience which were unique to women described by that



viewpoint. The four viewpoints generated by the Q study may not be indicative of four 'types' of woman, rather they may indicate views of women with different coping styles (dispositional) and/ or coping responses (situational) (Moos and Holahan, 2003). Personality and stress levels are thought to influence coping style and responses (Moos and Holahan, 2003; Afshar et al., 2015). Coping responses in particular are thought to be adaptable (Moos and Holahan, 2003). The views of participants were influenced by individual experience and knowledge of the issue under investigation. This was also evident within the interviews where participants spoke about experience and knowledge affecting coping. Unsurprisingly, there did not seem to be any interview participant whose views were congruent with the third viewpoint generated by the Q study. This particular view prioritised secrecy as a coping strategy. The participants who distinguished Factor 3 (section 5.14.3) gave very little qualitative data, which demonstrates the value of these findings and the use of Q methodology to understand more about this population. This viewpoint and the women it represents may be absent from qualitative research more generally, as there may be less willingness by women with this attitude-type to discuss their personal experience compared to women who hold other views.

There was no distinction between those who had sought help and those who had not in the distinguishing Q sorts for any of the four viewpoints generated by the Q study. This may imply that the attitudes of women experiencing urinary incontinence are less affected by help received than by social determinants. In the interview study, participants who had sought help but were currently not engaged with services gave a range of reasons for not returning to healthcare providers. These women found other ways of coping which allowed them to maintain their lives more-or-less as they had before, irrespective of whether they thought additional help may be beneficial. However, disengagement from health services by people with other health conditions is associated with low capacity for self-management (Coventry et al., 2014; Elders et al., 2014). This illustrates the importance of understanding psychosocial factors affecting women's experience of urinary incontinence and consequently their ability to cope with symptoms.

**Table 27 Comparisons between interview and Q study findings**

		<b><i>Q-sort Solution - Factors</i></b>			
		<b>Trial and error</b>	<b>Carry on regardless</b>	<b>Shameful secret</b>	<b>Wanting change</b>
<b>Interview Themes</b>	<b>Maintaining identity</b>	Leakage is not normal and there are negative attitudes towards it. Don't want to be stereotyped. Aware of the environmental impact of absorbent products. Coping is not always successful and pads used reluctantly.	Identity unaffected by leakage. Relationships and social activities are unchanged. Absorbent products meet expectations.	Leakage is concerning and isolating. The individual is responsible for prevention and management. Absorbent products are the easiest and most important way to cope with leakage. Able to participate in activities, but planning is not always successful.	Don't feel stereotyped, but find it difficult to maintain activities. Consider leakage as a natural ageing process. Use absorbent products but want better products. Feel responsible for coping effectively, but not for symptoms.
	<b>Communication</b>	Keep it secret but want to find more information. Prefer to talk to people in similar circumstances.	Talk openly to friends, but find it easier to talk to others in similar situation.	Discretion required. Don't want to admit they experience leakage.	Family and friends know, but conscious of others' negative attitudes. Good support networks.
	<b>Seeking help and information</b>	Know help exists through GP services, but prefer a passive approach to accessing help. Certain there is a cure, leakage is not normal ageing.	Not enough of an issue to seek further help. Happy to discuss with professionals. Always use pads, happy to do so as leakage is perceived as minimal.	Wouldn't choose to mention it or get help from the GP, possibly would go to a pharmacy instead.	Ambivalent as symptoms not as bad as others'. Leakage is natural and help is not necessary. Would prefer information more than intervention. More concerned with products than finding help.

### 6.3.1 Maintaining identity

Central to both studies was the need for participants to preserve a sense of self despite symptoms. This is congruent with Getliffe et al. (2007) who found self-perception was a major psychological impact of incontinence. One justification for this study to be conducted using the methods employed was to ascertain attitudes of women within a particular geographical area. Undertaking the study in the Yorkshire and Humber region enabled consideration to be given to the context of the culture to which women belonged. Cultures direct and manipulate not only understanding, but also the ways in which individuals within a culture speak about their understanding, through a symbiotic relationship (Bickhard, 2015). Hong (2009) defined culture as

*“...networks of knowledge consisting of learned routines of thinking, feeling, and interacting with other people, as well as a corpus of substantive assertions and ideas about aspects of the world... among a collection of interconnected individuals...”*

This definition implies that culture has internal and external elements, affecting and altered by individuals, as part of larger groups. The attitudes of the participants towards urinary incontinence were affected by the cultures of which they were part, similarly to findings of others (Siddiqui et al., 2016). Urinary incontinence could be considered a concealable stigmatising identity within many cultures (Garcia et al., 2005). Although the identity can be hidden from others, if it were to become known it has potential for social devaluation (Goffman, 1963). Women experiencing urinary incontinence may be vulnerable to discrimination based on their experience (Crocker et al., 1998). All participants expressed views that suggested awareness of the threat that urine leakage may pose to their identity, for some that also included potential for stigmatisation because of the use of absorbent products.

The views expressed by the first viewpoint in the Q study were congruent with many of the subthemes within the maintaining identity theme of the interview study. Women did not want to be stereotyped and they believed others had negative attitudes towards urine leakage. As noted in the introduction there are cultural understandings and moral rules within society which determine attitudes towards urination. Participants of this study were very aware of these

norms and sought to navigate these within their lives. These findings strengthen the knowledge about cultural understanding of leakage on women's experience and are congruent with many other studies which have considered women's experience in light of their culture (Chaliha and Stanton, 1999; Sande et al., 2009; Bradway et al., 2010; Siddiqui et al., 2014).

Maintaining identity was a key theme within the interview study, but the Q study showed women did not all have similar attitudes towards items relating to the self. Similarly, Quinn and Chaudoir (2009) found that surveyed participants of their US study did not all rate a range of concealable stigmatising identities central to the self (n=300). Psychological distress was associated with a stigmatising identity, but the association was dependant on how central the identity was to the self. Using those results to help interpret the findings of this study may imply that women represented by the viewpoint of Factor 2 in the Q study may not associate themselves with a stigmatising identity. Items relating to embarrassment, concealment and others' attitudes were ranked quite differently to the views expressed through the other Factors. This may be a protective feature, allowing women to continue with life unaffected by their leakage experience. The reasons behind this were not clear, however it could be hypothesised that selective 'moral disengagement' occurred therefore preventing negative perceptions of their circumstances (Bandura, 2002). This phenomenon has not been studied in relation to continence, but research on socially unacceptable health practices has shown that disengagement beliefs impact adherence to healthcare intervention (Dijkstra, 2009; Naughton et al., 2013). With this in mind, it may also explain why women with this view were the only participants of the Q study who didn't think that pelvic floor exercises may be helpful.

On the other hand, women whose views were expressed by Factor 3 showed that their response to urine leakage was to isolate themselves. Although this may not have been obvious to others around them as they continued to partake in activities, they felt a sense of responsibility to prevent and manage symptoms. Withdrawal in this way could make these women susceptible to emotional loneliness due to the difference between desired and actual interactions (Baarsen-Heppener et al., 2001). They were uncertain of what

others may think about urine leakage but they did not feel stereotyped, possibly because of the level of secrecy surrounding their experience. This may imply that the potential threat from leakage was more of a concern to their identity than lived experience. Social isolation is known to affect some people experiencing incontinence and has also been shown to be related to poorer outcomes (Hawthorne, 2008; Yip et al., 2013; Smith et al., 2018). Whilst taking responsibility for managing symptoms might be considered proactive, without the health literacy to support appropriate management, these women may maintain their identity through social isolation, which could risk their long term health (Smith et al., 2018). Isolation can result in emotional and social loneliness, which is also associated with increased mortality risk in older adults (Tilvis et al., 2011; Rico-Urbe et al., 2018).

The women who viewed urine leakage as a natural ageing process (Factor 4) had found a way to mitigate for the negative effects of leakage by justifying its occurrence as something which could be expected even if it wasn't inevitable. They were also able to maintain their normal activities, however they also benefitted from the support of those closest to them. They did not feel stereotyped but remained conscious of others' attitudes towards leakage. The women typified by this viewpoint may be exhibiting higher levels of emotional intelligence, as it has been suggested that people with higher emotional intelligence are more skilled at generating support from their social networks in times of difficulty (Brackett et al., 2006; Zeidner et al., 2016). People with good social skills may find it easier to identify sources of emotional support, which helps maintain wellbeing (Zeidner et al., 2016) and may increase feelings of control (Krause, 1987). Feeling in control may enable women to maintain their chosen identity.

Maintaining identity was expressed and facilitated by a number of means by all participants. The ways in which women seek to maintain their chosen identity may impact the ways in which they seek, understand and put into action information relating to continence. This will be explored further in relation to communication in the following section.

### 6.3.2 Communication

The knowledge that women who experience urine leakage have communication strategies to cope with leakage is of great relevance to ongoing research of the population under investigation. As previously discussed, the importance of maintaining identity was prioritised by participants of both studies. It could be hypothesised that this identity work is mediated by careful communication by women. Behaviours are interpreted by utilization of symbols and language, responses by others to those behaviours are shaped by shared cultural understanding (Markus and Kitayama, 2010). Social theories of stigmatisation have highlighted how symbolic interaction creates meaning for individuals' actions (Mead and Morris, 1967). How others respond to individuals influences self-conceptions, creating 'role identities' (Yang et al., 2007). The importance of language to expression and experience of other symptoms, particularly pain, is already recognised (Bourke, 2014) and may share some similarities with women's experience of urinary incontinence.

This is not the first study to show communication as an important theme in qualitative research on urinary incontinence. Brady et al. (2016) found that communication was also a key theme for patients experiencing urinary incontinence after stroke (n=15). This study found that patients struggled to speak to healthcare professionals about their continence needs in in-patient settings. It is likely that the level of dependence of the participants in Brady's study was greater than the participants in this study, however it is important to note the social difficulties caused by cultural understandings of incontinence appear to be similar across different settings. In both the Brady et al. (2016) study and in this study non-verbal communication was highlighted by participants. Visual cues, often emblematic in nature, were described. These visual cues informed an expected course of action. Cues had semiotic meaning to participants, however to have shared meaning the giver and receiver of the cues required a mutual understanding for it interpreted as intended (Wharton, 2009). Judgements were made by participants in this study based on whether the expected course of action was followed by the receiver, and in some cases also whether appropriate cues had been given by others. Negative judgements of others were made when they did not, or were not able to, meet the expected course of action. Participants hypothesised what others may think of them if

they did not follow the expected course of action, but none expressly stated that anyone had made negative judgements about them. Examples of visual cues given in this study included the visibility of absorbent products through clothing, visibility of leaked urine on clothing, placement of absorbent products when not being worn and odour from leakage. Fear of judgement by others was also considered by Getliffe et al. (2007), where similar visual cues were recounted by participants.

This interview study also found that women had a range of communicative strategies they used to help avoid and overcome potential difficulties that urine leakage or absorbent product use may cause. The views expressed within the Q study showed that attitudes towards leakage may affect the ways in which women communicate about their experience. Qualitative data helped to explain the placement of items within Q-sorts. Two viewpoints (Factors 1 and 4) suggested that although these women preferred to keep leakage secret they were able to talk to others in similar circumstances, or close friends when the need arose. However, what is particularly interesting is that the other two viewpoints suggested different communicative strategies. Those women who felt that their identity was unaffected by leakage (Factor 2) were able to talk openly to friends and health professionals. At the opposite end of the spectrum were women who did not want to even admit they experienced leakage and for whom discretion was imperative (Factor 3). Those women would not choose to mention symptoms to a doctor although they may be willing to approach a pharmacist instead, suggesting that a level of anonymity may be beneficial to women typified by this viewpoint when they help-seek. In addition to the social challenges of communication, low-health literacy may affect communication between health professionals and women experiencing urine leakage. This will be explored further in the next section.

### **6.3.3 Seeking help and information**

The relevance of healthcare to urine leakage was not immediately obvious to some participants in either study. This could be due to the varying levels of health literacy. Health literacy is described by Raynor (2012) as a tripartite concept. It includes the ability of an individual to read and understand

healthcare information; an ability to engage with healthcare processes; and the removal of complexity and barriers within healthcare systems to aid understanding and involvement. Nutbeam (2008) explains that whilst knowledge is important, health literacy is a personal asset that enables people to influence the wider determinants of health. It is perhaps this definition which is best suited to the women in this study who had not all sought help and who did not necessarily contextualise symptoms from a health perspective. In the interview study some participants suggested there was distinction between urine leakage, a social issue, and urinary incontinence, a health problem. Those who had not sought help suggested that severity of symptoms would have to increase before help was sought, which has been found previously in similar populations (Kinchen et al., 2003; Margalith et al., 2004; Schreiber Pedersen et al., 2018). However, the items which sought to distinguish attitudes on this topic within the Q study, items 9 and 13, were both consensus items, meaning these items were similarly ranked in all four Factors. Interestingly, whilst not statistically significant, Factors 2 and 3 both showed agreement with *“Leakage and incontinence are not the same thing”* (statement 13), which supports the findings of the interview study. Conversely, the viewpoints represented by Factors 1 and 4 showed that these women thought leakage and incontinence were comparable. To further illustrate the consideration made by participants when placing statement 13, the field notes for participant Q27 indicate that whilst the participant knew that incontinence and leakage were conceptually the same she did not consider herself incontinent, which affected the placement of the statement in this Q-sort, *“Knows that they are same (knowledge) but doesn't consider herself incontinent so in own experience thinks they are different (attitude).”* (Field note)

Other participants also spent considerable time deciding where statement 13 should be placed. As the condition of instruction asked women to sort the items based on their own experience, this might suggest a lack of parity between knowledge and experience, which may in turn affect help-seeking. Qualitative data collected during the Q study illustrated that in addition to knowledge about the symptom, knowledge about the availability of intervention also affected attitudes towards help-seeking. Using Table 27 as a guide, it appears that



attitudes towards help-seeking were not particularly positive. Whilst participants knew that help was available, reasons for not seeking help were as nuanced as previous literature has suggested (Sande et al., 2009; Apostolidis et al., 2012). The view from Factor 1 gave clear indication that these women believed that there was a cure for leakage and it was not natural ageing, or inevitable, they wanted to be able to access help passively with healthcare professionals taking the more active role. The internet was also viewed as a good way of accessing information about leakage, however this should be treated cautiously as Wagg et al. (2017) found that whilst participants in her study thought the internet would be a good place to gather information very few had done so, despite the majority having internet access. Online intervention has already been shown to have good outcomes for women with urinary incontinence, however the quality of continence information available through social media has been assessed previously as being generally poor (Sjostrom et al., 2013; Saraswat et al., 2016). This knowledge, combined with the findings relating to communication provides good insight into how healthcare strategies might be developed for women who may be motivated to use the internet for improving knowledge. The viewpoints from Factors 2 and 4 showed that help was not perceived to be necessary, although the women represented by Factor 4 would have liked more information about how to manage symptoms themselves, and were the most positive about the use of the internet for information-gathering. The women distinguishing Factor 3 may have had the lowest levels of health literacy of all participants. There was a great deal of uncertainty about symptoms, despite the high levels of concern these women had about the symptoms. Low health literacy has been linked with poor Quality of Life in older patients with long term conditions in the North of England (Panagioti et al., 2018), and despite urinary incontinence not being a condition in itself it may be a long term symptom for many women (Herschorn et al., 2008; Bilgic et al., 2010; Minassian et al., 2012).

In both studies there were a variety of views relating to accessing healthcare. These were very clearly distinguished in the Q study, although it is important to note that the most highly prioritised item relating to healthcare was statement 4 "*Leakage should be covered in routine check-ups*" which was viewed positively within all viewpoints. Several authors have recommended facilitation by

healthcare professionals as a way of identifying those experiencing urinary incontinence (Koch, 2006; Howard and Steggall, 2010; Vethanayagam et al., 2016). The findings of this study serve to support those recommendations.

#### **6.4 Relevance to policy**

There has been previous suggestion that stigma may cause health inequality (Muehrer, 2002; Quinn and Chaudoir, 2009; Hatzenbuehler et al., 2013). Yet, despite theories to suggest that cultural understanding plays an important role in whether particular identities are stigmatised or not, there is a paucity of high quality research conducted in Europe which considers the impact of stigma in relation to healthcare for urinary continence. This small study has added to the international evidence base by revealing that some women experiencing urine leakage may feel more stigmatised than others, but that the threat of stigmatisation is a concern for many more. It also showed that some women had stigmatising attitudes towards other women experiencing similar symptoms. This illustrated the importance of understanding cultural norms when designing policy. It may be unrealistic to expect women to 'publically' break cultural norms and policy should reflect this challenge with clear and practical guidance for professionals, in relation to symptoms and absorbent product use. These findings support the need for personalised care, as already defined by NICE guideline CG138, Patient experiences in adult NHS services (NICE, 2012b). As stigmatisation can come from the self, others and society, the way in which care is designed should ensure that women do not feel stigmatised by healthcare professionals or by the healthcare system by addressing perceived stigma (Wan et al., 2014; Southall et al., 2015).

The strength of feeling by participants towards aspects of healthcare within both empirical studies was clear. Perceived knowledge and attitudes of healthcare professionals affected women's attitudes towards help-seeking, as did ease of access, which is comparable to the findings of similar studies (Hägglund and Wadensten, 2007; Basu and Duckett, 2009; Schreiber Pedersen et al., 2018). NICE guideline CG138 recognises the need for understanding the willingness or ability of patients' to engage with services and the impact health beliefs may have on engagement, which is congruent with the

Nutbeam (2008) model of health literacy discussed previously. Despite guideline CG138 having been published a number years ago, there was concern from participants that care was not delivered, or may not be delivered in future, in a manner that met their needs. A NICE guideline exists for the management of urinary incontinence in women (CG171) and the UKCS have produced a policy regarding minimum standards for continence care in the UK (NICE, 2013; Bonner et al., 2014), however some studies focussed upon professional adherence to continence-specific guidelines have shown that health professionals may not be confident or willing to provide the most appropriate continence care (Teunissen et al., 2006; Shaw et al., 2007; Nguyen et al., 2013).

The findings of this study clearly demonstrated the need for psychosocial considerations to be accounted for in continence care. Concerns about the psychosocial impact of urine leakage were as important to women as the physical aspects. This was largely anticipated as Getliffe et al. (2007) previously identified a number of psychological and social impacts affecting women who used absorbent products to contain leakage. NHS England (2018) have practical guidance for Clinical Commissioning Groups which recognises that incontinence can have psychosocial impact but much of the guidance offered, as with the majority of guidelines relating specifically to continence care, focuses upon care for physical symptoms. Ostaszkievicz (2017) has begun to address this previously unmet need by creating a continence care framework for dependant patients, but there are additional opportunities to provide more holistic guidance to healthcare professionals who encounter other types of patients requiring continence care.

## **6.5 Relevance to practice**

Both the interview and Q study found that women described a great deal of uncertainty regarding causes of leakage, and the possibilities for treatment. The interview study also included data which suggested that women may attribute a cause or diagnosis based on limited and perhaps even incorrect, information. Bonner et al. (2014) stipulate that professionals undertaking initial assessment of women with urinary incontinence should have a range of

knowledge, clinical and professional skills. However, should information provided by a patient be incorrect or incomplete there is potential for delayed or inappropriate treatment irrespective of the level of competency of the professional. Professionals should be aware of the potential limitations of information presented to them, to enable appropriate assessment to be made.

The findings of both studies indicated that the ways in which healthcare professionals communicate with women was important to help-seeking and continued engagement with intervention. Terminology used by women may not be 'healthcare' terminology, there is also the possibility that terminology may be applied to symptoms incorrectly. The use of language in patient-professional interactions relating to continence needs was noted by Mitteness (1990) who recognised the impact of cultural understanding on help-seeking. The findings of this research also suggested there may also be avoidance of addressing the subject directly, or in a way that is not indicative of lived experience. To overcome this, healthcare professionals require understanding of cues that women may exhibit, to avoid appearing dismissive.

As other studies have already proposed, some women were keen for a passive approach to help-seeking, preferring to be asked about symptoms rather than to offer unsolicited disclosure (Peters et al., 2004; Wagg et al., 2017). Some women may be more willing to disclose to health professionals when asked directly, but like other sensitive subjects affecting proportionally more women than men, questions regarding incontinence may need to take a routine enquiry approach, rather than a screening approach (Taket et al., 2003). Whilst there is evidence that screening for urinary incontinence may be useful in some primary care contexts in the Netherlands (Visser et al., 2013), the results of such trials should be treated cautiously until further research can confirm that such an approach can be generalised to a UK setting. Unlike screening, a routine enquiry approach would enable healthcare practitioners to make a more personalised assessment, using language appropriate to the individual. There is already some evidence to suggest that a proactive approach by healthcare professionals encouraging older women to receive diagnosis and intervention for urinary incontinence may be cost-effective (Dekker et al., 2012; Vermeulen et al., 2016). Elstad et al. (2010) also suggest that continence related sequelae should be assessed, in particular the authors note anticipation of rejection

indicated by participants, which will be discussed further in relation to absorbent products in the next section (6.6).

Relationships between women and health professionals were perceived as either facilitative or as an obstruction to receiving help. In the interview study, some participants recounted instances of encounters with professionals. Few participants made a distinction between individual healthcare professionals and the services within which they worked; GPs in particular were seen as gatekeepers who determined whether women would receive help. The Q study was able to deepen this understanding by showing that all viewpoints demonstrated a need for trust between a women and health professional before disclosure. Barnard (2016, pp.293) suggests that in addition to professional attitude and behaviours which promote trust, there should also be commitment to gaining patients' trust, this includes a recognition of the "*social determinants of trust*", based on the cultural and social circumstances of the individual. Nurses were only perceived to know more by participants in the Q study because they were thought to have more time to listen and were likely to be women themselves. Whilst the item within the Q set did not distinguish a type of nurse, most participants who commented on this statement considered it in the context of Practice Nursing, which is unsurprising given that approximately one quarter of primary care consultations are now conducted by Nurses (Hobbs et al., 2016). A recent analysis of data obtained from the UK's Clinical Practice Research Database found that Nurse consultations in primary care did have slightly longer duration on average than GP consultations (Stevens et al., 2017). The findings of this study may lead to the proposition that women do not want to be rushed when they do decide to seek help and unless there is a long standing patient-professional relationship with a male professional, they would prefer to disclose to another women. Therefore given current UK practice, nurses may be in a better position to facilitate help-seeking and ongoing care for this population (Howard and Steggall, 2010). A Dutch study is currently underway to assess the effectiveness of nurse-led intervention for women using absorbent products, to improve continence guideline concordance in primary care (Jansen et al., 2017). The findings of this research suggest that there are opportunities for a similar UK-based study

to be conducted, as cultural differences may mean the Dutch results are not transferrable.

Although the majority of participants in the Q study stated they had sought help previously (n=14, 70%) qualitative data from the Q study suggested that help-seeking was rather more informal than might be assumed. Some had mentioned urine leakage to a health professional during consultations for other health issues, rather than making an appointment specifically to address leakage. Others had sought help for other urogynaecological symptoms and the resulting intervention had improved leakage as a secondary consequence. Finally, there were those who had sought help through 'non- standard' routes, for example accessing complementary or alternative therapy. Recognising that women may help-seek by these means again lends itself to a routine enquiry approach by health professionals. Professionals must be willing to act appropriately upon disclosure otherwise there may be an assumption, as has been found previously, that the professional isn't interested (Teunissen et al., 2006; Andersson et al., 2008; Wagg et al., 2017). Disinterest may lead to 'normalisation' and a reliance on absorbent products as a coping strategy.

## **6.6 Relevance to product development**

The findings of both the interview and Q studies provided new and important insight into women's views on their experience of using absorbent products. The relevance of the research to product development is discussed in relation to human factors, with consideration given to consumer needs. Human factors describes the relationships between people, products, and environment (Kohn et al., 2000). Much of the high quality research into absorbent products relates to functionality or usability (Clarke-O'Neill et al., 2002; Clarke-O'Neill et al., 2004; Fader et al., 2008a). However, based on the findings of this study there may be opportunity for manufacturers to adopt a human factors design-approach which recognises the complexity of the design problem.

The findings of this research suggest that it is imperative to consider a range of psychosocial factors at work when designing a product for urinary incontinence. Other industries already recognise the usefulness of understanding subjectivity alongside objectivity to improve product and service development (Kim and Lee, 2015). This research has found that participants required products which

met a primary physical need, but they also required products which would allow them to remain, as far as wider society was concerned, to retain their continent identity. Absorbent products were not solely providing practical utility, but also social utility. It could be postulated that this equated to a requirement for pleasure (Tiger, 2000). A continuation of social position afforded protection from stigma and being discredited, which could have occurred had individuals been labelled as incontinent. Anticipated rejection, which recognises the fear of stigmatisation was highlighted in this study through concerns about odour and visibility of products. Anticipated rejection may increase vulnerability to reduced mental wellbeing (Link et al., 1989). Social influences driving anticipated rejection of interview participants were important to the overall design of products, not simply functionality. Discretion was a product feature that some women in the Q study suggested they may be willing to pay more for. This finding serves to emphasise the importance of discretion to product design. Designing a product which considers the social requirements of women may reduce the level of anticipated rejection and increase the level of trust in the product. Brands who are able to provide trustworthy products are themselves more trusted by consumers (Blis, 2018). Trust is also important in terms of perceived product 'failure'. Like Getliffe et al. (2007), this study provided examples of women using smaller products more regularly rather than bigger, more absorbent products. Using smaller products improved discretion but may have reduced trust in the functionality of the product. A brand marketing study found that around 50% of women surveyed indicated that if a product failed more than once they would not buy that product again (Blis, 2018). This appears to be largely consistent with data from this study and others which found women taking a trial and error approach to absorbent product use (Paterson et al., 2003; Hayder and Schnepf, 2010).

There was an appetite for different types of product for different situations from many participants; a consensus item within the Q study. This finding cannot be fully explained by functionality alone, and therefore consideration of psychosocial aspects of product use may benefit future development of context-specific products. The Q study was also able to show that some women did not consider cost to be as important as function, which is congruent with the consumer hierarchy described by Blis (2018). Mukařovský (1970)

proposed that function could be divided into two distinct categories, that of unmediated function, encompassing practical and theoretical considerations, and emblematic function which includes symbolic and aesthetic qualities. Emblematic function was clear in the use of communicative strategies (section 6.3.2), but this concept may also be important to product design if anticipated rejection is to be overcome through use of products.

The findings of the interview study suggest that the shape and size of products were not always ideal and impacted on the function of the product, due to the fit within underwear or against the body. In addition to changes to the products themselves, participants suggested that clothes, and particularly underwear could be adapted to enable better functionality. The Q study also highlighted the importance of absorbent products for maintaining the secrecy of women whose views were defined by Factor 3; and the enthusiasm for product development by women whose views were defined by Factor 4. New products may ensure life choices remain unaffected by leakage. Co-creation of products in other industries has shown increase in consumers' satisfaction and repurchasing intentions (Lopez et al., 2017). A contemporary design process involving end users contributions from the early development stages could alleviate tensions which may currently exist in the design process. To incorporate emblematic function into products requires systematic change in the way that absorbent products are designed and marketed. Emblematic function may vary depending on the end user group. Although many of the concerns voiced in the interview study seemed to be similar, the Q study suggested that views towards changes to product design are not held by all, and that certain aspects are likely to be more well received by some women than others, as already noted by Fader et al. (2008a).

Some commercially available incontinence products have already become more aesthetically pleasing over the past few years, becoming available in various colours and styles which are less cumbersome, providing some protection from view beneath clothing. However, these changes are not available throughout product ranges, and are not usually provided by healthcare services. They may only go a small way to addressing the underlying need for social acceptability for women. The findings of the interview



study suggest that some women may be open to additional products which improve the functioning or usability of absorbent products.

Designing a more bespoke product range which caters for women with differing emblematic function criteria may allow manufacturers to tap into market shares which are currently under represented. The Q study participants all recognised that there were differences between products for incontinence and menstruation but interview data suggested that some women preferred sanitary towels rather than incontinence products. Choice of product type may be influenced by anticipated rejection and the emblematic function of the products, in addition to other more practical considerations such as absorbency or cost. The emblematic function of sanitary products may be less socially problematic for women of all ages. Emblematic function is highly important in fashion design and can be observed in underwear design particularly. Participants were not keen to change the style of underwear that they were used to (section 4.6.4). If women make choices about their regular undergarments based on emblematic function, it is possible that they also do the same for absorbent products. Addressing psychosocial issues related to urinary incontinence through product design may lead to the potential for better health outcomes by promoting social acceptability, autonomy and individuality.

The findings of both studies suggested that consideration of whether to use absorbent products was undertaken prior to use. There were a number of factors involved in these decisions but importantly psychosocial reasons for use or non-use were indicated in both studies. How women felt about the products in relation to themselves and their values was important. This was exemplified in the interview study and in the viewpoint of Factor 1 in the Q study, highlighting the importance of environmental impact of absorbent products.

The usability of current products was not always viewed as ideal. Within both studies women highlighted that the usability of products could be improved. Concepts relating to usability included aspects of the whole product life-cycle from purchase to disposal, which was also noted by Getliffe et al. (2007). Although there were women who were happy with currently available products, there remains scope to develop products in a number of ways. The time that products could be worn was important to those women who were typified by the viewpoints expressed in Factors 2 and 4. These women were likely to use

absorbent products and were keen for products to be useable for several hours before change was necessary. These women believed their symptoms were less severe than other people's, which may imply that perceptions of severity might influence the length of time women are willing to wear a product. There may be opportunities for product manufacturers to consider the implications of wearing a product for a longer length of time, for example odour control or information provided to women about 'wear time'.

The findings of the interview study found that women may be prepared to use reusable products, providing that functionality was not compromised. However, within the Q study only one viewpoint seemed to suggest this was the case. Six participants defined the view which prioritised reusable products. It was the most statistically significant viewpoint, however the other three viewpoints suggest that reusable products were a polarising topic. The desire to reduce environmental impact may need to be met through a variety of measures to ensure commercial viability. Socially and environmentally-conscious clothing purchases have been shown to be linked to level of knowledge on the subject (Kozar and Hiller Connell, 2013). However, priorities for absorbent products may be more closely linked to anticipated rejection, rather than knowledge.

This study has perhaps highlighted the 'wicked' nature of the design problems faced by absorbent product manufacturers. Wicked problems are those that are *'ill-defined or ill-structured'* because of the societal nature of the issue to be addressed (Rittel and Webber, 1973; Cross, 2007). Wicked problems cannot be overcome through science alone because there can be no exact and complete solution, only good-or-bad solutions according to the norms being used (Farrell and Hooker, 2013). Design of absorbent products has been led by an ongoing need for improved functionality and by the technological advances available in the textile industry. The interview study provided examples of product development desired by the participants. The Q study illustrated the heterogeneity of attitudes towards the topic. By reconsidering how absorbent products are designed and perceived by end-users and in wider society (Klein and Kleinman, 2002), innovation of absorbent products can be advanced. Advancement will benefit product users but could also have positive impact for commercial business and the healthcare industry alongside.

## 6.7 Suggestions for future research

Whilst this study has been able to provide new understanding of women's attitudes towards their experience of urinary incontinence and use of absorbent products, it also highlighted areas where future research may be beneficial to ensuring women receive the most appropriate care. The findings of this study suggest that women may not view their experience of urine leakage as a problem, rather it is an issue which is dealt with in accordance with a range of social factors. Participants of the interview study sought to maintain a narrative which was acceptable and unchallenged by urine leakage. Moreover, the use of absorbent products as a definitive coping strategy was not satisfactory to all. A decision to use absorbent products may be influenced by whether the products are perceived to be congruent with the narrative and social circumstances of the individual. However, further studies are required to determine whether these findings are transferrable to other populations. Due to the limitations of the study, it would be beneficial to conduct similar studies with women of different cultural backgrounds and in different geographical areas to ascertain whether the themes of the study are applicable to other groups of women. Due to the small sample size of both empirical studies conducted (n=11 interview study; n=20 Q study) transferability of the findings is limited, but may provide a basis for future research considering product use by women experiencing urine leakage. A limitation of this study was that health literacy was not addressed. It became clear through analysis of data that participant understanding of urinary symptoms and management was multifactorial and inconsistent. Increased knowledge of health literacy in this population would also be of benefit in shaping information and intervention which meets the needs of a range of women.

This research has illustrated the usefulness of Q methodology to the study of urinary incontinence and absorbent product use and there is opportunity to develop understanding of women's attitudes further by conducting larger studies. To overcome issues of engagement, consideration should be given to online Q sorting methods, for example FlashQ (Hackert and Braehler, 2006) which could mitigate for some of the recruitment issues noted in this thesis. In addition to strengthening the findings of this study, Q methodology could also be used to understand the attitudes of health professionals towards women's

experience of urinary incontinence and the use of absorbent products. This research found that the perceived attitudes of some health professionals was considered a barrier to receiving appropriate care.

This research did not seek to explore help-seeking, however the findings of both studies suggest that seeking information and help was a key aspect of women's experience. As women experiencing urinary incontinence may not always present to healthcare professionals in the manner expected of other non-stigmatised health concerns, there are opportunities for developing novel interventions which overcome difficulties, including communicative barriers, that women may encounter when help-seeking. Future research could investigate new models of symptom identification including routine enquiry methods. Taking a randomised controlled trial approach would ensure that benefits of intervention were adequately measured against usual-care.

There is also scope for further research into the design of absorbent products. Participants described idealised absorbent products and associated items which were innovative and which may meet more of their social needs. In addition to the products themselves, participants described the whole lifecycle of the products. There are a limited number of studies that address such issues, and therefore the opportunities to develop innovative products in conjunction with end users are numerous. Recognising the social needs of women will enable product designers to tackle current design flaws in novel ways.

## **6.8 Furthering the work of Getliffe et al. (2007)**

This discussion has provided an overview of the integrated findings of this research and has met the fourth research objective. It has considered aspects which synthesise with the Getliffe et al. (2007) study, but there are also key differences which increase knowledge about the topic under investigation. This study is able to provide additional insight into how women understand use of absorbent products in the context of their experience of urinary incontinence. Unlike Getliffe et al. (2007), this research recruited women regardless of absorbent product use. Including the views of women not using products

ensured further understanding of decisions and challenges relating to product use which may not have been captured otherwise. Understanding decisions not to use absorbent products is important to informing future product and service development for those women. Social and psychological implications of product use were important to many participants, not just those who used absorbent products. This study found that absorbent products were not always a preferred coping strategy, even by women who did use products.

'Holding urine' and 'ease of use' (as described by Getliffe et al. (2007)) may affect the ability to ensure discretion through use of absorbent products, but this study suggested the need for discretion was fundamentally a social issue enabling women to maintain an identity and roles. Absorbent products helped to maintain identity or challenge it. Getliffe et al. (2007) situated 'discreteness' within a superordinate theme of 'containing the problem' which had physical and psychosocial aspects, whereas in this study discretion was clearly related to social concerns. The pad ranking exercise in the Getliffe et al. (2007) study found that only 41.4% of participants wanted discrete products for day time use. It is possible that participants understood discretion as a concept relating to product shape and size, not as a means of avoiding identification by others, although the social need for discretion and potential psychological impact were clear in the quote used to exemplify 'pad discreteness' in the interviews conducted. This current study provides further awareness of why women may prioritise different aspects of their experiences, including need for discretion, by exploring attitudinal differences and the influences affecting these. The Q study facilitated distinction between participants, improving understanding of multiple factors which may affect women's attitudes. By comparing the findings of the interview and Q studies it was apparent that the priorities of women were not homogenous. This research has been able to expand the findings of Getliffe et al. (2007) by illustrating how attitudes towards urinary incontinence and absorbent product use may be affected by knowledge, experience and cultural norms.

Getliffe et al. (2007) noted that the ways in which women communicate about their experience was emotive and subjective. This study furthered this understanding by demonstrating that in addition to terminology used to describe experience, communication more generally was used as a coping

strategy. Communication enabled women to express themselves verbally and non-verbally by providing socially appropriate means of conveying messages about urinary incontinence, including by use or non-use of absorbent products. Getliffe et al. (2007) used the term 'problem' to describe the issues faced by participants. By recognising the importance of language and terminology, this study has advanced the understanding gained by Getliffe et al. (2007) by identifying that not all women recognise their symptoms as problematic, preferring other terms which more clearly reflect their experience and understanding of symptoms. The implications for policy, practice and product development from the knowledge gained have been discussed. Consideration will now be given to the methodological approaches taken to acquire this knowledge.

## **6.9 Critical discussion on the research approach**

The study engaged two empirical methods alongside a scoping review of the literature. This provided a valuable understanding of how women understand their experience of urine leakage and their use of absorbent products, building upon the work of Getliffe et al. (2007). Strengths and limitations of each of the empirical studies have previously been discussed in Chapters 4 and 5, as well as the individual studies' ability to meet the research aim and objectives. This section will provide a critical discussion of the methodological approach as a whole, deliberating its suitability to answer the research aim.

At the initial stage of research design it was decided that women who experienced urine leakage should be involved in developing the research. It was important to understand their views prior to developing the study to ensure that the research would address an topic that they thought was important. A priori understanding of the topic from a healthcare perspective may not have been congruent with the understanding that women had and therefore a healthcare-led approach to the research design would have been unsuitable. Traditionally, research into women's experience of urinary incontinence has considered the issue from a health perspective; a diagnosable symptom with a strong focus on physical aspects. Whilst there are studies that recognise the psychosocial impact of both urinary incontinence and absorbent product use,

these are fewer in number. Although this type of health research is essential to furthering professional knowledge to improve care for those who engage with services, it is unable to give a holistic overview of women's experience for those who do not actively engage with professionals, particularly of those women coping using shop-bought absorbent products, who may not consider continence issues as a health problem.

It was envisaged that gaining some early insight into women's views on urine leakage and absorbent product use may also promote better engagement with the population under investigation prior during the study. There are many political and funding drivers which promote the use of patients and public in research. Adopting such an approach ensured that the aim of the research had the potential to meet the needs of those it sought to investigate. As the interview study highlighted, information that participants share with professionals may not be reflective of lived-experience, further demonstrating the importance of engagement with women from the outset of the study, to mitigate for potential communication barriers.

The research aim, developed with input from the reference group furthered the existing evidence base by considering context of the research. To the author's knowledge no studies considering women's experience of urinary symptoms or the use of absorbent products have been conducted solely within the Yorkshire and Humber region prior to this study. Choosing this geographical location ensured that these women's voices would be represented within literature, as previous authors have suggested that culture may affect both help-seeking and understanding symptoms (Doshani et al., 2007; Kang and Crogan, 2008; Siddiqui et al., 2012; Cross et al., 2014). Additionally, by recruiting for both empirical studies within communities, rather than through healthcare providers or health-related organisations the study design removed health-framing of the research by enabling those women who may perceive urine leakage as a social rather than a health issue to participate. Due to the sensitive nature of the topic it was imperative to recognise that social influences could influence every stage of participation in the study, from recruitment through to provision of data. A number of recruitment techniques were employed which took into account some of the identified challenges to participation (Barr et al., 2000). Despite characterising the sampling as a convenience sample, considered decisions

were made in regards to the ways in which women were identified, approached and recruited. In this instance, convenience did not mean participation by women who were easily available, rather it acknowledged that due to the inherent complexity of researching hidden populations, some compromise was necessary to ensure the research could progress.

Moreover, the use of gatekeepers was not without its own challenges. The way in which gatekeepers responded to the request to advertise during face-to-face meetings was particularly interesting. Often the body language of gatekeepers would provide an idea of how willing they were to advertise the study. Whilst this data was not formally collected or analysed, it is notable that the non-verbal responses received (particularly from women) were sometimes negative; gatekeepers sought to physically distance themselves by stepping away, showed surprise or made a face of disdain. Such responses may relate to the stigmatizing nature of urinary incontinence. Some gatekeepers perhaps unconsciously revealed stigmatising attitudes (Kurzban and Leary, 2001). These attitudes may be indicative of the negative social responses assumed by women experiencing urinary incontinence in other literature (Garcia et al., 2005).

Conversely, there were gatekeepers who had first-hand experience of urine leakage and were keen to be able to advertise the study. These gatekeepers did not all experience incontinence themselves. Those who had not experienced urinary incontinence had witnessed the impact it had on someone else. These gatekeepers chose to disclose their experience and were much more positive in their response to the study. Interestingly, despite their willingness to engage and advertise the study, only one of the gatekeepers decided to participate in the study. On one occasion a gatekeeper wanted to include so much positive encouragement for the organisation's members to participate in the study, there was a danger of coercion. In this circumstance, working with the gatekeeper to develop a better way of introducing the study advertisement enabled a more neutral alternative to be found.

When advertising materials for the study were provided at the time of request, gatekeepers were more willing to advertise the study. This phenomenon was noted early in the main study and as a result when possible advertising materials were given to gatekeepers at the time of request. Timeframes from



request to advertising the study were reduced by including advertising materials; it also meant the action required by the gatekeeper was lessened, by reducing the need to converse about the study prior to advertising it. However this approach also meant that additional resources, such as poster printing, had to be increased to allow for 'waste'. Although providing advertising materials increased gatekeepers' willingness to advertise, it also came at a financial cost to the study. Providing advertising materials allowed gatekeepers to see exactly what they would be required to display. How gatekeepers perceived the study impacted on their engagement with it. Communicating the study effectively to gatekeepers developed throughout the course of the research; by recognising the social influences which may have affected gatekeepers there was an attempt to reduce 'courtesy stigma' (Ostaszkiwicz et al., 2016).

The sensitive nature of the topic also meant that careful consideration of methods for the empirical studies had to be made. As the research aim was to understand experience, methods which would elicit appropriate data were employed. Using a multi-method approach ensured that the objectives of the research could be met. Whilst there are those that argue that multi-method designs are epistemologically flawed (Ahmed and Sil, 2012), those in favour of such approaches suggest that multi-method designs illuminate the complexity of the social world (Sale et al., 2002; Moran-Ellis et al., 2006). Although qualitative interview studies have been previously conducted to explore women's experience of urinary incontinence or absorbent product use (Andersson et al., 2008; Getliffe et al., 2007; Hayder and Schnepf, 2010), the employment of Q methodology in this subject area was novel. Using Q methodology as a means of characterising attitudes facilitated deeper understanding of the findings from the interview study. The empirical studies provided new knowledge, building upon previous literature and adding to the existing evidence base. Both the interview study and the Q study were appropriate to address the aim and objectives of the study; in conjunction with one another they produced valuable insight into women's experience of urine leakage and the use of absorbent products, expanding existing understanding. After participating in the Q study some women were more receptive to interviewing as a method of data collection. It may have been beneficial to conduct interviews after the Q study had been conducted. Amending the

research design by conducting the Q study first and also permitting women to participate in both studies, may have increased the number of participants in both studies. This knowledge may provide future opportunities to establish a rapport with participants through Q-sorting, prior to conducting qualitative research.

Using the methodological approaches detailed in this thesis could be beneficial to other research on this topic. The knowledge that women who experience continence issues are willing to provide data through Q-sorting may enable other continence-related questions to be addressed using Q methodology. There is already a wealth of evidence that Q methodology lends itself well to sensitive subjects (Bryant et al., 2006; Westbrook et al., 2013; Butler et al., 2014), and now there is opportunity for its use for improving understanding of attitudes towards other continence-related topics. This is particularly important as the Q study generated a viewpoint which suggested there are women who cope with urine leakage secretly, preferring not to disclose their experience at all. As the findings from this study seemed to suggest that there may be barriers to re-engaging with healthcare after initial interventions have been undertaken, deeper understanding of attitudes towards care could facilitate more personalised care pathways. It might be suggested that this is a particularly important time for continence care in the UK, with an ageing population the need for these services may continue to grow. With absorbent product manufacturers directing much of their advertising in the UK at women, it might be hypothesised that some women could be unduly influenced by marketing information rather than evidence-based knowledge regarding urinary incontinence. Therefore to ensure appropriate, timely and patient centred-care for these women it was appropriate to investigate attitudes, to enable better care for these women in future.

## **6.10 Conclusion**

The aim of this research has been addressed by investigating women's understanding of their experience of urine leakage and the use of absorbent

products. It built on the work of Getliffe et al. (2007) to deepen understanding of this complex area of investigation by considering the experience of a range of women, not just those who currently use absorbent products. By reflecting potential changes in the years since Getliffe et al. (2007) undertook their research, this study has increased contemporary understanding of women's experiences.

The participants of this study were adult women who were experiencing urine leakage, and who lived within the Yorkshire and Humber region during the period of data collection. Although some participants had previously sought help, the majority of participants were not engaged with health professionals for their urine leakage at the time of data collection. Absorbent product use was amongst a range of coping strategies employed by the women.

A reference group of women were engaged with the research process from the outset. This public involvement activity identified barriers to research participation, in addition to ongoing sense-checking by experts-by-experience. Inclusion of the reference group improved the relevance of the study to those it sought to engage, particularly with regard to the terminology employed throughout the study.

A scoping literature review was undertaken to identify gaps in the literature and improve understanding of absorbent product use by women prior to conducting empirical research. Included studies were heterogeneous and did not provide a comprehensive understanding of the use of absorbent products by women. The review was able to ascertain that women did use absorbent products to cope with urinary incontinence but use of products was nuanced. Whilst absorbent products provided social benefits to women, their use also created challenges. Fear of product failure and impact on identity were identified as particular considerations. It was clear that the psychosocial implications of absorbent product use intersected with the psychosocial implications of urinary incontinence. This intersection became the focus of the empirical research.

For those participating in the interview study, maintaining a sense of identity was important to ensure a continuation of personal narrative, in spite of leakage symptoms. The ways in which participants communicated about their experience was influenced by social rules and expectations, which also

impacted on the strategies employed to manage leakage. Participants voiced a number of concerns, the most prominent of these was odour caused by leakage, followed by the symptom of leakage itself. Past experience of healthcare, in addition to understanding of symptoms, strongly influenced whether participants felt seeking help for leakage would be appropriate. Although not all participants used absorbent products as a coping strategy, all had views on their use. For some participants the desire for a socially-continent identity was so great that absorbent products were not able to meet their needs. Challenges faced when using absorbent products included concerns about product type, effectiveness of products and difficulties with disposal. These study findings are congruent with the work of Getliffe et al. (2007) and further illustrate that there are a number of psychosocial factors which influence absorbent product use by women. This study goes further by suggesting that women's understanding of urinary incontinence may also play a part in decision-making regarding absorbent product use. The use of a sociotechnical design model to further analyse interview findings highlighted the complexity of the systems which women operate within, and the complexity of product use. Priorities for product design were consistent with other studies which state that women require products which provide social-contenance and discretion. The physical features of products which were most highly prized by participants were level of absorbency, thinness and neutralising properties.

This study also characterised the attitudes of participants into four distinct viewpoints using Q Methodology. After analysis these viewpoints were labelled 'Trial and error', 'Carry on regardless', 'Shameful secret' and 'Wanting change'. The viewpoints reflected the most pertinent aspects of the differing attitudes. These viewpoints illustrated the ways in which participants understood their experiences of urine leakage, including absorbent product use. The viewpoints clearly showed that women prioritised different aspects of their experience, and that not all women had the same concerns regarding their experience.

A synthesis of the study findings provided greater insight into the experience of women. Both studies indicated that a combination of individual experience and knowledge affected attitudes towards urinary incontinence and use of absorbent products. There was no distinction of views between women who had sought help and those who had not, suggesting that social determinants

may have greater influence on women's attitudes than that of healthcare involvement. The findings demonstrated a strong need for personalised care, as stipulated in NICE Guideline CG138 (2012b). Despite other differences between viewpoints, stigmatisation was an overarching threat. This threat was perceived even during interaction with healthcare professionals, affecting help-seeking and engagement. Fear of stigmatisation was also a driver for social-incontinence and affected absorbent product use. Development of policies which recognise cultural norms may reduce stigma within healthcare settings. Healthcare professionals actively engaging in discussions, using culturally-sensitive terminology, may also improve trust and promote disclosure. Professionals should recognise communicative strategies used by women to tentatively broach the subject, including avoidance of socially-challenging descriptors and non-verbal cues. It is imperative that appropriate action is taken by healthcare professionals upon disclosure to avoid assumption of disinterest and to prevent 'normalisation'. A routine enquiry approach may facilitate disclosure and help-seeking, however future research is required to confirm this. The findings of this study suggest that nurse-led care may be most acceptable to women, particularly in Primary Care. Of particular note were the attitudes of women who felt a personal responsibility for symptoms, these women were the most secretive and may be the least well supported by health services. It is possible that they also the least well represented by current evidence. Improved health literacy may be of benefit to these women to prevent future decline and future research should consider how this might be achieved.

This study has demonstrated that women have a range of views towards their experience of urinary incontinence and absorbent products. Taking an integrated approach to the topic ensured a holistic understanding was gained. Implementation of a reference group promoted inclusion of experts-by-experience to the study, ensuring the appropriateness of the research aim, methods and findings. The novel use of Q Methodology provided a suitable approach to defining women's attitudes. The findings of this study offer clear evidence of similarities and differences between attitudes. This knowledge will facilitate improvements to personalised care in future. The combined findings of both empirical studies provide valuable evidence to support development of

future research, products and services to meet the needs of women experiencing urinary incontinence.

### **6.11 A reflective account of the PhD journey**

This section provides a brief account of the PhD as a transformational journey undertaken by the researcher. It highlights the development of characteristics which are important to an academic career in nursing. As a reflective account it is written in the first person to provide a personal narrative of the challenges and highlights of the PhD.

Five years ago when my supervisors explained that the PhD was a transformative process, I didn't have the capacity to understand what that meant. Now, as I look back on my development as a researcher, a nurse and as an individual, I recognise what an absolute privilege it has been. Whilst the PhD has culminated in this thesis, there has been so much more to the process than undertaking research and writing a thesis. I had the opportunity to teach pre- and post-registration nursing students and provided informal help to other research students. I presented my work numerous times and won prizes for my presentations (Appendix F). I undertook a wealth of training to gain a broad understanding of research practice (Appendix G). I joined various academic committees. I travelled. I networked. I immersed myself in academic life.

I could reflect on all the things that I have done, but I think it is more important to reflect on the person I have become. Although this research was not a heuristic study, aspects of heurism are apparent. Heurism involves the researcher using self-reflection alongside co-researchers, to facilitate an emotionally connected study. As a result of reflecting throughout the PhD process I have become a more versatile professional. By recognising my flaws and weaknesses, whilst also attempting to celebrate my uniqueness and successes, I have been proactive in developing my skills and character. Although it has been an absolute rollercoaster of emotion I have learned (in theory at least) that my academic ability is not directly linked to my self-worth.

Of course I want the academic achievement but I believe that I will have gained more than a qualification when I shake the vice-chancellors hand at graduation. Undertaking a PhD has been painful, isolating and difficult at times, but it created a resilience that I wouldn't otherwise have had. This resilience has been called upon many times throughout the last few years and has helped me personally and professionally. Four years ago I had a number of health issues, one of which has required ongoing monitoring. The experience of repeated appointments affected how I viewed management of women's health. My experience as a patient also altered my views on the experiences of the participants during this study. I am far more empathetic than I might have been prior to undertaking the PhD. I am also more critical of services that are provided and have been motivated to challenge practice that may indirectly have greater negative impact on women than men.

The PhD process gave me a unique opportunity for introspection, framed by my research and my health. I learned from it and have proactively adapted as a result. Whilst appreciating the opportunity I was given by undertaking a PhD, I am glad to have progressed into a new season. As much as I want to succeed as a nurse researcher and teacher, I have also learned the joy of watching other people succeed. To help other people to achieve has been an unexpected bonus, but one that I know I will get to enjoy more as my career develops. My professional relationships with students has improved as a result of my PhD experience. The quality of my teaching has improved and I am certain that the quality of my research will also be improved. I am excited about what lies ahead. I am keen to make a practical difference to people's lives through my work and whilst I feel very lucky to have undertaken a PhD, I am now enjoying my new role as lecturer and working collaboratively with others.

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## Appendix A Search strategy

### A.1.1 First search

<b>Databases searched for appropriate search terms</b>
MEDLINE PsychINFO
<b>Terms Used</b>
Population – women; female Concept – urine incontinence; pad, diaper Context –self-care; self-management; coping; quality of life

### A.1.2 Medline Search

	<b>Search term</b>	<b>Results</b>
1	Female/	1366452
2	Women/ or wom*n.mp.	176716
3	1 or 2	1371718
4	Urine/	1845
5	exp Urinary Incontinence/	4067
6	Incontinence Pads/ or Absorbent Pads/	106
7	diaper.mp.	194
8	Self Care/	7235
9	self-management.mp.	4205
10	"Quality of Life"/	44782
11	4 or 5	5897
12	6 or 7	294
13	8 or 9 or 10	52288
14	3 and 11 and 12 and 13	14

### A.1.3 PsychINFO Search

	Search term	Results
1	women.mp. or exp Human Females/	188280
2	urine.mp. or exp URINE/	4547
3	exp URINARY INCONTINENCE/ or incontinence.mp.	2070
4	incontinence pad.mp.	4
5	absorbent pad.mp.	4
6	diaper.mp.	87
7	exp Health Behavior/ or exp Self-Management/ or exp Self-Care Skills/ or exp Self-Efficacy/ or self-care.mp. or exp "Quality of Life"/	71777
8	2 or 3	6448
9	1 and 8	985
10	7 and 9	122
11	4 or 5	8
12	10 and 11	0

### A.1.4 Terms generated from initial searching

Population	Concept	Context
Women	Urinary incontinence	Health Behavior*
Female	Incontinence pads	Self-Management
	Absorbent pads	Self-Care
	Diaper	Self-Efficacy
		Quality of Life
		Daily activities
		Health

## A.2 Main Search

Electronic Databases Searched	Grey Literature Sources
MEDLINE EMBASE PsychINFO Scopus CINAHL All EBM Reviews (Including Cochrane & Health Technology Assessment)	OpenGrey continenceproductadvisor.org

Inclusion	Exclusion
Community-dwelling women Absorbent product use English language Year 2000 onwards	Men Children Institutionalised women Faecal incontinence Non-absorbent products Effectiveness of products

## A.3 Main search

MEDLINE, Embase, PsychINFO, All EMB Reviews (via Ovid) search 04.10.17

	Search term	Results
1	wome*n.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	1820900
2	limit 1 to yr="2002 - 2017" [Limit not valid in DARE; records were retained]	1548573
3	female.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	11807334
4	1 or 3	12064827



5	incontinence.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	123871
6	urinary incontinence.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	59603
7	5 or 6	123871
8	absorbent pad.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	244
9	absorbent product.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	40
10	incontinence pad.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	149
11	diaper.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	3504
12	8 or 9 or 10 or 11	3854
13	health behavio*r.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	126611
14	self-management.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	40503
15	self-care.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	89573
16	self-efficacy.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	84106
17	quality of life.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	782685
18	daily activities.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	30556
19	health.mp. [mp=ti, ot, ab, tx, kw, ct, sh, hw, tn, dm, mf, dv, fx, nm, kf, px, rx, an, ui, sy, tc, id, tm]	5139200
20	13 or 14 or 15 or 16 or 17 or 18 or 19	5637389
21	4 and 7 and 12 and 20	286
22	limit 21 to yr="2002 -Current" [Limit not valid in DARE; records were retained]	252

## Scopus search 05.10.17

	Search terms	Results
1	wom*n AND urinary incontinence AND absorbent products AND ( LIMIT-TO ( LANGUAGE,"English" ) ) AND ( LIMIT-TO ( PUBYEAR,2017) OR LIMIT-TO ( PUBYEAR,2016) OR LIMIT-TO ( PUBYEAR,2015) OR LIMIT-TO ( PUBYEAR,2014) OR LIMIT-TO ( PUBYEAR,2013) OR LIMIT-TO ( PUBYEAR,2012) OR LIMIT-TO ( PUBYEAR,2011) OR LIMIT-TO ( PUBYEAR,2010) OR LIMIT-TO ( PUBYEAR,2009) OR LIMIT-TO ( PUBYEAR,2008) OR LIMIT-TO ( PUBYEAR,2007) OR LIMIT-TO ( PUBYEAR,2006) OR LIMIT-TO ( PUBYEAR,2005) OR LIMIT-TO ( PUBYEAR,2004) OR LIMIT-TO ( PUBYEAR,2003) OR LIMIT-TO ( PUBYEAR,2002) )	158

## CINAHL 05.10.17

	Search terms	Results
1	(MM "Incontinence Aids+") AND (MM "Urinary Incontinence") AND "( women or female ) OR urinary incontinence AND absorbent pad"  Limiters - English Language; Published Date: 20020101-20181231; Language: English  Expanders - Apply related words; Apply equivalent subjects  Search modes - SmartText Searching	130

## A.4 Quality assessment of review literature

Qualitative Studies assessed using the EPHPP Quality assessment tool for quantitative studies (Effective Public Health Practice Project, 1998)

Question	Quantitative studies				
	Fader et al (2014)	Grzybowska et al (2015)	Higa and Loped (2007)	Teunissen and Lagro-Janssen (2009)	St John et al (2013)
<b>Are the individuals selected to participate likely to be representative of the target population?</b>	Somewhat likely	Very likely	Very likely	Very likely	Somewhat likely
<b>What % of selected individuals agreed to participate?</b>	Not applicable	55.7%	77%	55%	Not applicable
<b>Indicate the study design</b>	Shopping experiment	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional
<b>Was the study described as randomised?</b>	No	No	No	No	No
<b>If yes, was the method of randomisation described?</b>	Not applicable	Not applicable	Not applicable	Not applicable	Not applicable
<b>If yes, was the method appropriate?</b>	Not applicable	Not applicable	Not applicable	Not applicable	Yes
<b>Where there important differences</b>	Yes	Can't tell	Can't tell	Yes	Yes

Question	Quantitative studies				
between groups prior to intervention?					
If yes, indicate the percentage of relevant cofounders that were controlled (either in design or analysis)	Can't tell	Not applicable	Not applicable	Can't tell	Can't tell
Was the outcome assessor aware of the intervention or exposure status of participants?	Yes	Not applicable	Yes	Yes	Yes
Were study participants aware of the research question?	Yes	Can't tell	Can't tell	Can't tell	Can't tell
Were data collection tools shown to be valid?	Can't tell	No	No	Can't tell	Can't tell
Were data collection tools shown to be reliable?	Can't tell	No	No	Can't tell	Can't tell
Were withdrawals and dropouts reported in terms of numbers and/or reasons per group?	Yes	No	Yes	No	Not applicable
Indicate the percentage of participants	Can't tell	Can't tell	Phase 1 = 77%	Can't tell	Clinic=60% Community=68%

<b>Question</b>	<b>Quantitative studies</b>				
<b>completing the study</b>				Phase 2= 93.8%	
<b>What percentage of participants received the allocated intervention or exposure of interest?</b>	100%	Not applicable	Not applicable	Not applicable	Not applicable
<b>Was the consistency of the intervention measured?</b>	Not applicable	Can't tell	Not applicable	Not applicable	Not applicable
<b>Is it likely that subjects received an unintended intervention? That may influence results?</b>	No	Can't tell	No	No	No
<b>Indicate the unit of allocation</b>	Individual	Not applicable	Not applicable	Organisation	Not applicable
<b>Indicate the unit of analysis</b>	Individual	Can't tell	Individual	Individual	Individual
<b>Are the statistical methods appropriate for the study design</b>	Yes	Yes	Yes	Yes	Yes
<b>Is the analysis performed by intervention allocation status rather than actual intervention received?</b>	Can't tell	Can't tell	Not applicable	Not applicable	Not applicable

Systematic review quality assessed using the Critical Skills Appraisal Programme (2017) Systematic review checklist

Question	Reviews
	Fader et al (2007)
Did the review address a clearly focused question?	Yes
Did the authors look for the right type of papers?	Yes
Do you think all the important, relevant papers were included?	Yes
Did the review authors do enough to assess the quality of the included studies?	Can't tell
If the results of the review have been combined, was it reasonable to do so?	N/A
What are the overall results of the review?	Women prefer disposable products for light UI
How precise are the results?	Good
Can the results be applied to the local population?	Can't tell
Were all important outcomes considered?	No
Are the benefits worth the harms and costs?	Can't tell

Qualitative studies quality assessed using the Critical Skills Appraisal Programme (2017) Qualitative research checklist.

Question	Qualitative			
	Andersson et al (2008)	Anger et al (2011)	Getliffe et al (2007)	Li et al (2007)
Was there a clear statement of the aims of the research?	Yes	Yes	Yes	Yes
Is a qualitative methodology appropriate?	Yes	Yes	Yes	Yes
Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes	Yes
Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes	Yes	Yes
Was the data collected in a way that addressed the research issue?	Yes	Yes	No	Yes
Has the relationship between the researcher and participants been adequately considered?	Can't tell	Yes	Can't tell	No
Have ethical issues been taken into consideration?	Yes	Yes	Yes	Yes
Was data analysis sufficiently rigorous?	Yes	Yes	Yes	Can't tell
Is there a clear statement of findings?	Yes	Yes	Yes	No
How valuable is the research?	May be transferrable to similar populations.	Could be built upon. Focus group findings possibly limited.	Useful for understanding use of product use by women who self-identify as incontinent	May be transferrable to similar populations

## Appendix B Ethics

### B.1 Reference group ethical approval letter

Faculty of Medicine and Health

Research Office

University of Leeds  
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Clarendon Way  
Leeds LS2 9NL  
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**UNIVERSITY OF LEEDS**

09 June 2014

Mrs Amy Hunter  
PhD Student  
PhD Suite, Room  
3.35 Baines Wing  
School of Healthcare  
University of Leeds, LS2 9JT

Dear Amy

Ref no: **SHREC/RP/445**

**Title: How do community dwelling women with undiagnosed urinary incontinence conceptualise their use of teatime containment products, and how can these concepts be adapted for commercial product design?**

Thank you for making the requested amendments to the documentation for the above project following review by the School of Healthcare Research Ethics Committee (SHREC). I can confirm a favourable ethical opinion based on the documentation received at date of this letter:

<i>Document</i>	<i>Version</i>	<i>Date Submitted</i>
Amy Hunter Ref Group Consent Form	1	11.04.14
Amy Hunter Ref Group Signed ethics application	1	11.04.14
Amy Hunter Ref Group Participant Info Sheet	1	11.04.14
Amy Hunter Ref Group Signed Low Risk Assessment	1	11.04.14
ICIQ-UI_Short_Form_(UK_English)[1]	1	11.04.14
Amy Hunter ICIQ__permission_letter_UI_SF(jul04)_-_AHunter[1]	1	11.04.14
Amy Hunter Ref Group Interview Topic Guide	1	11.04.14
Amy Hunter Ref Group Introductory Email	1	11.04.14
Amy Hunter Ref Group Meeting Info	1	11.04.14
IC1Q-UI_SF_-_summary J2005)(1]	1	11.04.14
Amy Hunter Ref Group V2 Signed Low Risk	2	02.06.14
V2 Amy Hunter Ref Group Consent Form	2	02.06.14



V2 Amy Hunter Ref Group Info Sheet	2	02.06.14
V2 Amy Hunter Ref Group Introductory Email	2	02.06.14

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to

implementation. Please contact the Faculty Research Ethics Administrator for further information [FMHUniEthicsleeds.ac.uk](http://FMHUniEthicsleeds.ac.uk)

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The SHREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

The committee wishes you every success

with your project. Yours sincerely

**Dr Ruth Brooke**

**Chair, School of Healthcare Research Ethics Committee**

## B.2 Main study ethical approval letter

Faculty of Medicine and Health  
Research Office

University of Leeds

Worsley Building  
Clarendon Way  
Leeds LS2 9NL  
United Kingdom

rtli +44 (0) 113 343 4361



**UNIVERSITY OF  
LEEDS**

27 February 2015

Mrs Amy Hunter

Postgraduate  
Researcher School of  
Healthcare Medicine and  
Health 3.35 Baines Wing

University of Leeds, LS2 9JT

Dear Amy

**Ref no: SHREC/RP/492**

**Title: Women's attitudes to their experience of urine leakage and their use of absorbent textiles.**

Thank you for submitting your documentation for the above project. Following review by the School of Healthcare Research Ethics Committee (SHREC), I can confirm a favourable ethical opinion based on the documentation received at date of this letter.

<i>Document</i>	<i>Version</i>	<i>Date Submitted</i>
Amy Hunter Ethical_Review_Form	1	08.01.15
Amy Hunter High Risk Fieldwork RA form	1	08.01.15
Amy Hunter interview Consent Form	1	08.01.15
Amy Hunter Main study Info Sheet	1	08.01.15
Amy Hunter Q Consent Form	1	08.01.15
Demographic Data collection tool	1	08.01,15
Lone working risk_assessmentform	1	08.01.15
North Leeds Life article	1	08.01.15
Recruitment 1 poster	1	08.01.15
Recruitment 2 poster	1	08.01.15
Recruitment 3 poster	1	08.01.15
Recruitment 4 poster	1	08.01.15
Recruitment 5 poster	1	08.01.15

Recruitment email	1	08.01.15
Recruitment leaflet	1	08.01.15
Signed application and risk assessments	1	08.01.15
Sources of information for participants	1	08.01.15
South Leeds Life article	1	08.01.15
Topic guide	1	08.01.15
Verbal consent procedure for use before telephone interviews	1	08.01.15
Amy Hunter Telephone Interview Consent Form	1	10.02.15
SHRECRP 492 Reviewer Comments Response included	1	10.02.15
V2 Amy Hunter Main study Info Sheet	2	10.02.15
V2 Verbal consent procedure for use before telephone interviews	2	10.02.15

Please notify the committee if you intend to make any amendments to the original research as submitted at date of this approval. This includes recruitment methodology and all changes must be ethically approved prior to

implementation. Please contact the Faculty Research Ethics Administrator for further information [FMHUniEthics@leeds.ac.uk](mailto:FMHUniEthics@leeds.ac.uk)

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The SHREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

it is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

The committee wishes you every success with your project.

Yours sincerely

**Dr Kuldip Bharj, OBE**

**Chair, School of Healthcare Research Ethics Committee**

## B.3 Ethical approval amendments

Faculty of Medicine and Health

Research Office

University of Leeds  
 Woodley Estate  
 Clarendon Way  
 Leeds LS2 9JL  
 United Kingdom

0114 352115 3x3 2774



UNIVERSITY OF LEEDS

31 March 2015

Mrs Amy Hunior  
 Postgraduate Researcher  
 School of Healthcare  
 Medicine and Health  
 3.36 Baines Wing  
 University of Leeds, LS2 9JT

Dear Amy

Ref no: SHREC/RP492 – Amendment\_1

**Title:** Women's attitudes to their experience of urine leakage and their use of absorbent textiles.

Thank you for submitting the amendment to the above named project.

This has been reviewed and I can confirm on behalf of the School of Healthcare Research Ethics Committee (SHREC) that ethical approval is granted and the amendment may be implemented based on the documentation received at date of this letter.

Document	Version	Date
SHRECRP492 Amendment Request 1	1	26 Mar 2015
Staff Home Page Recruitment	1	26 Mar 2015

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. SHREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

The committee wishes you continued success with your project.

Yours sincerely

Dr Kuldip Bharg, OBE  
 Chair, School of Healthcare Research Ethics Committee

Faculty of Medicine and Health

Research Office  
University of Leeds  
Worsley Building  
Carnegie Way  
Leeds LS2 9NI  
United Kingdom

04470 113343

31642



UNIVERSITY OF LEEDS

08 February 2016

Mrs Amy Hunter  
Postgraduate Researcher  
School of Healthcare  
Medicine and Health  
3.05 Baines Wing  
University of Leeds, LS2 9JT

Dear Amy

Ref no: SHREC/RP/492

Title: Amd 2 - Women's attitudes to their experience of urine leakage and their use of absorbent textiles

Thank you for submitting the Notice of Amendment to the above named project.

This has been reviewed and I can confirm on behalf of the School of Healthcare Research Ethics Committee (SHREC) that ethical approval is granted and the amendment may be implemented based on the documentation received at date of this letter.

Document	Version	Date Received
SHREC RP 492 27.02.15 Signed 2nd Amendment_form	1.0	29/01/2016
Newsletter document for second ethical amendment	1.0	29/01/2016

Ethical approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. SHREC takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

Please note: You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, and other documents relating to the study. This should be kept in your study file, and may be subject to an audit inspection. If your project is to be audited, you will be given at least 2 weeks notice.

It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

The committee wishes you continued success with your project.

Yours sincerely

Dr Kuldip Bharj, OBE  
Chair, School of Healthcare Research Ethics Committee

## **B.4 Approval for data collection time extension**

Dear Amy

**SHREC/RP/492 - Women's attitudes to their experience of urine leakage and their use of absorbent textiles**

*Many apologies for the delay – Kuldip emailed me with the outcome just before I went on annual leave and I've only just picked it up.*

The Chair has agreed that the proposed amendment can be logged as a 'Notice of Change' and can be implemented with immediate effect. No further action is required from you.

Please retain this email in your study file for audit purposes.

Best regards  
Rachel

**Rachel de Souza**

**Faculty Research Ethics & Governance Administrator**

Faculty of Medicine and Health

Room 10.111b, Level 10

Worsley Building, Clarendon Way

University of Leeds, LS2 9NL

Tel: 0113 3431642

[r.e.desouza@leeds.ac.uk](mailto:r.e.desouza@leeds.ac.uk)

<http://www.leeds.ac.uk/medhealth>

**B.4.1 Reference group participant sheet****School of Healthcare, University of Leeds****Participant Information Sheet – Reference Group****Experiences of women self-managing urine leakage using ‘pads’, and the implications for product design.**

I would like to invite you to become a member of a reference group for the above named study, but before you make a decision please read the following information

**What is the purpose of this study?**

Urinary incontinence is any leakage of urine (wee) that can't be controlled. Sometimes a lot of urine is leaked, sometimes it may be just a few drips.

This project will uncover the views of women that have not received any help or guidance for their leakage from doctors or nurses. Lots of women decide to cope on their own and choose to buy or make their own products for containing leaked urine.

I hope to find out how women contain leakage in their everyday lives, and whether managing leakages causes any problems.

Because I believe that the views of these women are so important, I want to work with women who have some knowledge of leakage, to help me design the best study possible. The women that work with me will be called the reference group.

**Who is doing the study?**

My name is Amy Hunter and I am a PhD student at the University of Leeds. I have worked in both the healthcare and textile industries and have a particular interest in making sure that women's views are fairly represented to ensure they receive the best care possible.

My contact details are -

Amy Hunter  
PhD Suite Room 3.35  
School Of Healthcare  
Baines Wing,  
University of Leeds,  
LS2 9JT  
Email – [hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)  
Telephone 0113 343 3202

My Supervisors are Professor Andrea Nelson and Dr Elaine McNichol, who are both based in the School of Healthcare and can be contacted through the main school switchboard 0113 343 1202.

### **Who is being asked to participate?**

I am recruiting women who have some knowledge of undiagnosed urine leakage to be part of my reference group. The group will be made up of a small number of women whose expertise I believe will be of value to the project.

### **What will be involved if I take part in this study?**

You have four weeks in which to decide whether you would like to be involved in the study. If you do not contact me within four weeks, I shall assume that you are no longer interested in taking part .

The reference group will work alongside me to help design the study. This work will be broken into four sections.

1. A one-to-one interview with me to discuss your views about managing continence. This will take approximately 1 – 1.5 hours (This is the only time you will need to attend the university as part of this project). The interview will be audio-recorded and typed up in full. The recording will then be destroyed.
2. Completion of two short questionnaires, comprising of four questions to understand more about any leakage you experience, and four questions regarding your age and background.
3. Feedback on interviews, study methods and results. This will involve my asking for your feedback by email exchanges and/ or telephone calls (whichever is more convenient for you). It will also involve reading and commenting on documents (no more than 4 pages, at any one time). It is likely that this will be ongoing for the duration of the project and will be intermittent depending on the current phase of the project. I anticipate that it will take approximately half an hour of your time for each feedback request, and that on average you will only provide feedback once a month. You will need to have a good understanding of written and spoken English. All information gathered at this stage will be stored electronically.
4. Reflecting on the reference group experience. Once the study is complete, I would like to hear your views on being part of the study. This can be arranged as a face to face meeting or done by telephone / written comments, according to your preference.



**What are the advantages and disadvantages of taking part?**

The advantages of being part of the project are as follows –

1. You will be given £80, as a good will gesture, to be part of the reference group. This payment will be broken down into one payment of £20, and two payments of £30. Payment will be made at the end of each academic year. Some women may feel they would prefer not to have financial acknowledgement of their assistance; however this can be negotiated on an individual basis.
2. You will have your travel and childcare expenses paid for the times that you attend interviews or meetings relating to this project.
3. You will gain further insight into the research process and how participation can influence research projects and outcomes.

The disadvantages are –

1. This project will take up some of your time (Up to 15 hours) over a prolonged period (approximately 30 months). This is reflected in the payment you will receive.
2. You may find some parts of the study touch upon personal topics around continence and related issues. If you are affected by the topic of the study then I will signpost you to services that may be of benefit, should you request it.

**Can I withdraw from the study at any time?**

You are able to withdraw from the study at any time; however payment will reflect the time spent involved in the study.

Should you wish to withdraw from the reference group, the information you have already given regarding the research design cannot be withdrawn, as it will have been used to influence the next stage of work.

If you wish to withdraw your consent for interview data to be used, this can be done up to two weeks after the interview has been conducted. The decision to withdraw at interview stage would mean that you would be unable to continue as a reference group member.

*Anonymised* information provided may be used in future *related* academic research carried out by Amy Hunter, and may be shared with other researchers involved in these future projects.

**Will the information obtained in the study be confidential?**

The information given by you will always be treated in confidence, none of the information that you give me will be written in a way that makes you identifiable. You will be given a pseudonym

(a made up name) so that I can refer to the information you give me in my work. All your information will be stored securely on the University IT system and will not be accessible by anyone other than myself.

The audio recordings that will be made during the interviews will be transferred electronically to the University IT system and original recordings will be destroyed as soon as practicably possible.

Information given by telephone and email will also be retained and stored electronically for use in the study and protected by a secure password.

In some situations, handwritten notes may be more appropriate for collecting information. All handwritten notes will be transcribed to electronic format and originals securely stored or destroyed as appropriate.

The only people who will be able to view your personal data are myself and my supervisors. We are all bound by rules which mean we are unable to do anything to cause you harm and have a duty of care to yourself and others. There is one exception to this confidentiality agreement. If you tell me something that suggests you or someone else could be at risk, we must act to safeguard that person.

The data handling procedures that will be used to save, store and move data all comply with the Data Protection Act 1998.

Members of the reference group are expected to keep information shared with them confidential. The study should not be discussed with anyone outside of the research team.

### **What will happen to the results of the study?**

1. I will write a report, called a thesis, outlining what I have found. This will be assessed by the university and will be the basis of my PhD. The thesis will contain information that you have provided me with, but you will remain anonymous.
2. I will inform other people who might benefit from the research; this may include submitting written work to journals and talking at conferences. The data you provide will inform this work, however you will remain anonymous.
3. I will write a report for you, which I can send to you if you would like to see what the outcomes have been. The data you provide will inform this work, but you will remain anonymous.

**Who has reviewed this study?**

Ethical approval has been granted by the School of Healthcare Research Ethics Committee for the use of a reference group within this study (SHREC/RP/445 09.06.14).

**If you agree to take part, would like more information or have any questions or concerns about the study please contact -**

Amy Hunter  
PhD Suite, Room 3.35,  
School Of Healthcare,  
Baines Wing,  
University of Leeds,  
LS2 9JT

Email – [hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)  
Telephone 0113 343 3202 or 07847 614007

***Thank you for taking the time to read this information sheet.***

**B.4.2 Participant information sheet**

**School of Healthcare, University of Leeds**

**Participant Information Sheet**

**Women's attitudes to their experience of urine leakage and their use of absorbent textiles**

I would like to invite you to participate in the above named study, but before you make a decision please read the following information.

**What is the purpose of this study?**

Many women experience urine leakage. The purpose of this study is to understand more about women's views towards urine leakage and the use of absorbent products (e.g. pads, liners etc).

**Who is doing the study?**

My name is Amy Hunter and I am a PhD student at the University of Leeds. My contact details are at the end of this information sheet.

My Supervisors are Professor Andrea Nelson and Dr Elaine McNichol, who are both based in the School of Healthcare and can be contacted through the main school switchboard 0113 343 1202.

**Who is being asked to participate?**

I am recruiting any women who experience urine leakage. The amount or frequency of leakage is not important, neither is the use of absorbent textiles.

**What will be involved if I take part in this study?**

You will be asked to take part in one of the study phases below. You will not be required to take part in both. If you have a preference for which phase you would like to take part in please inform the researcher; where possible your preferences will be accommodated.

1. **Interview.** You will answer some questions about your experience of leakage. The interview will last approximately one hour.

- If you would prefer to remain anonymous, a telephone interview can be arranged.
2. **Q-sort.** You will be asked to rank statements by how much you agree or disagree with them. This process will take up to 90 minutes, although in the majority of cases I expect it to take no more than an hour. Q-sort requires a face-to-face meeting.

Face to face meetings will take place at the University of Leeds, unless you are unable to travel, in which case arrangements can be made for the researcher to visit your home.

### **What are the advantages and disadvantages of taking part?**

The advantages of being part of the project are –

4. You will be involved in research which could change future care and products.
5. You may benefit from the opportunity to talk to someone about your leakage in an understanding and private atmosphere.

The disadvantages are –

3. This project will take up some of your time
4. You may find talking about your experience is difficult. I can provide you with information about services that may be of benefit, should you request it.

### **Can I withdraw from the study at any time?**

You are able to withdraw from the study up to two weeks after data-collection, without giving a reason if you have provided your details. This will be the case for all face-to-face meetings.

Interviews given anonymously by telephone cannot be withdrawn, as the information will not be identifiable.

### **Will the information obtained in the study be confidential?**

The information given by you will be confidential. However, if you tell me something that suggests you or someone else could be at risk, I must act to safeguard that person. Should you wish to remain anonymous by completing a telephone interview, you will be asked to consent to your anonymity being waived in this instance. This will not affect the anonymity of your data within the study.

All your information will be stored securely on the University IT system and will not be accessible by anyone other than myself. The only people who will be able to view your

information are me and my supervisors. Personal information will be stored separately from all other information you provide.

The audio recordings that will be made during the interviews will be transferred electronically to the University IT system and original recordings will be destroyed as soon as practicably possible.

All handwritten notes will be transcribed to electronic format and originals securely stored or destroyed as appropriate. All other paperwork will be kept securely on university premises.

The data handling procedures that will be used to save, store and move data all comply with the Data Protection Act 1998.

*Anonymised* information provided may be used in future *related* academic research carried out by me (Amy Hunter) and may be shared with other researchers involved in these future projects.

**What will happen to the results of the study?**

4. I will write a report, called a thesis, outlining what I have found. This will be assessed by the university and will be the basis of my PhD
5. I will inform other people who might benefit from the research; this may include submitting written work to journals and talking at conferences.
6. I will write a report for you, which I can send to you if you would like to see what the outcomes have been.

**Who has reviewed this study?**

Ethical approval has been granted by the School of Healthcare Research Ethics Committee (SHREC/RP/492/ 27.02.15).

**If you agree to take part, would like more information or have any questions or concerns about the study please contact -**

Amy Hunter

Email – [hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)

Telephone 0113 343 3202 or 07847 614007

***Thank you for taking the time to read this information sheet.***

## Appendix C Posters and topic guide

### C.1 Topic guide

#### 1. Goals – What are women’s priorities in dealing with urine leakage?

What is your experience of leakage?

Are there certain things that you do to help cope with or reduce leakage?

Why do you do these things?

Priorities for improving or maintaining situation.

#### 2. People – How do relationships affect experience?

Are your close relationships, with family or friends affected by leakage?

What support do you receive from them?

How does leakage affect your interaction with other people outside of your closest relationships?

Do you have any close friends or family members that experience leakage?

#### 3. Culture – How do cultural expectations and beliefs affect experience?

What do you think other people, in general, think about urine leakage?

Is it difficult to talk about leakage?

Are there certain words or phrases that you prefer to describe leakage?

Health professionals use very specific language to describe leakage, their terms include ‘urinary incontinence’. What do you think about this term?

Would you ever use ‘incontinence’ to describe your experience?

What do you think is the cause of your leakage?

What made you think this is the cause?

**4. Processes/ procedures – Are there routines that are specifically affected by leakage?**

What extra organisation do you have to do to prevent/ minimise any leakage?

Do you ever adapt your clothing choices to take account of leakage?

Are there activities that you have stopped or adapted because of leakage?

What are your concerns in doing these activities?

Does it affect your work, whether that's paid work or other things you expect to do?

**5. Buildings/ Infrastructure – Does knowledge change experience?**

Is it important to know the location of toilet facilities when you go out?

What concerns do you have about going to different places?

Have you noticed any changes to your body due to leakage?

What do you do to reduce the effects of leakage on your body?

Have there been changes over time?

**6. Technology – What use of technology is made to improve experience?**

What is your experience of using absorbent textiles, such as pads or panty-liners?

How do these help?

Are there disadvantages to using pads?

Size/ disposal/ availability etc.

What other products have you used?

Which products would you consider in future?

Have you used the internet to find out more about leakage? Which sites?

**A. Cost – What are the costs of urine leakage?**

Do you ever consider the environmental impact of using absorbent textiles?

Do you have direct or indirect financial costs because of leakage?

E.g. pads, new clothing, washing clothing, soft furnishings



**B. Stakeholders – What consideration is given to external organisations?**

Do you think that you or other people are disadvantaged because of leakage?

Does anyone benefit?

How do you feel about the advertising of absorbent products in the media?

Are these adverts directed at people like you?

What sources of information would you use to find out about leakage?

**C. Regulatory frameworks – What healthcare options are women aware of?**

Are you aware of what healthcare options are available for leakage?

Where would you access healthcare?

Do you think a good relationship with health professionals is important?

Do you think that professionals would treat you sensitively?

If you chose to access healthcare, do you feel confident that your needs would be met?

Do you think you should have to ask for help, or would be better to include leakage as a question in a routine health-check?

**Additional Qs - Type of leakage**

When

How much

How often



School of Healthcare

FACULTY OF MEDICINE AND HEALTH



UNIVERSITY OF LEEDS

# I have a problem

I need your help to complete my PhD. Could you spare one hour to tell me about your experience of urine leakage?

Women who experience urine leakage often want to keep it a secret

In return for your time, I will –

- ✓ Value your participation
- ✓ Respect your views
- ✓ Provide anonymity

If you would like to know more about the project, or are interested in taking part, please contact me.

Ethical Approval SHREC/RP/492/27.02.15

**POSITIVE CHANGE**

Amy Hunter

0113 343 3202

[hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)

Amy Hunter  
[hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)

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[hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)

Amy Hunter  
[hcaeh@leeds.ac.uk](mailto:hcaeh@leeds.ac.uk)







## Appendix D ICIQ Permissions

Please reply to:

*Dr. Nikki Cotterill, PhD BSc (Hons)*

Research Associate/Nurse

Tel: (0117) 950 5050 x2228

e-mail: [nikki\\_cotterill@bui.ac.uk](mailto:nikki_cotterill@bui.ac.uk)

Amy Hunter  
School of Healthcare  
PhD Suite  
Room 3.35  
Baines Wing  
University of Leeds  
LS2 9JT

Dear Amy

Please find enclosed a copy of the **ICIQ-UI SF** questionnaire, as described in the paper Avery K, Donovan J, Peters T, Shaw C, Gotoh M, Abrams P. ICIQ: a brief and robust measure for evaluating the symptoms and impact of urinary incontinence. *Neurourology and Urodynamics*. 2004;23(4):322-30. A summary detailing the questionnaire's development and instructions for users is also enclosed. Please note that the questionnaire is under copyright. It may be used if it is quoted clearly, and it must be used in its entirety, as presented in the copy enclosed. It is not possible to use parts of the questionnaire in isolation in any studies without the written permission of the ICIQ study group. The scoring system is clearly stated on the questionnaire.

If you have any questions or comments, please do not hesitate to contact me. If you use the questionnaire I would be grateful if you could let me know details about your study, and any results that you present or publish.

With best wishes.

Yours sincerely

Dr. Nikki Cotterill (on behalf of the ICIQ study group)

Encl.

## Appendix E

### E.1.1 Crib sheets for factor interpretation in Q study

Statements ranked at +4 and +3 (strongest agreement) within each factor.

Factor	Statements at +4	Statements at +3
<b>Factor 1</b>	<p>4. Leakage should be covered in routine check ups</p> <p>29. Attitudes towards leakage are negative</p> <p>30. It is easier to talk to someone with similar issues</p>	<p>3. There isn't enough information about how to manage leakage.</p> <p>10. It is difficult to admit experiencing leakage</p> <p>20. Knowing where the nearest toilet is located is important</p> <p>37. The environmental impact of absorbent products is not acceptable</p>
<b>Factor 2</b>	<p>21. Leakage does not affect my life choices</p> <p>24. The leakage I experience is not as bad as other people's</p> <p>30. It is easier to talk to someone who experiences similar issues</p>	<p>4. Leakage should be covered in routine check-ups</p> <p>26. Leakage does not reduce enjoyment of activities</p> <p>32. Leakage does not affect personal relationships</p> <p>38. Products should be designed to last for several hours before they are changed</p>
<b>Factor 3</b>	<p>10. It is difficult to admit experiencing leakage</p> <p>18. Absorbent pads are the easiest way to manage leakage</p> <p>20. Knowing where the nearest toilet is located is important</p>	<p>19. Maintaining secrecy is a priority when experiencing leakage</p> <p>35. A premium product that guaranteed discreetness would be worth paying for</p> <p>40. Absorbent products should not be fragranced</p> <p>41. There should be products designed for different situations</p>
<b>Factor 4</b>	<p>29. Attitudes towards leakage are negative</p> <p>35. A premium product that guaranteed discreetness would be worth paying for</p> <p>38. Products should be designed to last for several hours before they are change</p>	<p>3. There isn't enough information about how to manage leakage</p> <p>24. The leakage I experience is not as bad as other people's</p> <p>27. Leakage is a sign of a naturally ageing body</p> <p>41. There should be products designed for different situations</p>



Statements ranked at -4 and -3 (strongest disagreement) within each factor.

<b>Factor</b>	<b>Statements at -4</b>	<b>Statements at -3</b>
<b>Factor 1</b>	15. There is no cure for leakage 27. Leakage is a sign of a naturally ageing body 42. Absorbent pads for leakage & sanitary towels are the same	2. I wouldn't use the internet to find out information about leakage 12. Leakage is inevitable 14. I don't worry about leakage 21. Leakage does not affect my life choices
<b>Factor 2</b>	16. I feel responsible for the leakage I experience 39. Absorbent products are not comfortable to wear 43. A reusable product would be better than a disposable one	19. Maintaining secrecy is a priority when experiencing leakage 25. I try to forget the times that leakage caused me embarrassment 33. Using an absorbent product is a last resort 34. Absorbent products don't meet my lifestyle needs
<b>Factor 3</b>	14. I don't worry about leakage 31. I don't worry about odour from leakage 33. Using an absorbent product is a last resort	25. I try to forget the times that leakage caused me embarrassment 39. Absorbent products are not comfortable to wear 42. Absorbent pads for leakage & sanitary towels are the same 43. A reusable product would be better than a disposable one
<b>Factor 4</b>	2. I wouldn't use the internet to find out information about leakage 14. I don't worry about leakage 31. I don't worry about odour from leakage	21. Leakage does not affect my life choices 22. Improving lifestyle does not reduce leakage 26. Leakage does not reduce enjoyment of activities 42. Absorbent pads for leakage & sanitary towels are the same

Statements that were ranked higher or lower for one factor compared to others.

	<b>Statement</b>	<b>Ranked highest in</b>	<b>Rankest lowest</b>
1.	Education about leakage should start in school	F1 & F4 (at +1)	F3 (at -2)
2.	I wouldn't use the internet to find information about leakage	F2 (at 0)	F1 (at -3)
3.	There isn't enough information about how to manage leakage	F1 & F4 (at +3)	F2 (at +1)
4.	Leakage should be covered in routine check-ups	F1 (at +4)	F3 (at +1)
5.	Pharmacies should offer information about ways to manage leakage	F3 (at +2)	F1, F2 & F4 (at 0)
6.	Nurses understand more about leakage than doctors	F1, F3 & F4 (at +2)	F2 (at -1)
7.	It isn't possible to get help for leakage without making a GP appointment	F3 (at +1)	F2 & F4 (at -1)
8.	It is important to trust a health professional before talking about leakage	F1 (at +2)	F2 (at 0)
9.	I don't think leakage is a medical problem	F3 (at -1)	F1, F2, F4 (at -2)
10.	It is difficult to admit experiencing leakage	F3 (at +4)	F4 (at 0)
11.	Leakage is a warning sign for another issue	F1 & F4 (at 0)	F2 (at -2)
12.	Leakage is inevitable	F4 (at 0)	F1 (at -3)
13.	Leakage and incontinence are not the same thing	F2 & F3 (at +1)	F1 & F4 (at -1)
14.	I don't worry about leakage	F2 (at +1)	F3 & F4 (at -4)
15.	There is no cure for leakage	F3 (at 0)	F1 (at -4)
16.	I feel responsible for the leakage I experience	F3 & F4 (at +1)	F2 (at -4)
17.	Pelvic floor exercises do not prevent leakage	F2 (at +2)	F3 & F4 (at -2)
18.	Absorbent pads are the easiest way to manage leakage	F3 (at +4)	F1 (at 0)
19.	Maintaining secrecy is a priority when experiencing leakage	F3 (at +3)	F4 (-1)
20.	Knowing where the nearest toilet is important	F3 (at +4)	F4 (at +1)

21.	Leakage does not affect my life choices	F2 (at +4)	F1 & F4 (at -3)
22.	Improving lifestyle does not improve leakage	F2 (at 0)	F4 (at -3)
23.	It is possible to successfully plan for leakage	F1, F2 & F4 (at 0)	F3 (at -2)
24.	The leakage I experience is not as bad as other people's	F2 (at +4)	F1 (at -1)
25.	I try to forget the times leakage caused me embarrassment	F4 (at +2)	F2 & F3 (at -3)
26.	Leakage does not reduce enjoyment of activities	F2 (at +3)	F4 (at -3)
27.	Leakage is a sign of a naturally aging body	F4 (at +3)	F1 (at -4)
28.	There is a stereotype for someone that experiences leakage	F1 (at +1)	F2, F3 & F4 (at -1)
29.	Attitudes towards leakage are negative	F1 & F4 (at +4)	F2 (at -1)
30.	It is easier to talk to someone who has similar issues	F1 & F2 (at +4)	F3 & F4 (at +2)
31.	I don't worry about the odour from leakage	F1 & F2 (at -2)	F3 & F4 (at -4)
32.	Leakage does not affect personal relationships	F3 (at +3)	F1 (at -2)
33.	Using an absorbent product is a last resort	F1 (at +1)	F3 (at -4)
34.	Absorbent products don't meet my lifestyle needs	F4 (at +1)	F2 (at -3)
35.	A premium product that guaranteed discreetness would be worth paying for	F4 (at +4)	F1 (at 0)
36.	Cost of absorbent product is as important as performance	F2 (at 1)	F4 (at -2)
37.	The environmental impact of absorbent products is not acceptable	F1 (at +3)	F2 (at -1)
38.	Products should be designed to last for several hours before they are changed	F4 (at +4)	F3 (at 0)
39.	Absorbent products are not comfortable to wear	F1 (at +2)	F2 (at -4)
40.	Absorbent products should not be fragranced	F3 (at +3)	F4 (at 0)
41.	There should be products designed for different situations	F3 & F4 (at +3)	F1 & F2 (at +2)
42.	Absorbent products for leakage and sanitary towels are the same	F2 (at -2)	F1 (at -4)
43.	A reusable product would be better than a disposable one	F1 (at +1)	F2 (at -4)

## Appendix F Presentations

DATE	TITLE	LOCATION
15.09.17	<b>Using Q methodology to determine attitudes of women to their experience of urinary incontinence and use of absorbent pads</b> Presentation	<i>ICS Annual meeting, Florence, Italy</i>
17.01.17	<b>So, what do women <i>really</i> think of absorbent products for urine leakage?</b> Presentation	<i>Nonwovens research group, University of Leeds</i>
07.06.16	<b>Co-designing research for women's urinary incontinence</b> Presentation	<i>STTI European Conference, Utrecht, Netherlands</i>
23.10.15	<b>My involvement in the WRDTC student-led seminar series</b> Presentation	<i>WRDTC, Bramhall Lane, Sheffield</i>
21.10.15	<b>(In)Appropriate Language</b> Presentation (1 <sup>st</sup> prize)	<i>School of Healthcare PGR conference, Baines Wing</i>
	<b>Absorbing Lives. Attitudes of women experiencing urine leakage.</b> Poster presentation. (1 <sup>st</sup> prize)	<i>Materialities of Care conference, University of York</i>
19.06.15	<b>Absorbing Lives. Attitudes of women experiencing urine leakage.</b> Presentation	<i>STTI Phi Mu Conference, Weetwood Hall, Leeds</i>
04.12.14	<b>Absorbing Lives. Attitudes of women experiencing urine leakage.</b> Poster presentation. (2 <sup>nd</sup> prize)	<i>Showcase Conference University of Leeds</i>
24.10.14	<b>Reframing Research. Using the transfer process to improve study design.</b> Poster presentation. (1 <sup>st</sup> prize)	<i>School of Healthcare Conference University of Leeds</i>
17.07.14	<b>Recruiting a 'hidden' group. Women with undiagnosed urinary incontinence.</b> Presentation	<i>School of Healthcare Lunchtime Seminar Series</i>

<b>01.07.14</b>	<b>Co-designing Research for absorbent products.</b> <b>Invited speaker.</b> Presentation	<i>HEA Patient-led Innovation Day University of Leeds</i>
<b>24.06.14</b>	<b>Understanding how women conceptualise use of absorbent products for urinary incontinence.</b> Presentation	<i>Nonwovens Research Group University of Leeds</i>
<b>23.06.14</b>	<b>Independent Women. Improving absorbent product design by understanding the needs of women experiencing urine leakage.</b> Poster presentation	<i>Faculty of Medicine and Health Conference Weetwood Hall, Leeds</i>
<b>04.02.14</b>	<b>Pressure ulcer prevention</b> <b>Poster (1<sup>st</sup> prize – general audience)</b>	<i>School of Healthcare</i>
<b>15.01.14</b>	<b>Absorbing Knowledge. Improving absorbent textile product design by understanding the needs of women who experience urine leakage.</b> Presentation	<i>N.I.R.I., University of Leeds</i>
<b>08.01.14</b>	<b>What do women with undiagnosed urinary incontinence think about using absorbent pads?</b> Presentation	<i>Service Users and Carers Forum Networking Day School of Healthcare</i>

## Appendix G Training and Development

### G.1 Courses Attended (Research-related & generic)

Date	Course Title	Course Provider eg: Faculty/SDDU	Transferable skills gained
07/10/13	<b>Endnote</b>	Library	Able to use the basic applications of EndNote confidently and have some knowledge of the functions between EndNote and MS Word.
08/10/13	<b>Public Engagement in Research</b>	SDDU	Appreciate new ways of making my project more understandable to the public. Have created a simple research statement and have also considered the implications of creating a public engagement strategy, considering needs of public, funders and other stakeholders.
11/10/13	<b>Starting your research degree</b>	FGS	Developed knowledge of university systems and sources of information that will be of benefit throughout PhD process. Also knowledge of basic ethical considerations and clearer idea of ethics approval process within UoL.
Semester 1	<b>Qualitative Research Methods Module HECS5237M</b>	FGS	Knowledge of quantitative methods improved, and better understanding of the process of undertaking qualitative research and analysis within healthcare. Basic understanding of popular methodologies and epistemologies - able to use this information to direct own research. (Assessment mark 70%)
25/10/13 Updated annually	<b>Online modules – Fire safety Manual Handling Revitalising H&amp;S H&amp;S for DSE users</b>	IT services, University of Leeds	General appreciation of H&S issues in the work place. Was able to make adjustments to my own working practice to ensure better safety.
07/11/13	<b>The Mental Capacity Act and Vulnerable People</b>	FGS	Concepts of vulnerability and capacity explored. Developed ideas about participant information sheets and also ethics review to ensure participants are treated in a way which meets the criteria of the MCA (2005).

08/11/13	<b>Milestones and Time Management</b>	SoH	Overview of the next year. Able to see that my current planning and deadline setting is to an adequate standard and at this point I am meeting the expectations that have been set. Good opportunity to tell others of interesting courses which may benefit them.
12.11.13	<b>Communication via Email</b>	FGS	Email etiquette for formal and informal emails. Aware of pitfalls of using certain styles of writing and gained knowledge of how to be more effective when emailing and when not to use email.
18.11.13	<b>Entrepreneurs and Education Challenge Workshop</b>	School for Start Ups (At Leeds Uni)	Networking opportunity and understand more about how the university can assist entrepreneurialism. Also new understanding of why enterprise is important to the university and how I can use this to my advantage in future.
19/11/13	<b>Search and Save.</b>	FGS	Better appreciation of searching techniques for electronic databases including use of subject headings and how Endnote can be used to assist in these searches.
06/12/13	<b>Preparing for Transfer</b>	FGS	Understand the process of transfer and the documents that I will need to use prior to transfer. Networked with others from other schools and made links that may be useful going forward.
12/12/13	<b>Project Managing Your Research</b>	FGS	Learned about techniques that can be useful in project management, breaking tasks into smaller sections and being realistic about goals.
14/01/14	<b>Working Efficiently with your Supervisor</b>	FGS	This was useful as it enabled me to see some of the pit falls which could happen within the relationship between myself and my supervisors. I do not have any concerns about my relationship with my supervisors but I feel more confident about having discussion with them should that ever occur.
11/02/14	<b>Writing for Research Students</b>	FGS	This allowed me to understand the idea of grammar of authority and how my sentence construction can change the meaning of a sentence. I also learned helpful tips to encourage writing and had opportunity to critique my own and others work. I found peer comments about my work useful. I also thought it interesting to see the different styles of academic writing, they are different depending on discipline and I may find a style that suits me better and which is still acceptable within the health field.

13/02/14	<b>Ownership, confidentiality and secrecy</b>	SDDU	The practicalities of assuring confidentiality, secrecy and ownership in research. I learned the differences between anonymity and confidentiality and also how to write a clause into consent documents that would allow for data to be used for future research but that would provide participants with confidence. I learned that large funding bodies now encourage data to be used for research after primary studies have been completed.
19/02/14	<b>Using Social Media To Create Impact</b>	White Rose Doctoral Training Centre – Social Science Pathway. University of York	I learned how to use Twitter and blogging to create a professional online presence, including the best ways to engage with audiences and how I can effectively showcase my work. I gained experience of using the websites to improve my confidence.
26/02/14	<b>Writing Bootcamp. How to write for publication. Part 1</b>	FGS	The basics of language needed to be able to construct a scientific article. Sentence length was a particular consideration for me.
03/03/14	<b>Where to Publish. Part 2</b>	FGS	Considering which journals to approach with papers and how the application process works. Also gained insight into the impact factor versus citations consideration.
12.03.14	<b>Ethics and Governance</b>	School of Healthcare	Understand the process of applying for ethics approval in the school and NHS. Awareness of time frames and common pitfalls.
17/03/14	<b>How to Publish. Part 3</b>	FGS	This session showed me how to construct an article, from outlining, through to reviewing prior to submission.
18/03/14	<b>Systematic Reviews</b>	Julia Maz - SoH	This day presented a broad overview of how to conduct a thorough systematic review and why it is necessary to be transparent in methods and dissemination
21/03/14	<b>Research with human Participants</b>	FGS	Understanding the ethics of working with people in my research. This course covered much of the same content as the Ethics and governance session attended previously
24/03/14	<b>Abstract Writing. Part 4</b>	FGS	I am now able to write an abstract, containing all the relevant material. I understand some of the common mistakes of abstract writing and how to avoid them.



Semester 2	<b>Mixed Methods Research Module HECS 5238M</b>	SoH	A broad understanding of mixed methods research including Q methodology. Opportunity to present own question to group. Critically analysed MMR texts using tool by Long and Godfrey, discussed critiques in class. (Assessment mark 76%)
Semester 2	<b>Capturing and Handling Data Module MEDR5320M</b>	Faculty	A basic overview of statistical methods used in quantitative research.  (No assessment)
31/03/14	<b>Countdown to submission. Part 6</b>	FGS	Able to write an effective covering letter and select peer-reviewers for articles submitted to journals. Also recapped on the type of access I would need to have to meet funder/ uni requirements and the cost implications of this
01/04/14	<b>Effective Poster Presentations</b>	SDDU	I now have the basic skills to be able to create an effective and interesting poster, which demonstrates the understanding of the audience.
03/04/14	<b>Copyright. Part 5</b>	FGS	I understand the importance of copyright in relation to any work I publish and the impact that signing away copyright may have on my thesis.
13.05.14	<b>Giving Effective Seminar and Conference Presentations</b>	FGS	Strategies to improve presenting at conferences, considering audience, structure and purpose of speech. Useful group exercises, had feedback to work on talking slower and being careful with the language I use.
15.05.14	<b>Ethical issues in Online research</b>	FGS	Ethics, rather than the legality of online research. Discussion about what is private and public, and how information can be used legitimately. Also about the difference between the deep web and what is easily available. Wide audience, some information not applicable to healthcare.
16.05.14	<b>Scientific Research Philosophy and Methodology. Putting theory into Practice</b>	FGS	Refreshed key knowledge about underpinning philosophy and methodology within every stage of my research, ensuring that it is articulated well in the documents I write.

16.05.14	<b>Data Protection and research</b>	FGS	The legalities of keeping my work safe. Built on earlier information and reiterated the need for basic security measures, as well as more complex ideas. Discussed what constitutes private data- context specific. Also, when can confidentiality be breached in research (this was rather different to own professional regulations).
19.05.14	<b>NVivo Fundamentals</b>	IT Services	Basic functions of NVivo 10. Understand how to import documents and how NVivo can be used to assist analysis of text, websites, pictures and videos. Also learned about the modelling function.
18.08.14	<b>Word for Thesis and Long Documents</b>	IT Services	Learned short cuts to format and style documents. Also learned how to link documents so that chapters can be written separately and linked to a final thesis.
23.10.14	<b>Understanding the impact of research perspectives Reflexivity training day -</b>	White Rose Doctoral Training Centre	Learned more about objectivity, subjectivity and inter-subjectivity. Subjectivity can be researched objectively – this is me.  Learned the importance of reflexivity and how that can be applied to research.
05.11.14	<b>Poster Boost workshop</b>	SDDU	Judging criteria for the showcase conference. Recap on the poster workshop attended previously.
06.11.14	<b>Impact – what it is and how to do it</b>	SDDU	Understanding the RAE, also considering impact in short and long term situations.
10/02/15	<b>Continence nursing lecture and tutorial</b>	Karen Nelson York and Scarborough NHS Trust - SoH	Overview of continence nursing and discussion about the involvement of nurses in any discipline when UI is disclosed. Also discussed the aids that are available for management.
05/03/15	<b>Ethical Reviewer Training</b>	Janet Holt - SDDU	Overview of what is expected and not expected from a reviewer. Also discussed how methods and ethics can overlap but to stay away from methodology problems.  Discussed cases that had different ethical issues and what the outcomes of review might be.
14/04/15	<b>Auditing Ethical Review Applications</b>	SDDU	An overview of the auditing process and the expectations on auditors and those being audited.
13/04/15-29/05/15	<b>Assessment for learning in STEM teaching</b>	FutureLearn Uni of Leeds MOOC (12 hrs)	

12/05/15	<b>Career Interview Skills</b>	SDDU	Preparation before, during and after interview. Consideration given to possible questions, key attributes of researchers and opportunity for feedback through mock interview.
08/06/15	<b>Advanced Presentation Skills</b>	SDDU	Opportunity to practice presentation skills and get feedback. Understanding importance of posture, information presented verbally, non-verbally and through presentation software.
03/08/15	<b>Excel - Fundamentals</b>	IT Services	Learning how to use worksheets appropriately, finding and printing data and basic formulas.
17/08/15	<b>Excel – Manipulating Data</b>	IT Services	Learning how to use pivot tables, and other features of Excel which were not covered in the fundamentals training.
14.10.15	<b>Three Minute thesis Training</b>	SDDU	Info on how to present my research in three minutes, to a general but intelligent audience
10.12.15	<b>NVivo training. Part 2</b>	IT Services	Advanced knowledge in the use of NVivo for analysing data.
07.01.16	<b>SoH Tutoring Training</b>	Paul Marshall, SoH	How to access and update VLE, use lecture capture and what to expect from tutoring within the SoH
14.01.16	<b>Teaching small groups</b>	SDDU	How to be effective in facilitating learning with small groups of students. How to deal with issues. How to check understanding.
16.09.16	<b>Word for Long documents. Part 2</b>	IT Services	Additional training on using Word effectively for the thesis, and recap on Part 1.