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**URINARY TRACT INFECTION IN WOMEN AGED 18-64:  
DOCTORS', PATIENTS', AND LAY PERCEPTIONS AND  
UNDERSTANDINGS.**

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## **ABSTRACT**

This thesis provides an insight into the problems of urinary tract infection (UTI) through the eyes of women sufferers, non-sufferers, and health professionals. It describes the use of language and metaphor in women's descriptions. It investigates current ideas and knowledge published in academic journals, in books, and on the Internet, and assesses the quality of currently available web-based information.

The thesis is based almost entirely on qualitative methodologies. I used grounded theory for the studies of lay and professional ideas. Focus groups preceded one-to-one interviews. The study of language and metaphor is derived from lay interviews and uses discourse analysis. I based the studies of Internet information on two surveys, one year apart, of popular websites drawn from four commonly used search engines. I rank ordered popular websites and assessed information in the 'top twenty' using content analysis and a simple, predominantly binary, scoring system based on an internationally recognised set of criteria.

Folklore and myths, often passed down the generations, and sometimes shared by doctors, are important factors in women's health beliefs. Early learning experiences during medical training may contribute disproportionately to doctors' beliefs. UTIs cause embarrassment, and women rarely discuss their illness with male friends and relatives. They are also happier to discuss their problems with female health professionals, though they more commonly cite shared experience rather than embarrassment as the reason for this choice.

Since these studies were completed, a major project concluded that delayed prescriptions should be used for UTI. The natural history of this illness and women's prior use of self-management prior to attendance suggest that this strategy may not be readily accepted.

Nurses and pharmacists are keen to manage UTI. As UTI lends itself to management by algorithm, delegation to professionals other than doctors may be effective. Easy access to antibiotics increases resistance; fear of this inhibits the implementation of devolved care.

The quality of information on the Internet is variable and some of the most popular sites score poorly when compared against recognised criteria. Better quality sites are becoming more prominent when searching the Internet through popular search engines, and efforts to improve this source of information are important.

Future research is probably best directed at information transfer and new models of delivery of care.

## DECLARATION OF AUTHORSHIP

All the material in this thesis is my own, and has not been published elsewhere.

Collaborators on individual chapters are acknowledged in the 'methods' sections, where their contributions are listed.

## STATEMENT OF COPYRIGHT

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Thanks to my family, Terri, Emma, Jane and Oliver for their support (and jokes) during my extended period of study, and to Emma for her collaboration on two of the chapters. I take this opportunity to remind them that I am not trying to enter the Guinness Book of Records for the longest time to complete a PhD!

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## **CHAPTER 1 INTRODUCTION**

*Was immer du tun kannst oder traumst es zu können, fang damit an  
(Whatever you can do or dream you can do, get started on it.)*

*(Johann Wolfgang von Goethe)*

### **1.1 IMPORTANCE OF UTI**

50% of women will suffer from at least one urinary tract infection (UTI) during their adult life. UTIs account for around 5% of consultations in General Practice and are the second commonest infection after respiratory infections (1). 15% of community use of antibiotics is for UTIs (1). A few women will suffer significant morbidity from the effects of pyelonephritis, an infection of the kidney substance, usually caused by infection ascending from the bladder. Most of those suffering morbidity will have underlying causatory abnormalities. 25% of those who have had one infection will have at least one further infection, and sometimes, multiple recurrences (2). Some will develop interstitial cystitis, a debilitating disease of unknown aetiology presumed to originate from recurrent UTI.

### **1.2 WHAT WE ALREADY KNOW ABOUT PATIENT AND PROFESSIONAL PERCEPTIONS OF UTI**

Prior to the commencement of the PhD I identified only one study that attempted to describe patients' experiences (3). This study, from Norway, however, did not use an in-depth qualitative method of analysis; there was also no attempt to match patients' experiences with clinical diagnosis. There is no known past or present primary care research involving men or women without symptoms.

Another study described the beliefs of GPs and women about the risk factors for UTI and evaluated the influence of beliefs on clinical management (4). It suggested that UTI was an embarrassing subject for both women and their doctors. Neither women nor doctors appeared willing to communicate their thoughts to each other. Popular publications and websites promote the idea that sex is intimately associated with UTI though other risk factors are also suggested. An Internet-based diagnosis and management tool however, suggests that many commonly held beliefs about risk factors have no basis in evidence (5).

Prescription of an antibiotic is often the only response to urinary symptoms, and clinical management, as well as beliefs, is often not evidence-based (4). This study was undertaken prior to the 1998 Standard Medical Advisory Committee (SMAC) report, "the Path of

Least Resistance” (1), on antibiotic prescribing, which recommended that uncomplicated cystitis be treated with an empirical short course of treatment, but suggested that only half of the women presenting with cystitis required treatment. It has been recognised for some time that blind initial treatment is practised by many general practitioners (95%) and decisions on treatment are not related solely to physical symptoms and signs, or the results of investigations (6). A recent health technology assessment (HTA) advocates the use of delayed prescriptions (7), though a qualitative part of this study may not have clearly established the acceptability of this prescribing mechanism

A number of studies have shown that symptoms alone have a place in the prediction of a diagnosis of UTI, and others have indicated that near-patient dipstick testing is a useful adjunct, especially when applied to the ability to exclude disease (the negative predictive value). These tests may, however, perform differently in different populations.

### **1.3 AIMS OF THE PHD**

At its inception, the main aim of this PhD was to validate the use of patients’ symptoms as a tool for diagnosing UTI without reference to specific investigations. The emergence of new knowledge, from the PhD and from newly published studies, as well as changes in circumstances, conspired to alter my perception of this aim.

Firstly, we discovered unexpectedly rich data when we looked at patients’ perspectives. This initial study, originally conceived to provide information on symptom presentation, uses grounded theory, a qualitative methodology with an intense iterative approach. As I had wide timelines, we felt it was appropriate to expand the breadth and the remit of the interviews. Additionally, the discovery of the frequent use of metaphor in women’s descriptions led to a sub-analysis of this phenomenon, presented here in a separate chapter.

The second study on professional perspectives also expanded. The expected diversity of opinions did not materialise, which had the effect of extending the time to saturation whilst we looked for more subtle clues to the differential approaches of doctors. An early focus group unintentionally included nurses. Their perspective differed subtly from their medical colleagues and I decided to explore this further in a separate sub-area of the project. Having included nurses, it appeared logical to include pharmacists. Furthermore with the expansion in the role of pharmacists since I conceived this PhD, it seems likely that in the future they will play a significant part in the management of women with UTI, and any results from this study are relevant to this expectation.

My third study became less important, and more difficult, with time. This study was designed to bridge the knowledge gap that exists between the theory of a prodromal stage to UTI, when standard investigations can mislead, and the concept of clinical management on the basis of symptoms alone. I had intended to triangulate information from literature searches and the first two studies to provide a sound basis on which to test the relevance of a symptom checklist against a non-standard but more sensitive laboratory diagnostic procedure. Two significant studies on symptomatic management of UTI were published after I commenced my PhD in 2003 (8, 9). Whilst they didn't bridge the knowledge gap, they showed that symptom-based management was effective, a conclusion that was subsequently supported by national guidance published in 2006 (10). This questioned the benefits of a partly laboratory-based study, which would be less influential on doctors' management. Two other events also affected the decision: early in my PhD my clinical supervisor for this project tragically died; secondly, increasing laboratory mechanisation and pressure on resources reduced the feasibility of the study. The test, 'low count urine cultures', also hadn't been tested in a UK primary care setting. In its place, we commenced a fourth study, suggested by an expert in this particular field after a presentation at the University of Durham with invited guests from the Health Sciences unit. I decided to survey available information on cystitis on Internet sites and to make an attempt to compare this with expressed needs of patients and to some assumed wishes from patient narratives obtained during my first study. Like the other two studies it was a predominantly qualitative study, but used content analysis, a simpler, less iterative methodology. In the future, knowledge about patient perceptions may enable us to empower women to take a more active role in the management of their own illness, especially if we can provide good quality information both in the doctor's surgery and from cyberspace.

This, and the knowledge about professional beliefs may help us to provide better information and education for both the traditional givers of care the GPs. It will also be relevant to many other professionals in the wider primary care team, who are beginning to supplement or even take over the traditional function of the GP. A condition such as UTI, generally perceived as uncomplicated, is a likely candidate for delegated management.

#### **1.4 PARTICIPANTS**

Symptom patterns are different depending on patients' age (11). This PhD uncovers the experiences of women aged 18-64, but also considers the different attitudes, expectations, perceptions and medical differences (e.g. post-menopausal) within sub- groups.

I used a mixture of purposive and opportunistic sampling. Organising patient focus groups proved difficult, and after two theoretically sampled groups (the recording of one unfortunately marred by a technical hitch) we used one-to-one interviews for symptomatic women. The majority of interviews were undertaken by female interviewers to minimise potential embarrassment. In order to fully understand women's health beliefs I also involved divergent focus groups of men as well as women without a history of UTI.

GPs were primarily represented in the professionals' focus groups, though later groups involved just pharmacists and nurses. Most groups were purposively sampled to gain specific views, but in these busy times they were difficult to organise without a secondary educational enticement. Despite the problems, group research proved more successful than individual sessions. Registrars, more easily accessed, provided a relatively large input and proved to be useful commentators on their environment, peers and teachers. We were also able to triangulate the views of nurses, pharmacists and doctors.

The Internet search for information sheets was carried out on the four most popular search engines: Yahoo, Google, Ask, and MSN and the 20 most popular sites overall were surveyed in detail. The survey was repeated a year later and an assessment of the changes, for better or worse, was performed in order to see if information technology is likely to provide better answers for sufferers in the future.

## **1.5 PERSONAL MOTIVATORS**

There never was a grand 'master-plan'! Many people's research interest arises from personal experience, from reading the literature, or from colleagues or academic staff (12), or more poignantly from personal tragedy. My interest, however, was objective rather than subjective, having had no such experiences.

Attempting to make logical connections between the individuality of patients in the ways in which they present, and the reported certainty of confirmatory investigations has always been a source of intrigue. However, the uncertainty inherent in primary care always leaves one feeling that more needs to be done to bridge the gap between the evidence base and reality. As time has passed I have become more confident of using patient symptoms and intrigued by common linguistic quirks in unrelated patients, and less enamoured with the benefits of inflexible investigations.

My journey to this PhD started with mentoring our senior nurse on an "audit" (more probably observational research) of dipstick testing: she felt that there was duplication

between their testing and the laboratory. After initial excitement of producing positive results, extending the “audit” eventually proved inconclusive, though the appetite was whetted. For a diploma course I facilitated a practice guideline on UTIs and assessed its impact – we still use it almost unchanged almost 15 years on, and it is widely copied (some of the registrars I have interviewed recount the guidance but are unaware of its source!). It formed a substantial part of our Beacon Practice status 1998-2000 (antibiotic prescribing). In the late 1990s I undertook the authorship of a chapter on UTI in children for ‘Clinical Evidence’ (a BMJ publication). Ironically, my experience with adult UTI led to the child UTI authorship, whereas now the opposite is often true. A return to adult UTI appeared simpler for the PhD as I wished it to be based in primary care. I was awarded a Regional Research Fellowship at the second attempt in 2001 and the PhD began in February 2002.

### **1.5.1 REFLEXIVITY: SETTING OUT ON THE JOURNEY**

I am a low antibiotic prescriber, but always felt justified in prescribing for a condition that whilst rarely a cause of great morbidity, seemed disruptive and very uncomfortable. Like many other doctors, I felt that women with UTIs represented a quick consultation due to the simplicity of management, and finding hidden depths of meaning wasn’t fully expected. Backed by our interpretation of evidence, we had even reduced the consultation to the completion of a mini-questionnaire and an automatic short course of treatment for women who had two major symptoms of UTI. Urine samples are requested but aren’t routinely sent to the laboratory.

During my time running Beacon Practice groups, I found the initial scepticism of some doctors to evidence and guidance frustrating, but during the PhD I sensed that changes were gradually occurring. I find some of our non-medical advice illogical but encourage self-care where I can. I have a soft spot for alternative medicine whilst retaining scepticism of some of its perceived benefits. Having been brought up in a rural community I find the folk beliefs in this project quaint.

### **1.6 SUMMARY**

I have outlined my journey from an initial wish to sort out the evidence on investigation and management to being intrigued by a wealth of qualitative data that I came across in my originally small-scale exercises in assessing patient and professional health beliefs. The PhD that follows is, therefore, a much changed but ultimately much more unique perspective on this illness than was originally envisaged.

## CHAPTER 2 CLINICAL AND METHODOLOGICAL BACKGROUND

*At the beginning of my journey, I was naive. I didn't yet know that the answers vanish as one continues to travel, that there is only further complexity, that there are still more interrelationships and more questions (Kaplan, 1996)*

### 2.1 INTRODUCTION

Even at the outset, the emphasis of this PhD was qualitative. The studies on patient and health professionals perspectives' were both planned as grounded theory projects in order to uncover women's understanding of their illness and the reasons for health professionals' apparently varied responses. The study of metaphor was conceived after much of the data had been collected. We initially applied a generic thematic, and latterly discourse analysis. For the Internet study we used simple survey techniques and then content analysis for our examination of website information. We used a scoring system developed for this PhD and based on European guidance to assess the quality of Internet sites. The two main studies were planned as predominantly focus group research, but circumstances meant that one-to-one interviews were widely utilised for discovering women's views. We also used brainstorming and pragmatic variants of focus groups.

Firstly in this section, I have condensed the background information on the epidemiology, aetiology, diagnosis, prognosis, and management of UTI, gathered for the original study of symptoms and low-count urines. It remains as a reference point for the views expressed in the qualitative studies and for the website information. Secondly, I have included a section on the literature of health beliefs and the models constructed to aid assessment of this aspect of health understanding. The models seek to explain the processes that lead to a patient's decision to consult with their doctor, but as the emphasis was on women's experiences of UTI, I haven't included the extensive literature on this subject. Thirdly, I have presented the academic background to the predominant interview methods and methodology: grounded theory and focus groups. I have discussed in less depth the method of one-to-one interviews and the methodological underpinning of the two additional projects on metaphor and Internet information. Finally, I have presented a justification of the methods used in the studies, and an assessment of the rigour of the research undertaken using well recognised criteria.

## **2.2 EPIDEMIOLOGY**

### **2.2.1 AETIOLOGY OF UTI AND RELATED CONDITIONS**

#### **2.2.1.1 Cystitis**

Cystitis is caused by uropathogenic bacteria in the faecal flora that colonise the vaginal and periurethral openings, and ascend the urethra into the bladder (13). Urine is, however, a poor culture medium for many bacteria due to its acidity, high urea concentration, and variable osmolality. Protection is also given by the constant flow of urine and regular bladder emptying (14).

Although susceptibility patterns have changed, the spectrum of agents causing community-acquired UTI has remained relatively constant (15). *Escherichia coli* (*E.coli*) accounts for 75% to 90% of cases (15). *E.Coli* binds to alpha d-Mannose, a monosaccharide (sugar) that is present on the bladder urothelium (lining) (16), but it is less prevalent in patients where host factors play a predominant role in the aetiology of the infection. *Staphylococcus saprophyticus* accounts for 5% to 15% of UTIs in young women (15, 17); and enterococci and non-*E.coli* aerobic gram-negative rods, such as *Klebsiella* species and *Proteus mirabilis*, account for 5% to 10% (18, 19).

#### **2.2.1.2 Pyelonephritis**

Pyelonephritis is an inflammatory process of the kidneys and adjacent structures (14). It is most commonly caused when bacteria in the bladder ascend the ureters and invade the kidneys (20). In some cases, this may result in bacteria entering and multiplying in the bloodstream (14, 20). Although less well studied, the spectrum of agents causing uncomplicated pyelonephritis is similar to that causing acute cystitis (15, 17, 21).

#### **2.2.1.3 Complicated and uncomplicated infections**

Most urinary infections occur in women who are otherwise healthy (22); these are termed uncomplicated infections. Complicated pyelonephritis (or cystitis) occurs when upper (or lower) UTIs are associated with urinary tract abnormalities, and conditions causing long-term inflammation (14). They include anatomical or functional defects of the urinary tract, recent urinary tract instrumentation or catheterisation; these are associated with a wider range of infecting organisms than in uncomplicated infections (22). *Klebsiella* and *Proteus* appear with increased frequency in complicated UTI (23).

#### **2.2.1.4 Asymptomatic bacteriuria**

This is defined as the presence of bacteria in two consecutive urine samples in the absence of typical symptoms (10). It appears in women of all ages (10, 24), but is more common in the elderly and women with diabetes (10). Asymptomatic bacteriuria is universal in catheterised patients (10).

#### **2.2.1.5 Recurrent cystitis**

A recent Cochrane systematic review defined recurrent UTI (RUTI) in healthy non-pregnant women as three or more episodes of UTI during a twelve month period (25), though two episodes in the last six months is also commonly used in the literature.

A recurrence is defined clinically as a relapse if it is caused by the same species as caused the original UTI, and if it occurs within 2 weeks after treatment. It is considered re-infection if it occurs more than 2 weeks after treatment of the original infection (26).

#### **2.2.1.6 Urethral syndrome**

Urethral syndrome is defined as ‘symptoms suggestive of a lower tract urinary infection but in the absence of significant bacteriuria with a conventional pathogen’ (27). Between a quarter (28) and a half (27) of patients visiting their GP by reason of frequency and/or dysuria do not have significant bacteriuria, though they may have pyuria (29-31). Acute urethral syndrome may be caused by sexually-transmitted pathogens, or non-infective causes (such as trauma, allergies, anatomical features and co-existing medical conditions) (27). It also occurs in women with acute lower urinary tract symptoms and a low bacterial count, or without demonstrable bacteriuria, or vulvo-vaginal infection (14). A transitional phase of UTI, where urethritis precedes the onset of cystitis may explain these findings (27, 29, 31, 32). In the UK, a small study suggested that fastidious organisms cause urinary symptoms (33), but larger studies found no such association (29, 34).

#### **2.2.1.7 Pyuria**

Pyuria is the presence of  $\geq 10^4$  leucocytes/ml in fresh urine. It is present in 96% of symptomatic women with positive MSUs but in only 1% of women with no symptoms and a negative MSU (14). Pyuria without bacteriuria may be associated with chlamydial infections, but is equally common in the absence of obvious infection (30), from vaginal leucorrhoea (29), or when UTIs fail to meet laboratory criteria for diagnosis (30, 31). Rarer causes include a stone, foreign body, neoplasm or renal tuberculosis (10). In nursing homes



more than 50% of elderly women have pyuria (35). Pyuria is a frequent response to febrile illness in children (24); it is unclear whether this happens in adults.

### **2.2.1.8 Interstitial cystitis**

Interstitial cystitis can mimic UTI. It is a chronic pelvic pain syndrome of unknown aetiology where the bladder wall is inflamed and irritated; it is accompanied by frequency and urgency of at least six months duration (36). It can be diagnosed by ruling out other diseases (37, 38).

## **2.2.2 INCIDENCE**

### **2.2.2.1 Cystitis**

Urinary tract infections (UTIs) are common with an estimated annual global incidence of at least 250 million cases, and are costly to both patients and healthcare funding systems (39). They are one of the most common reasons for women to visit healthcare professionals (10, 40, 41), and are the second commonest infection after respiratory infections (1). 15% of community use of antibiotics in the UK is for UTIs (1).

An exact incidence rate is difficult to extract, but the assertion that in any given year, about 1 in 20 women presents to their GP with symptoms (1) appears, until recently, to be a fair approximation. Calculations from RCGP morbidity statistics suggest that 3.38% of women aged 15-64 had around 1 million consultations in 2007 for cystitis (42). In addition, 1-2% of lower urinary infections are coded as urethritis rather than cystitis (43). Calculations from the 2001 figures (42) suggest a much higher incidence for UTI of 5.68%; in 1981 it was 6.25% (44). It is impossible to ascertain if the reduced incidence is real or artefactual.

Population based studies show that despite its common presentation to healthcare professionals, many women do not visit physicians for symptoms of UTI (41). In a sample of women from US 10.8% of them aged 18 and older reported at least one presumed UTI the past year (45). As well as confirming that this is a very common disease, it also suggests that less than 50% of women with UTI present to their GPs.

Estimates of the lifetime incidence of one or more UTIs for adult women vary widely from 10 (14)-60 % (46), though most sources err on the higher side of these figures. A common quote is that half of all women have at least one UTI in their lifetime (40, 47).

The incidence of UTI is highest in young women (14). 33% of women have had a UTI by the age of 24. As 10% of girls have had a UTI by the age of sixteen (24), it seems likely that about 25% of women have their first UTI in their first eight years of adulthood.

### **2.2.2.2 Pyelonephritis**

Data for the incidence of pyelonephritis in the UK is less detailed. In 2007, 8/10,000 women were recorded as receiving a diagnosis of 'kidney infection', though this figure included all age groups; women aged 15-24 had the highest incidence of 16/10,000 (43). These figures are lower than quoted elsewhere. In the USA, the estimated annual incidence per 10,000 people is quoted as 27.6 (48), and in South Korea, 35.7 (49). Data recording methods are different in each country. Figures for other countries are unknown. In another study the overall incidence of pyelonephritis is quoted as 16/10,000 (50); the rate doubles for women aged 15-29 and is lowest for women aged 50-64. Localization studies indicate that as many as 30% of women who present with a cystitis-like syndrome may have sub clinical upper urinary tract involvement (51).

The highest incidence of pyelonephritis occurs during the summer months (50, 52), whereas cystitis is predominant in the winter months (42). Women are approximately five times more likely than men to be hospitalised with acute pyelonephritis (53).

### **2.2.2.3 Recurrent cystitis**

Up to 50% of women suffering a UTI will develop recurrence (13), almost always because of re-infection rather than relapse (26). As many as 10-20% of women experience frequent recurrent UTI, occurring as often as every two weeks (47). Most women presenting with UTI will, therefore, have had a previous infection, and in one study of women presenting to their GP, 90% had had previous infections (54).

## **2.2.3 RISK FACTORS**

### **2.2.3.1 Sex and contraception**

The association between sexual intercourse and acute cystitis in women has been recognized for generations in folk wisdom (e.g. "honeymoon cystitis"), but researchers have been less certain of this association (55). In fact, a causal relation between two very common events, intercourse and acute cystitis, is difficult to establish (56).

Early evidence for sex being involved in the aetiology of UTI comes from an epidemiological study comparing nuns and married women (57). It is thought that bacteria are forced into the bladder during intercourse, predisposing to UTI. An increase in bacterial counts in the bladder after intercourse indirectly supports this theory (58). A prospective cohort study showed that among sexually active young women the incidence of symptomatic urinary tract infection is high, and the risk is strongly and independently

associated with recent sexual intercourse, recent use of a diaphragm with spermicide, and a history of recurrent urinary tract infections (59). In a case-control study, intercourse frequency, spermicide use itself, and a new sex partner during the last year were also found to be associated with an increased risk of UTI (60). It is uncertain as to whether a particular coital position or sexual practice is more likely to lead to acute cystitis (56).

Condoms are associated with an increased incidence of UTI (61). Adding a spermicide-coating further increases (7.4 - 11.5 times) the risk of UTI, the highest risk occurs with the use of Nonoxynol-9 (61). Contraceptive diaphragms double the risk of UTI (62); similarly, spermicide was identified as the likeliest cause (62), rather than the original theory of urethral irritation (63). Spermicide alters normal vaginal flora and facilitates colonisation with pathogens (64). Oral contraceptives don't predispose to UTI (65).

#### **2.2.3.2 Pregnancy**

Cystitis is commoner during pregnancy because of changes in the urinary tract and uterus. Symptomatic bacteriuria occurs in 17-20% of pregnancies (66), a rate well above the normal annual incidence of UTI. 10-30% of women with bacteriuria in the first trimester develop upper urinary tract infection in the second or third trimester (10).

#### **2.2.3.3 The menopause**

Genito-urinary atrophy may increase the risk of bacteriuria (10). The proposed mechanism for this, is an increased vaginal pH and a reduction in vaginal *Lactobacillus*, allowing gram negative bacteria to grow and act as uropathogens (67).

After the menopause the main risk factors are vaginal prolapse, cystocele, post-voidal residue, changes in vaginal flora, and urinary incontinence (67). The association of recurrent UTI with sexual habits, such as frequency of sexual intercourse and the use of spermicides is not as positive as in younger women (67).

#### **2.2.3.4 Urinary tract abnormalities**

Pelvic anatomical differences may predispose some women to recurrent UTI, especially those with no other risk factors (68). Urine voiding disorders such as those associated with prolapse, multiple sclerosis, bladder cancer, or bladder stones increase the risk (60). Around 90% of patients with a long-term indwelling catheter develop bacteriuria within 17 days of its introduction (22). Women with any urinary tract abnormality are more prone to pyelonephritis refractory to oral therapy or complicated by bacteraemia (20).

### **2.2.3.5 Diabetes**

Lower tract infections are commoner in diabetes (69) and ascent of infection is easier, probably due to deficiency of local immune mechanisms and increased adherence of bacteria to the linings of the urinary system (70).

### **2.2.3.6 Habits and clothing**

There is no evidence that tampon use, poor urinary hygiene, frequency of urination, wiping patterns, douching, the use of hot tubs, or the wearing of tights predisposes women to recurrent infections (65, 71).

### **2.2.3.7 The influence of microbes**

Virulent uropathogens are much more important in patients without abnormality than in those who have a functional or anatomical abnormality of the genitourinary tract (72). P-fimbriation of E Coli has been linked to an increased risk of pyelonephritis (73, 74). Antimicrobial use adversely affects the vaginal flora in animals and humans (75), and recent use of antibiotics is strongly associated with a risk of cystitis (60, 76, 77).

### **2.2.3.8 Genetics and family history**

A genetic predisposition to recurrent UTI is suggested by the association of recurrent UTI in certain age groups with the ABH blood group non-secretor phenotype, a maternal history of UTI and early age at onset of UTI (72).

## **2.2.4 RISK FACTORS RELATED TO PATTERNS OF UTI**

### **2.2.4.1 Pyelonephritis**

As with cystitis in reproductive-age women, sexual behaviours and patient and family history of UTI are associated with increased pyelonephritis risk. Diabetes and incontinence also seem to independently increase the risk for pyelonephritis (48).

### **2.2.4.2 Asymptomatic bacteriuria**

The risk factors for asymptomatic bacteriuria are the same as for symptomatic UTI (78).

### **2.2.4.3 Recurrent UTI**

Little research has been performed to identify risk factors specific for recurrence. In a large, case controlled study of women (60) the strongest risk factor for recurrence in a multivariate analysis was the frequency of sexual intercourse. 12-month spermicide use and new sex partner during the past year, age under-16 at first urinary tract infection and a UTI history in the mother were also associated; blood group and secretor phenotype were

not associated with recurrent UTI (60). In young women, risk factors for sporadic UTI are also risk factors for recurrence (60).

## **2.2.5 PROGNOSIS**

### **2.2.5.1 Natural history**

There is little evidence on the long-term effects of untreated cystitis. One RCT suggested a spontaneous cure rate of 24% (79), but a review suggests that up to 40% of acute uncomplicated UTIs spontaneously regress within four weeks (47, 80); progression to pyelonephritis is infrequent, but symptoms of cystitis sometimes persist for several months (81). An NHS guideline states that mild UTIs usually resolve spontaneously in a few days (5), but doesn't identify the evidence-base.

In one study, dysuria disappeared after a median time of three days with an antibiotic compared to five days with placebo; 41% of those given a placebo still had dysuria after seven days (54). Frequency (of urination) appears to be the symptom that lasts longest: this remained a moderately severe (or worse) problem for an average of 3 days after antibiotic treatment in one study, compared to 6 days without treatment (7). Neither study assessed the total duration of symptoms (7, 54).

Women with a baseline rate of more than two infections a year, over many years, are likely to have ongoing recurrent infections (82).

### **2.2.5.2 Complications**

Complications of UTI include urosepsis, renal impairment, and renal abscess (20). Underlying renal disease, diabetes mellitus, and immuno-suppression may worsen prognosis, but there is no good long term evidence about rates of sepsis or death among people with such conditions (20). One study suggests that renal scarring occurs in 46% of women after pyelonephritis but is rarely clinically significant (83). Pyelonephritis in pregnancy, however, is associated with increased morbidity and rarely, mortality (66).

### **2.2.5.3 Asymptomatic bacteriuria**

Asymptomatic bacteriuria is a benign condition except in pregnancy. It rarely persists (78) and doesn't seem to impair renal function or shorten life (10, 22). Symptomatic UTI develops within one week after 8% of occasions on which a culture shows asymptomatic bacteriuria, as compared with 1% of occasions when cultures are negative (78). There is, however, no evidence that treatment of asymptomatic bacteriuria in adult women

significantly reduces the risk of symptomatic episodes, either in women with, or without, co-morbidity (10), and may be harmful in diabetics (10, 84).

Pregnancy is the only situation where national guidance recommends active intervention (10). Asymptomatic bacteriuria occurs in 2-10% of pregnancies (85) and, if not treated, 10-30% of mothers will develop acute pyelonephritis (10). Asymptomatic bacteriuria has also been associated with low birth weight and preterm delivery (85).

## **2.3 DIAGNOSIS OF UTI**

The diagnosis of UTI is primarily based on symptoms. Individually, symptoms are rarely diagnostic, but in combination their accuracy is greater. Signs and examination findings are generally unhelpful in uncomplicated cystitis, but have more value where upper UTI is possible. Laboratory culture has historically been the benchmark for diagnosis of UTI, but studies have shown that women who respond to treatment may have bacterial counts below the traditional threshold for diagnosis.

Urine dipstick tests, microscopy and dip slides have all been studied to see if they can further improve diagnostic accuracy. Other studies have looked at symptom score systems, or combinations of symptoms and tests. All fall short of ideal.

Tests have little impact on the likelihood of UTI when two or more symptoms are present, especially if these are dysuria and frequency. When the diagnosis is less certain, the presence of vaginal symptoms, and/or a negative urine dipstick test is useful in excluding UTI in women at low risk of complications.

### **2.3.1 WHEN IS A TEST USEFUL**

Clinically useful tests increase or decrease the likelihood of disease by a factor of ten: a positive likelihood ratio (LR+) of +10 or a negative likelihood ratio (LR-) of 0.1 (86). Tests are useful when they cause the likelihood of disease to cross test-treatment thresholds, below 25% or above 65% chance of disease (87). Dipstick tests in the presence of moderate pre-test probability of UTI are clinically useful (88).

### **2.3.2 SYMPTOMS AND CLINICAL DIAGNOSIS**

Urinary frequency, dysuria, and suprapubic discomfort are regarded as the characteristic symptoms of cystitis (44). Recent guidance suggests that a typical clinical encounter includes a physical examination as well as a history (10), though almost all the literature and interviews with clinicians fail to include this in the assessment of UTI except in certain well-defined situations. One review points out that only one finding, costo-vertebral

tenderness, has an effect on the probability of UTI, and examination can therefore, safely be omitted in the absence of vaginal symptoms (40).

### 2.3.2.1 Investigation by history alone

The diagnostic accuracy of clinical assessment for UTI remains uncertain (40, 41), even though the probability of bacteriuria in otherwise healthy women who present to their GP, or emergency care, with symptoms of acute UTI is estimated at between 50-80% (7, 10, 40, 41, 89). If dysuria and frequency are both present then the probability of UTI is increased to >90% (10, 40). In contrast, history taking and physical examination cannot reliably lower the post-test probability of UTI when one or more typical symptoms are present (40). A systematic review places the negative predictive value (NPV) of (a lack of) appropriate symptoms at a meagre 50% (41). Only the presence of vaginal symptoms reduce the probability of finding bacteriuria (10, 40). Compared to a reference standard of UTI confirmed by low count culture, GP diagnosis has a sensitivity of 70.8%, a specificity of 38.8%, a positive predictive value (PPV) of 79.7%, and an NPV of 28.2% (89); another study in the UK suggested 80% of clinical diagnoses were correct (90).

Women with recurrent UTI (i.e. most women attending with UTI) are able to self-diagnose in 84% - 95% of cases, depending on the scientific criteria for laboratory confirmation (91, 92). Self-diagnosis increases the probability of UTI four-fold (40).

A systematic review assessed the symptoms presented by women with possible UTI (40). Four symptoms and one sign significantly increased, and another four symptoms and one sign significantly decreased, the probability of UTI. The two most powerful were histories of vaginal discharge or vaginal irritation (40). A combination of dysuria and frequency but no vaginal discharge or irritation gave a LR+ of 24.6 (40), which translates to a 96% chance of UTI (93). It may seem odd that negative findings are the most powerful, but positive symptoms 'use up' some of their predictive power in causing women with UTI to seek medical attention in the first place.

**Table 1: symptoms that increase the likelihood of UTI**

Symptom	LR+	95% CI
Dysuria	1.5	1.2-2.0
Frequency	1.8	1.1-3.0
Haematuria	2.0	1.3-2.9
Back pain	1.6	1.2-2.1
Costo-vertebral angle tenderness	1.7	1.1-2.5

**Table 2: symptoms that decrease the likelihood of UTI**

Symptom	LR-	95% CI
Absence of dysuria	0.5	0.3-0.7
Vaginal discharge	0.3	0.1-0.9
Vaginal irritation	0.2	0.1-0.9
Absence of back pain	0.8	0.7-0.9
Vaginal discharge on examination	0.7	0.5-0.9

Two later studies add useful information. The first produced similar outcomes on the significance of individual symptoms, and additionally found two further significant findings: a LR+ of 1.29 for urgency and 1.16 for tenesmus (strangury) (9). The second excluded women with vaginal symptoms (which may alter the significance of other symptoms) and found that only dysuria and nocturia were independently predictive of UTI (7). In a further validation study dysuria, but not nocturia, remained independently predictive of UTI (7). Frequency, urgency, and haematuria, when rated as moderately severe problems, were found to be significantly related to a diagnosis of UTI, but weren't independently predictive of disease; in fact the symptom of urgency, added nothing to diagnostic accuracy when assessed in this way (7).

### **2.3.2.2 Using symptom scoring tools**

A recent study concluded that accurate clinical prediction rules incorporating symptoms, signs, and near-patient testing are required, since individual symptoms are an inadequate guide on which to base diagnostic testing and antibiotic decisions in primary care (8).

A symptom scoring system performed better than GP diagnosis, but was less accurate, though more sensitive, than a computer predicted probability (94). The scoring system varied depending on age; it appears too cumbersome and its benefits insufficient to warrant its routine use. A more recent study derived a simple clinical rule of 'two of: cloudy urine; smelly urine; dysuria, rated at least moderately severe; nocturia, rated at least moderately severe' (7). When applied prospectively its performance was less adequate than a dipstick rule; even when the rule was modified to 'any cloudy urine, nocturia or dysuria' it still missed a third of women with UTI (7).

### **2.3.2.3 Diagnosing upper UTI**

There are no clinical features or routine investigations that conclusively distinguish acute pyelonephritis from cystitis (5) but the presence of symptoms for more than seven days (95), back pain or fever increase its probability (10). Experts recommend diagnosing acute pyelonephritis based on evidence of a UTI with loin pain or a temperature over 38°C (5).



#### **2.3.2.4 Differentiating UTI from a sexually transmitted infection (STI)**

UTIs and early pelvic infections due to STI may cause similar symptoms. A simple history and urine dip to establish a diagnosis of UTI may result in over-treatment of UTIs and under-treatment of STIs (96). 17.3% of women with symptoms suggesting UTI presenting to a New York urban emergency department had an STI; the only predictor, on logistic regression, was more than one sex partner in the past year. No other element of the history or pelvic examination helped differentiate those who tested positive for an STI (96). Another study in a teenage health clinic also noted that 65% of those with sterile pyuria had an STI, mainly trichomoniasis or gonorrhoea (97). Both of the populations represented by these studies are very unlikely to be representative of women who present to primary care in the UK with UTIs. A study in an inner-city general practice in London found only 1-4% of women had STIs (98), so the New York findings must be interpreted with caution.

#### **2.3.3 DIAGNOSIS THROUGH COLLECTION OF URINE SAMPLES**

Accurate diagnosis of UTI is difficult. There is no convenient and universally applicable 'gold' standard test (99). The mid-stream clean-catch technique replaced catheterisation around fifty years ago as the collection method of choice (100). A diagnosis of UTI depends on culturing micro-organisms from urine (44), classically a single organism present in a high concentration - usually  $10^5$  colony forming units (cfu) per ml (101); this determines the presence of a UTI in 80% of cases (10, 41). 'Low count bacteriuria' is generally defined as  $10^2$ - $10^4$ cfu/ml and is said to occur in 1/3 women (102) with typical symptoms of UTI seen in general practice (103). Tests that suggest or prove the presence of bacteria or white cells in the urine may contribute additional information to inform management but rarely have important implications for diagnosis (10). Contamination of samples is not uncommon (24), but instructing women about the 'clean-catch' technique appears to be of little benefit (100). An early morning sample is better for estimating nitrites in the urine (10, 22), but there is no evidence of other advantages. If urine specimens cannot be cultured within four hours they should be refrigerated immediately, or collected in bottles containing preservatives e.g. boric acid (24).

#### **2.3.3.1 Near-patient testing**

##### **2.3.3.1.1 Microscopy**

Studies of microscopy show a wide variation in sensitivity (60-100%) and specificity (49-100%) to predict significant bacteriuria in symptomatic women (10). It is used by few GPs

even when support is available (104), and isn't recommended in primary care because of concerns regarding health and safety, maintenance of equipment, and training (10).

#### **2.3.3.1.2 Dip-slide**

This is a simple device for the quantitative diagnosis of a UTI, suitable for general practice (105). Sensitivity of dip slides in general practice is 73% and the specificity is 94% (106).

#### **2.3.3.1.3 Urine dipstick testing**

Urine dipsticks are used in 92% of consultations for UTI (89), and are the commonest near-patient test (7), but the quality of supportive evidence is poor (10). Dipsticks fail to provide a definitive diagnosis, but aid clinical assessment in certain circumstances. They carry an appreciable risk of error when used without clinical appraisal (94). Test strips may be stored and used incorrectly (107). Dipstick tests are indicated for women with minimal signs and symptoms, whose prior probability of UTI is around 50% (10). Where only one symptom or sign is present, a positive dipstick test is associated with a 80% probability of bacteriuria; negative tests are associated with much lower probability (around 20%) (10).

Nitrite testing is highly specific (108, 109) and false positives, in the absence of technical error, are unknown (94). This test only detects gram-negative bacteria and is affected by dilute urine and recent voiding (110, 111). The leucocyte esterase (LE) test detects pyuria (44) and boasts around 90% sensitivity. Its performance is otherwise mediocre (44, 108, 112) and dependent on the setting. It is most sensitive in general practice (113). Blood is present in the urine in 50-72% of UTIs (7, 44, 94). Contrary to previous findings (94, 114), a recent study found blood to be more predictive of UTI than the LE test (7). Proteinuria has no significant predictive value (7). Test accuracy is highest when either nitrite or LE or both are positive; the sensitivity of this combination is 75% and specificity 82% (115). The presence of both findings increases the likelihood of UTI more than seven times (9) and the specificity rises to 96% whilst the sensitivity drops to 44% (113). Combinations involving blood on dipsticks don't appear to improve performance (7).

#### **2.3.3.1.4 Visual appearance and offensive smelling urine**

A recent study in UK general practice found cloudy urine to have a specificity of 73% and a sensitivity of 49% for predicting symptomatic bacteriuria (7); previous studies found a higher sensitivity of 90% (10, 114). It is prone to observer error (10). Offensive smelling urine is a relatively uncommon symptom/ sign, occurring in only 19-29% of women with

UTI, and 4-19% of those without (7, 94). It has a sensitivity of 22-29%, specificity of 81-89%, and LR+ of 1.5-2.0. It adds no significant value to other tests (7).

## **2.4 TREATMENT**

A first step is to decide whether women have cystitis or pyelonephritis, and complicated or uncomplicated UTI (15). Specific patient factors, such as severity of symptoms, allergic history, results of recent microbiological tests (if available), risk factors for resistance (15), and accessibility of medical care are also important (15). Women with recurrent UTI are often re-infected with the same organism even months later.

### **2.4.1.1 Antibiotics**

Nearly 90% of women with acute urinary symptoms are treated with antibiotics (8). Current UK guidance supports the use of trimethoprim or nitrofurantoin for three days for non-pregnant women of any age with symptoms of acute lower urinary tract infection, and seven days of ciprofloxacin where there are symptoms or signs of upper UTI (10).

Trimethoprim is the first choice of treatment in the UK (10), internationally (89), and in the USA, if resistance rates are low (116). It is cheap and causes relatively little disruption of the gut flora (117). Resistance is too common to recommend it for the empirical treatment of a life-threatening infection such as pyelonephritis (10), but it concentrates well in urine, which increases its effectiveness and makes it suitable for treating cystitis (15). Resistance to trimethoprim is also associated with concurrent resistance to other antibiotics, resulting in multidrug-resistant uropathogens (118, 119).

Nitrofurantoin is a re-emerging treatment effective against most gram-positive and some gram-negative uropathogens (15), especially E.Coli (89). It is used for cystitis because it attains very high concentrations in the urine (15), but it is inappropriate for upper UTI as it cannot achieve effective concentrations in the blood (10). Alkalinising agents, often used in self-management strategies, reduce its effectiveness up to twenty-fold (10).

In the 1970s, Ampicillin was commonly used for treatment of acute cystitis. Increasing resistance, lower efficacy and more adverse effects mean aminopenicillins are no longer recommended for the empirical therapy of UTI (116). They may still be an appropriate choice during pregnancy or when enterococci are suspected (116). The related antibiotic, Co-amoxiclav has a wider spectrum of activity and reduced bacterial resistance. It is used as a second line treatment of upper UTI (10). There may be unexpected failures when treating organisms susceptible to Co-amoxiclav if there is resistance to Ampicillin (15).

Prior to SIGN guidance, oral cephalosporins were considered alternative first-line drugs for cystitis (22). Cefalexin is still useful for pregnant women with upper UTI (5); Cefixime is a second-line therapy for upper UTI in adults (10). Resistance to Cefalexin is low in the UK (120) but perhaps not elsewhere (15). It is more active than trimethoprim in the laboratory but clinically less effective for cystitis (11) and may be associated with greater relapse after treatment (5). Cephalosporins disrupt the gut flora more than alternative treatments (117), even though penicillins cause more resistance (121). Extended range cephalosporins are a significant cause of clostridium difficile infections (122).

Fluoroquinolones are broad-spectrum antibiotics, but are active against only 60-70% of enterococci (123, 124) and resistance, often multi-drug (125), is increasing (10). They are relatively expensive, may damage tendons or trigger epilepsy (5), making them unsuitable for the empirical treatment of cystitis in the UK (10, 116, 126). First-line therapy for out-patient treatment of upper UTI in adults in the UK and the USA is Ciprofloxacin (10, 116).

#### **2.4.1.2 Non-antibiotic measures**

Symptomatic treatment may help to reduce unnecessary prescribing of antibiotics by controlling symptoms and allowing time for microbiological investigation (11). In one study, around one third of women used non-medical preparations, including cranberry, urine alkalinisers, herbal, and homeopathic treatments (54), independent of whether they received antibiotics. In another study, about a third of women used non-medical treatments prior to consultation, but this mostly consisted of increased fluid intake` (8).

##### **2.4.1.2.1 Medications**

Antispasmodics (127), and oral treatments that alkalinise the urine may alleviate symptoms of cystitis (22). The effectiveness of cranberry juice is uncertain in the acute management of UTI (128, 129).

##### **2.4.1.2.2 Physiomechanical means**

Suggested general measures to treat urinary infection include drinking more to increase urinary output, and an analgesic or antipyretic for pain or fever (5, 22). Despite this there is no evidence that increased urinary output is beneficial (5).

#### **2.4.1.3 Antibiotic resistance**

The increasing prevalence of antimicrobial resistance in the 1990s resulted in campaigns to reduce antibiotic prescribing. However, overall antimicrobial prescribing in the UK has once again risen, albeit slightly (130).

Within the community setting, exposure to antibiotics is a strong risk factor for resistant *E. coli* UTI (77), and repeated or prolonged treatment is likely to be contributory (10). Laboratory analysis is only recommended in certain circumstances. Professionals with low investigation rates are more likely to follow guidelines and paradoxically appear to have high rates of antibiotic resistance (10) as they are less likely to investigate uncomplicated UTIs. Antibiotic resistance has been linked to more serious, bacteraemic, illness (130). Resistant infections also cause increased work load in general practice, mainly through re-attendance (131, 132). General practitioners face two sometimes competing imperatives: firstly to choose an effective treatment for the individual; secondly to minimise resistance in the population by using antibiotics responsibly (133).

#### **2.4.1.3.1 Individual factors associated with the development of resistance**

Antimicrobial resistance among the pathogens that cause community-acquired UTIs is increasing (123, 124, 134). Resistance to trimethoprim, perhaps the most commonly prescribed urinary antibiotic in the UK, is significantly associated with age, sex, and recent exposure to the drug (76). Increased resistance to trimethoprim disappears if there is no further exposure to the antibiotic for more than six months (76). The potential to reduce resistance by reducing use is often much less certain and seems likely to vary with the particular combination of organism and antimicrobial agent (1). One study, however, does show that local resistance patterns to antibiotics, including trimethoprim, varies with the number of relevant prescriptions dispensed (135). To reduce the development of resistance it is also important that clinicians prescribe adequate doses of antibiotics (136).

Oestrogen exposure (oral contraceptive pills or hormone replacement therapy) within the past 6 months has been linked to resistance, although the mechanisms are unknown (137). Other factors such as use of other antibiotics, steroids, diabetes, and recent hospitalisation did not affect resistance (15, 138). Resistance is 2-5 times more likely in women with complicated UTIs, and in older women (103). Resistance patterns are also determined by the incidence of non-*E. coli* infections (139).

#### **2.4.1.3.2 Regional and national variations in resistance**

The susceptibility patterns of uropathogens causing acute uncomplicated UTI are changing, reducing the safety and effectiveness of empirical therapy for affected patients. This change is not uniform, varying from region to region or within different patient groups (116, 123). The North-East of England has relatively high trimethoprim resistance (120). Levels of resistance to antibiotics also shows marked national trends (123). These trends

are likely to reflect different patterns of use. Antibacterial agents can be bought openly without prescription in many developing countries; the emergence of resistance is further encouraged by inappropriate treatment, incorrect dosing and counterfeit drugs (1). In other countries, e.g. Spain, restrictions are flouted, increasing resistant bacteria (1). One study comparing two countries found little difference in bacterial resistance in samples from dysuric women managed in primary care despite four-fold differences in prescribing and significant differences in overall rates of antibiotic resistance (140). This may suggest that appropriate medical management for uncomplicated UTI has least impact on the emergence of resistance

#### **2.4.1.3.3 Is laboratory evidence of resistance important?**

Laboratory results may overestimate resistance in adult women (132, 141) as many antibiotics used in UTIs achieve high concentrations in the urine (15), the level of antibiotic exceeding that used on sensitivity disks. A review estimated that even with 20-30% resistance to trimethoprim, clinical cure rates will still reach 85-88% (15), compared to 95% when cystitis is caused by susceptible strains (15, 19, 116). One study comparing two quinolones and co-trimoxazole showed equal clinical success (19) despite differences in resistance rates. Symptoms persist longer on average when an organism resistant to the chosen antibiotic is responsible for a UTI (7, 131, 132), but less than if no antibiotic was given (7). Initial bacterial eradication is slightly inferior when women are treated with antibiotics to which their UTI is resistant but results are similar at 28 days (31). Bacterial eradication rates are similar when treating pyelonephritis caused by resistant bacteria, but clinical response is much less: 35% (21). In upper UTI, therefore, urine should be taken for culture before empirical treatment is started and the treatment changed if there is an inadequate response to the antibiotic (10).

#### **2.4.1.4 Length of antibiotic treatment**

Three day courses are sufficient for cystitis (10). 5-day courses, however, are commonly prescribed in Germany (89) and around 50% of prescriptions for cystitis in one UK study were for 5-7 days (8). Antibiotic therapy for 3 days is similar to prolonged therapy (5-10 days) in achieving symptomatic cure during uncomplicated UTI treatment, while the longer treatment is more effective in obtaining bacteriological cure (142). In otherwise healthy adult non-pregnant women with acute uncomplicated bacterial cystitis, single-dose therapy is generally less effective than the same antimicrobial used for longer durations (116), despite using a triple dose tablet. Infections with *S. saprophyticus* may be less

adequately treated with three day courses of treatment (116). Limiting the prescription of antibiotics for uncomplicated cystitis in otherwise healthy women to three days reduces the selection pressure for resistance (1).

Upper UTIs generally receive 7-10 days treatment (143). UK guidance suggests seven days of ciprofloxacin for upper UTI, but because of a lack of evidence, recommends two weeks' treatment for other antibiotics (10).

#### **2.4.1.5 An empirical approach to treatment**

Current management of UTIs is usually empirical without the use of a urine culture or susceptibility testing to guide therapy (15, 91), and this appears to be appropriate when the history is typical (8, 40), and in the absence of features suggesting upper UTI (15). Women who do not fall into this category or those in whom the diagnosis is not clear should have a urine culture, and therapy should be tailored accordingly.

Empirical treatment isn't a new phenomenon: in 1983, a study reported that blind initial treatment was practised by 94% of GPs (144). GPs no doubt made pragmatic decisions to treat UTIs empirically before the emergence of full supporting evidence. It is recognised that clinicians base such decisions on intuitive test-treatment thresholds (87).

The rationale for empirical treatment without investigation is based on the narrow and predictable spectrum of agents causing acute cystitis, their susceptibility patterns (40, 102), and the high likelihood of UTI in symptomatic women. Some consider it appropriate to institute antibiotic therapy when there is a 50% chance of infection (145). The presence of one typical symptom predicts infection at this level. GPs are six times more likely to treat empirically when women have symptoms of dysuria with or without frequency (8).

Surprisingly, a report on the emergence of antibiotic resistance supports an empirical treatment approach (1). Urine testing is reserved for failed treatment, for patients who have anatomical defects of the urinary tract or complications (1, 15) or for recurrent symptoms two to four weeks after the completion of treatment (71). Urine cultures usually become available only after the patient has been on therapy for a day or two and has generally responded (102). Furthermore, some GPs have inadequate laboratory support, depending on the time in the week, or for geographical reasons (94).

##### **2.4.1.5.1 In comparison: traditional management strategies**

The traditional strategy is to perform a culture and treat on the basis of results. It is stated that this conservative approach meets the immediate concern of the patient and better

ensures a proper diagnostic workup and successful cure (127); whilst waiting for results, women's symptoms can be relieved with urinary analgesics or antispasmodics (127). A UK clinical support website suggests that UTIs are generally self-limiting and antibiotics shorten symptoms by only one day on average (5). If true, though I could find no evidence for this assertion, non-antibiotic or delayed treatment strategies would be reasonable. Postponing treatment for more than 48 hrs whilst awaiting an MSU result, however, causes women to suffer, on average, a 37% longer duration of moderately severe symptoms (7).

#### **2.4.1.5.2 Does empirical treatment lead to overuse of antibiotics?**

Whilst there has been a recent drop of 19-26% in the use of antibiotics for respiratory infections, there has been only a 6% drop in antibiotic use for urinary symptoms (8). Current clinical practice may result in 20-40% patients receiving unnecessary antibiotic treatment (7, 8, 146) according to traditional diagnostic criteria. No such studies, however, have been conducted using the more inclusive low-count cultures. Women with mild symptoms may consider not using an antibiotic (147).

#### **2.4.1.5.3 Alternative strategies to empirical treatment**

Protocol-based treatment results in more appropriate prescribing than the individualised approach chosen by GPs (89), but empirical treatment of all symptomatic patients implies unnecessary antibiotic prescriptions. If prescriptions are based on dipstick tests 79% of women take antibiotics, 74% if based on MSU results, 73% if based on symptom scores, 72% if a delayed prescription is given. This compares to 97% when antibiotics are offered immediately (7). Empirical treatment based on symptoms wasn't tested.

A recent HTA (7) and a number of other studies or reviews (8, 9, 115, 146) favour a dipstick strategy. Treating women with classic cystitis symptoms and pyuria rather than empirically would decrease unnecessary antibiotic use from 40% to 26%, though a third of women with UTI wouldn't receive immediate antibiotics (146). If nitrites are added to the model more women receive immediate antibiotics without any increase in inappropriate antibiotic use (146). Another review suggests that a dipstick strategy is not the most cost-effective, but should be considered to inhibit the emergence of resistant organisms (148). However, women with dysuria and frequency and negative dipstick tests almost always respond to antibiotics (54).



#### **2.4.1.6 Management of UTI by telephone consultation**

The role of telephone consultation in the management of UTI is unresolved. General practitioners may be less inclined to prescribe over the phone than other specialities (149). A key recommendation of a report on the development of resistance was to “limit antibiotic prescribing over the telephone” (1). UK guidance doesn’t recommend the use of telephone consultation (10), even though taking a history is perhaps the most important part of the diagnosis of UTI, and another guideline suggests its use for women with recurrent UTI (150, 151). Evidence also shows that telephone consultation by nurse practitioners for UTI is as effective and safe as a standard consultation, is preferred by women, and is likely to be cost-saving (152, 153). STIs may be missed, but the evidence on this is limited (152).

### **2.5 PREVENTION OF UTI**

#### **2.5.1.1 Prophylactic antibiotics**

Opinions differ on when to start prophylaxis, ranging from two to six recurrences per year (25). Continuous antibiotics for 6-12 months reduce the rate of UTI during prophylaxis when compared to placebo (25), but it does not modify the natural history of recurrent UTI. When discontinued, even after extended periods, more than 50% of women will have another infection within three months (25). Nitrofurantoin may be more effective than trimethoprim but is associated with more side-effects (25).

Post-coital administration of antibiotics is an established method giving on-demand treatment (91). Antibiotic use in one study was a third of that using daily prophylaxis, and was equally effective (154). Another method is to supply women with antibiotics to use at the onset of symptoms suggestive of a recurrence of cystitis (91). Since women correctly diagnose 84% of recurrent infections, this strategy should be effective.

#### **2.5.1.2 Non-antibiotic measures**

##### **2.5.1.2.1 Oestrogens**

Genitourinary atrophy may increase the risk of bacteriuria (10). In postmenopausal women, topical vaginal oestrogen cream decreases the risk of recurrent urinary tract infections (67). It doesn’t appear to restore the population of protective lactobacilli or alter vaginal pH and is less effective than antibiotic prophylaxis (155), but may still be appropriate for some women (10). The effectiveness of oral oestrogens is uncertain (13) as studies are of low methodological quality.

#### **2.5.1.2.2 Cranberry Juice**

Cranberry juice (or capsules) may decrease symptomatic UTIs for women with recurrent infections (128), but not for women presenting with acute UTI (156). They are less effective than antibiotics but don't contribute to antibiotic resistance (157). Lingonberries (128) and blueberries (56) appear to have similar effects. Chemicals in all of these fruits appear to reduce bacterial adherence to the linings of the urinary system (56).

#### **2.5.1.2.3 Probiotics**

A small trial suggested that intra-vaginal lactobacilli may prevent UTI (158).

#### **2.5.1.2.4 Physio-mechanical intervention and the effects of clothing and hygiene**

Many non-pharmacological interventions have been proposed to prevent UTI. These arose from medical consensus, and are not readily tested by conventional trials (159).

A 1973 review lists the physio-mechanical interventions as: frequent voiding; wiping front to back; double micturition (two attempts to empty the bladder one after another); K-Y jelly for lubrication during intercourse; post-coital voiding; increasing fluids (159). Post-coital voiding appears unlikely to have a significant role in preventing UTIs, but studies have come to different conclusions (59, 65, 160). No other physio-mechanical intervention appears to help (59, 65)

The same review also listed many suggestions regarding clothing and hygiene: keeping the perineum clean; showering (or using a bidet) rather than bathing; changing underwear daily, wearing cotton garments (as artificial fibres are more likely to cause sensitivity); vaginal deodorants, antiseptics, applied directly or added to bath water, and enzymatic detergents (but not soap) were also listed as likely skin irritants (159). Many of these suggestions continue to dominate medical advice despite a lack of evidence of benefit.

#### **2.5.1.2.5 Health education**

Health education leaflets help to reduce the frequency of recurrent cystitis (11) though a systematic review found that printed educational materials had no overall effect on patient outcomes in a range of diseases (161). A positive approach to diagnosis and prognosis is associated with a shorter duration of symptoms independent of any other variable (7).

### **2.5.2 WHY DO GPs AND NURSES INVESTIGATE UTI AND WHY DO THEY TREAT UTI?**

Decisions on treatment are not related solely to physical symptoms and signs, or the results of investigations (6). GPs are ten times more likely to prescribe if they perceive that the patient expects it (162). Several studies have demonstrated marked variation among

physicians in the strategies used to diagnose and manage women with acute dysuria (102). In a Danish study, GPs, microbiologists, and urologists responded differently to vignettes, at both an individual and a speciality level (149). In two further studies, 137 physicians reported 82 separate management strategies with marked differences in cost (163), and 201 physicians reported 50 different strategies (164).

### **2.5.2.1 Investigation and defensive medicine**

Though some of the rising tide of intervention and investigation may be associated with quality of care (165), more than half of UK GPs and around a quarter in the Netherlands admitted to over-investigating for purely defensive reasons (166, 167). As these studies are more than ten years old, these figures may be an under-estimate.

Investigations may be carried out to meet patient expectation rather than clinical need (166). Malpractice fear accounts for significant variability in decision-making and is associated with increased hospitalisation of low-risk patients and increased use of diagnostic tests (168). Fear of litigation is associated with greater use of tests which have no benefits for patients (166). Defensive tests generally result in fewer abnormal findings (167). Doctors with heavier workloads and those who have to wait for laboratory results for more than 24 hours order more investigations (169).

### **2.5.2.2 Should we investigate women with suspected UTIs?**

Urine is the commonest microbiology laboratory specimen, and is increasing annually by 5-10% (170). Urinalysis is one of the commonest examinations at the point of care (171). In one study 63% of women with suspected UTI had their urine cultured, and 44% had a dipstick test, or microscopy (8). There are 10-fold differences between GPs in the rates of ordering these tests (172). Frequent users of laboratory diagnosis with high rates of positive samples use culture to confirm dipstick analysis, whereas frequent users with low rates of positive samples use culture to confirm clinical diagnosis; low users of laboratory diagnosis use empirical treatment, but may over-treat (173).

### **2.5.2.3 Does correct diagnosis “matter”**

The clinical significance of missing a true-positive result will depend on the population being examined. This ranges from possible fetal mortality in pregnancy, where there is a low pretest probability of UTI, to little evidence of excess morbidity in uncomplicated UTIs in women, in who there is a high pre-test probability of UTI (145). Urine should be cultured when upper UTI is considered (e.g. the presence of back pain or fever) as the

clinical risks of treatment failure are increased (10). Microbiological diagnosis underestimates infection in acutely dysuric women and most women with symptoms of dysuria and frequency but negative dipstick tests respond to antibiotic treatment, whatever their culture result: a 50% benefit over placebo at three days, and 31% at seven days (54). There are also errors in the collection of specimens, their storage and their analysis.

#### **2.5.2.4 Decision-making in the management of UTI and the effect of guidelines**

In one study, most patients with urinary symptoms were not treated according to current guidelines, and GP's diagnostic and therapeutic accuracy was low (89). A guideline implementation project on the management of UTI in Norway had little impact on physician behaviour despite identifying and addressing barriers to change (151). A 5.1% reduction in laboratory tests was the only change. The authors suggested that their complex, passive intervention inhibited change (151).

Guidelines facilitate delegation. In an implementation study, initial coordination of care by nurses increased from 21% of cases pre- to 78% post- guideline (164). At the same time, fewer urine samples were cultured, and shorter antibiotic courses administered but these changes were limited to nurse-coordinated cases. There were no other changes (164).

#### **2.5.3 FOLLOW UP**

Routine follow up is not needed for lower UTI. Women with upper UTI should be reviewed after 24 hours to assess response (5).

In cystitis, women can confidently be told that their symptoms will most likely resolve quickly, but that they should return if symptoms are not improving by four days, sooner if symptoms worsen (133). Post-therapy urine cultures are not indicated in women with uncomplicated acute cystitis since persistent asymptomatic bacteriuria does not pose a health risk for women who are not pregnant (102). Post-therapy cultures should be obtained if symptoms persist or if they recur soon after treatment (102), and in women who are pregnant, have complicated infections, or repeated recurrences (22).

#### **2.5.4 REFERRAL**

##### **2.5.4.1 Admission for acute pyelonephritis**

Women with acute episodes of upper UTI who do not respond to treatment within 24 hours should be referred to hospital (174) or if systemic symptoms appear (10). A review from the USA suggests that women with uncomplicated UTI, no nausea or vomiting and pyrexia

< 38.3 °C can be treated as an outpatient with oral therapy but patients with complicated pyelonephritis should be hospitalised and treated with intravenous antibiotics (15).

#### **2.5.4.2 Referral for haematuria and proteinuria**

Both blood and protein are found in conditions other than UTI (143). Visible painless haematuria is a reason to refer urgently (175). UTI, on the other hand, is associated with painful haematuria, and urgent referral is only recommended if the infection is recurrent or persistent in patients aged 40 and over, or if an infective cause cannot be confirmed (175). Patients aged 50 and over with unexplained microscopic haematuria should be urgently referred; under 50, proteinuria and raised serum creatinine are indications for a non-urgent referral to a renal physician (176).

#### **2.5.4.3 Referral for chronic or recurrent problems**

Recurrent UTI is a common reason for referral of women to urologists but there are no guidelines or papers describing the criteria for referral or investigations to undertake (10). Referral for investigation should be considered for women who persistently fail to respond to treatment (5), but prophylaxis with antibiotics or cranberries should be tried first (10). Flow rate studies may be useful (177). Imaging rarely reveals a correctable abnormality in the absence of other indications, such as persistent haematuria; similar conclusions were reached on cystoscopy by some (178, 179) but not all studies (177).

One study audited referrals to a urological department and showed that only 23% of women referred for recurrent UTI had two or more positive MSUs in the past twelve months (their criteria of an appropriate referral) though 31% of women referred without infection had potential markers of serious disease (180).

#### **2.5.5 COSTS**

There is limited evidence on the costs of UTI, and studies calculate costs in different ways. UTI causes significant morbidity for individuals and incurs an economic cost, which may not be included. The common nature of UTI makes it a national problem.

In financial terms, the direct health costs of an episode of acute cystitis in the USA range from \$40 to \$80 (56), though variations in management strategies may lead to much wider differences (163). In the UK, antibiotics account for only 13% of the total primary care costs for patients with lower UTI and only 2-8% of the costs for patients with upper UTI. Visits to the GP account for the majority of costs (181).

In terms of occupational cost the patient loses about one day of productive activity (56). Another study calculated that each episode of UTI results in an average of six symptomatic days and two restricted activity days, as well as time lost from work (182).

#### **2.5.5.1 Cost-effective approaches to management of UTI**

In one study, implementing a guideline on UTI management reduced costs by 35%, but changes to management occurred only in nurse- (but not GP-) coordinated cases (164).

Another study modeled approaches suggested by UK GPs (148). Prescribing empirical antibiotics was the most cost-effective strategy. Sending a sample to the laboratory for culture as well as prescribing empirically marginally increased symptom-free time, but at significantly extra cost: £215 for one symptom-free day. All other strategies were more costly and reduced symptom-free time (148).

Adding dipstick analysis to a strategy of prescribing empirical antibiotics would increase costs by £714 per primary care group (assumed population 100,000) but reduce antibiotic prescriptions by 820 per year, of which 86% would be unnecessary (148), but helping to reduce resistance rates. Dipsticks are likely to be cost-effective in symptomatic women with low probability of bacteriuria (<50%); urine culture would only be cost-effective when the prevalence is yet lower (<20%) (148), as would occur with a woman with one symptom and a negative dipstick test (10).

#### **2.5.5.2 Side-effects, resistance rates, and cost-effectiveness**

Cost-effectiveness in the management of UTI appears to involve a number of balances. Costs may appear small, but do not take into account the full additional costs of resistant UTIs in the community and, given the high prevalence of UTIs, the overall costs to the health service are substantial (183). Emergence of resistance varies for each antibiotic. In one study, the overall cost for fluoroquinolones equalled that for co-trimoxazole, and was less than that of amoxicillin or nitrofurantoin, which both had higher rates of side-effects and treatment failures (184). The initial cost of a fluoroquinolone may be mitigated by overall improved outcomes (184), but widespread use may hasten the emergence of resistance to these drugs (15) and their cost-effectiveness could, therefore, be short-lived. Another study concluded that single-dose co-trimoxazole was the most cost-effective management strategy due to a three- to fourfold reduction in side-effects (185).

In the past, doctors have appeared to readily accept new antibiotics, prescribing them to overcome resistance (186). As resistance develops to antibiotics, drug costs increase and

patients are exposed to new drugs with less proven safety (11). Recently, reducing antibiotic prescriptions, including ciprofloxacin and cephalosporins, has been a priority and this spiral may have been broken.

## **2.6 SUMMARY OF THE CLINICAL BACKGROUND OF UTI**

UTI is very common in adult women and its diagnosis and management have been thoroughly researched; it has been the subject of a national guideline (10). Routine investigation appears unnecessary and empirical treatment on the basis of classical symptoms (90% predictive) has been accepted as standard treatment for many years. Increasing antibiotic resistance is a worldwide concern, less so in the UK, and alternative strategies have been trialled. Most recently, a more complex assessment of UTI, including near-patient testing, and delayed prescriptions has been advocated (7). Some risk factors for UTI have been identified but there is an incomplete picture of their relative importance and the effect of the body's own defences. UTI causes marked symptoms but infrequently causes major morbidity in otherwise healthy adult women. The economic cost is high, due to the high incidence of UTI, and loss of productivity.

## **2.7 HEALTH BELIEFS AND CONSULTING BEHAVIOUR IN PRIMARY CARE**

*To write prescriptions is easy, but to come to an understanding of people is hard.*  
(Franz Kafka)

### **2.7.1 CONCEPTS OF HEALTH AND DISEASE**

Symptoms are an everyday part of most people's lives and many people with illness do not consult their doctor. The decision to consult is not based simply on the presence or absence of medical problems. Rather it is based on a complex mix of social and psychological factors (187). Unlike hospital practice, patients in primary care more commonly present with undifferentiated illness. It is estimated that 50% have no identifiable pathology, 35% have self-limiting conditions, and only 15% require active treatment for disease (188). Poor health status and social disadvantage increase both 'objective' medical need and in turn, consultation rates, but consulting behaviour is influenced by many other factors.

The consultation is a transaction of lay and professional explanatory models (189) but GPs and patients may have separate worlds of experience and different agendas (4). Factors that may hamper this communication include not only the differing beliefs and belief systems, but also social and symbolic power differentials (190), and differences in expectations and perceptions of what is permitted within the context of the consultation (4, 191). GPs are

said to investigate the framework of patients' knowledge in fewer than a third of consultations, and make active attempts to explore what patients mean in only 14% (192).

Lay beliefs affect the behaviour of people in seeking medical help when they experience symptoms of illness. They are important in doctor-patient interaction and hence in the communicative context in which diagnosis is made (193). To understand lay beliefs it is important to consider definitions of ill health, disease, and illness.

#### **2.7.1.1 Health and ill-health**

Health and disease cannot be defined merely in terms of anatomical, physiological, or mental attributes. Their real measure is the ability of individuals to function in a manner acceptable to themselves and to the groups of which they are part (194).

A survey of 9000 individuals on the meaning of health (195) found that 15% were unable to think of anyone who they defined as being 'very healthy', and over 10% couldn't give an answer on the state of their own health. Some of these thought of themselves as enjoying poor health, some had a lack of concern for healthy behaviour, but some, especially younger correspondents thought of health as ordinary, or the 'norm', and thus found it difficult to describe. Some viewed health as the absence of disease. This 'negative' concept of health - a state of 'not being ill' - was often used to describe other's health. Some even considered themselves healthy despite disease, where they had good control of its effects or its symptoms. Previous work suggested that middle-class women saw health in terms of being fit, being active and taking exercise (196) whereas avoidance of being ill and 'getting through the day' was a working-class phenomenon (196, 197). Work and health are particularly interrelated (198), though more so for men.

Ill health is comprised of both objective (disease) and subjective (illness) states. For many, including GPs (199), health is seen in a vacuum (200) or as a state of not being sick (198).

#### **2.7.1.2 Disease or illness?**

Models of patients' health beliefs, based on illness and influenced by culture, differ from doctors' models, based on disease and influenced by science and scientific teaching.

Diseases are named pathological entities that make up the medical model of ill health. Illnesses are the subjective response of patients to being unwell (201). Illness represents "what the patient feels when he goes to the doctor" and disease represents "what he has on the way home from the doctor's" (202), and similarly "disease is something an organ has" and "illness is something that a man has" (202). Another description suggests that illness is



a change in state of being and social function (in a negative way); disease, on the other hand, is an abnormality of the structure and function of body organs or systems (203).

### **2.7.1.3 Health Beliefs**

Beliefs appear to represent an amalgam of family and neighbourhood teaching, information from health professionals, and ideas from the media. Women may adapt doctors' ideas but keep their original beliefs. They look for explanations in their past history, take an holistic view of their illnesses, and are aware that they might be influenced by 'folk knowledge' (195). Chains of cause are popular: symptoms leading on to a diagnosis, or one disease triggering off another e.g. "coughs going down onto chests" (causing bronchitis).

#### **2.7.1.3.1 Beliefs relevant to UTI and folklore**

Around 25% of women (12/46) mention UTI, cystitis, or kidney infections in response to in-depth questions about their health beliefs (195). Of these only one in three directly attributes UTI to infection; a few attribute it to childbirth or the menopause. Most don't impute cause, but this may be an indication of uncertainty rather than lack of belief. The bladder and kidneys are thought of as sites in the body where bugs lodge more easily and damp, or clammy, conditions are thought to favour bugs (195). Women think temperature changes and damp housing specifically increase susceptibility to UTI, but think stress, heredity, poverty, temperament, and individual traits are generic illness triggers (195). Degeneration and idiopathic causes are often not considered, but the study didn't look at whether this was through a lack of experience, personal or others. Colds and chills are often put down to "foolish behaviour" e.g. "not wrapping up", but illness is not usually ascribed to the self. It is more acceptable to blame the environment than one's own body.

### **2.7.1.4 Identification of being ill**

Explanatory models (204) suggest that lay beliefs are illness, not disease-based. Illness is felt to be a weakness, causing women to be functionally unfit, and "giving in to disease".

#### **2.7.1.4.1 Why do people label themselves as 'ill'**

Defining oneself as being ill usually follows a number of subjective experiences such as changes in regular bodily functions such as urinary frequency; unusual bodily emissions such as blood in the urine; changes in bodily appearance; changes in functions or senses; changes in behaviour or emotional states, or physical symptoms such as pain or abdominal discomfort (190). Most people experience some of these abnormal changes in their daily lives, though usually in a mild form. 91% of adults had one or more abnormal symptoms in

the two weeks prior to one survey, but only 16% had consulted a doctor (191). Thus abnormal symptoms alone are insufficient for people to label themselves as 'ill', and further influences are necessary to obtain a label. In another study of middle-class Americans symptoms were considered as illness if they interfered with the usual daily activities, were recent in onset and ambiguous i.e. difficult for the layman to diagnose (205). The process of labelling can be a personal statement. On the other hand it can be attributed by other individuals and by statements such as "you look pale today" (190).

#### **2.7.1.5 Consulting behaviour**

Most patients who experience illness symptoms develop an explanatory model. More frequently than doctors realise, they attribute these symptoms to serious and potentially life-threatening medical conditions. Few patients spontaneously disclose or offer their ideas, concerns, and expectations, but present them instead as clues. Active listening is a skill for recognizing and exploring patients' clues (206). Without this communication skill, patients' real concerns often go unrecognised by health care professionals. Clues are presented as: expression of feelings (especially concern or worry); attempts to understand or explain symptoms; speech clues that underscore particular concerns of the patient; personal stories that links to medical conditions or risks; behaviours suggestive of unresolved concerns or unmet expectations. A deeper understanding by physicians of the true reasons for the visit increases patient satisfaction and improves outcomes.

##### **2.7.1.5.1 Why at times do patients appear unduly concerned?**

Sometimes there is a mismatch between doctors' ideas of illness and those of their patients. Patients often feel considerably worried by conditions that appear mild to their physicians. A qualitative study of 30 primary health care patients in Sweden found that some patient concerns arose from fears about, and associations with, family history, especially where it involved disability, mortality, or the threat of it (207). Conditions perceived to have been overlooked sometimes appeared to be a major source of concern (207). The need to seek urgent attention is mildly related to socio-economic deprivation, but a lack of available appointments, is more strongly related to the perception of urgency (208).

##### **2.7.1.5.2 The need for explanation**

The disturbing reality of disease experience gives rise to questions such as "why me?" and "why now?" The offering of a diagnosis is not enough, and anxiety will be alleviated only if some indication is given of how the situation might have come about (209).

Women from less skilled and socially deprived backgrounds favour infection, heredity, family susceptibility and agents in the environment as causes of disease (210). They tend to reject natural degeneration and the idiopathic as explanations, and found inevitability and randomness frightening. Their models of disease processes were in principle no different to, or less sophisticated, than medical science, but often incorrect. Their ideas come over in simplistic terms, but they still look at a problem from different angles, acknowledging multiple causation and risks (210). They stress the importance of knowing about cause, attempt rational explanations, and note the importance of linking together life-events. It may be inappropriate to over-simplify, and increased consultation may result from poor explanations (210).

#### **2.7.1.5.3 What happens in consultations when perceptions differ?**

Studies of somatisation disorders help us to understand what happens when patients' and doctors' perceptions are poles apart. Patients perceive the explanations of most doctors as being at odds with their own thinking; their respective viewpoints are not merely disparate but in conflict (211). Patients are convinced of their own perceptions of the reality of the circumstances and view doctors' information as limited and fallible. Their understanding of symptoms involves weighing and scrutinising doctors' explanations along with other sources of information but most explanations fail to connect, causing a feeling of rejection. Negative test results are equated with absence of cause and labelling illness is perceived as stigmatising or an indication that doctors don't understand, or believe, the symptoms (211). If doctors acquiesce with patients' medical explanations for their symptoms, the collusion, whilst not viewed as rejection, undermines patients' confidence in the previous openness or even the competence of their doctor. On the other hand patients are empowered by explanations that impute tangible, usually physical, causal mechanisms, for which they cannot be blamed, and shared management that invokes internal adjustments or suggests external factors that can be influenced (211). Such explanations are consistent with patients' essentially physical conception of the body and its functions (212).

## **2.8 MEDICAL MODELS AND HEALTH BELIEFS**

Medical models are not homogenous and consistent, and there is no uniform standard of 'Western' or 'scientific' medicine. Though international, there are enormous variations in the way 'Western-style medicine' is practised in different parts of the world, and both between and within countries (190). Each physician has a repertoire of interpretative

models e.g. biochemical, immunological, genetic, environmental etc. with its own unique perspective on a disease (213). The perspectives of psychiatrists will differ from the perspectives of surgeons, but at the same time multiple and manifestly contradictory models are used by different psychiatrists in explaining mental illnesses e.g. psychosis (204). Medical models are also not static and can be affected by scientific discovery (190). Recently, changes in medical education and a greater emphasis on personal, sociological, and anthropological perspectives of health and illness have significantly influenced the practice of medicine. Patients presenting over a period of time may find themselves being managed in new and different ways. I have summarised some of the well-established models that seem relevant to the series of studies on UTI.

### **2.8.1 FOLKLORE AND THE FOLK MODEL**

Physicians, as individuals, and as members of specific groups, are immersed in folk culture as well as being part of the ‘medical world’. They bring with them assumptions, experiences, prejudices and inherited folklore from family, community, religion or social class. Physicians may impose their own cultural values unconsciously. Folk beliefs can not only survive the impact of scientific medicine, but can actually be reinforced by the contact (214). Episodes of illness frequently occur outside and separate from the health care system (203, 214) but non-compliance may also occur after 30% of prescriptions. Non-compliance is taken as evidence of disjointedness in beliefs (214).

The folk model of health belief has four diagnostic categories arranged effectively in a “two-by-two” table: one axis consists of hot or cold, the other wet or dry conditions (214). Wet conditions are those where temperature change is accompanied by other symptoms and abnormal amounts of body fluid e.g. urine. Dry conditions on the other hand, have no such extra symptoms. In colds and chills, the abnormal temperature change is seen as by-product of a personal battle with the natural environment, especially with areas of lowered temperature. Damp or rain (wet) or cold winds or draughts (dry) can penetrate the skin and cause similar conditions within the body. Wind at body temperature is viewed as merely ‘fresh air’, though especially older people may consider cold air harmful.

Peripheral areas of skin are seen as more vulnerable e.g. colds occurred after getting wet feet. Juxtapositions of hot and cold environments such as walking on a cold floor whilst having a fever were seen as harmful. Environmental temperature changes are viewed with suspicion e.g. autumn, or returning home after a trip to hotter climates. Cold moves round the body after it has entered: ‘damp feet’ causes ‘stomach chills’ or other illnesses (214).

Colds and chills are one's own responsibility, unlike fevers, and are due to carelessness or lack of foresight. Fevers are thought to be due to invisible, malevolent, entities: bugs, germs, and viruses. Folk remedies emphasise the return to normality by treating cold with hot drinks or food, a warm bed, or generating body heat by tonics or food. Other remedies stress the need to dry up excess fluid returning illness from a wet to a dry state (214).

## **2.8.2 THE HEALTH BELIEF MODEL**

The health-belief model is the most widely used approach to the explanation of medically-based actions (215). Some primary care studies are based on this model, though most use variations rather than the original template (187, 215). It assumes that subjective health considerations determine how people act, such as consulting their GP (216). The original model considered that consultation was determined by the value placed on a goal (desire to avoid illness etc.) and the belief that a specific action will achieve that goal (attendance/treatment etc.) (217). Subsequent variations considered that consultation is triggered by: the perceived threat to health, including severity; the extent to which the patient believes a consultation will be effective in reducing the threat; and, 'cues to action', which might be internal (symptoms) or external (media, interpersonal interactions) (187, 215). Pain, disruption, the embarrassment associated with symptoms and their familiarity also predict attendance (218). The way people perceive their complaint may differ considerably from the way the complaint should be viewed objectively (219). The perception of threat is itself influenced by general health values, specific beliefs about seriousness, and vulnerability to disease. The more benefits, and the fewer barriers people perceive, the greater the possibility that they will consult their GP (215). The frequency of symptoms, duration, or awareness of cause and concerns about general health don't predict consultation. Patients may consult to obtain more information, rather than medical treatment, and the perceived efficacy of self-care is an important factor in behaviour (215).

### **2.8.2.1 Criticisms of the Health Belief Model and socially-based belief models**

This model can be seen as researchers' attempts to force people into a pre-determined theory of their choosing (220), or in other words, a self-fulfilling prophecy. The model may give insufficient attention to the populations being studied, and there may be a lack of critical awareness about the changing of beliefs after events have taken place (220). People may discuss their ideas in interview situations, relating to the interviewer - interviewee relationship itself and may be reticent, or wish to conform to social 'norms' or expectations e.g. not being a "moaner" (220). People tend to justify illnesses to allow expressions of

illness to be seen as within the bounds of normality or acceptability (221). It is also difficult to assess the extent to which individuals hold shared ideas about health and illness, how these originate and are maintained, and the inconsistency in people's attitudes and what this implies about health in everyday life (220). Social pressures or habit, may act as triggers to consultation and the model may apply differentially across social-class (220).

Based on the philosophies of Emile Durkheim, an alternative position argues that understanding is not individual, but social, involving collective representations that make the world tangible (222). Whilst this allows for previously ignored social factors, it relies on an assumption that illness and health are social conditions, which is only partly true.

A model based on social identity theory suggests that individuals define themselves in terms of the characteristics of a particular social group. GPs may, therefore, voice opinions based on an accepted biomedical model. Women sufferers may compare themselves to those with more severe disease, as the model predicts a bias towards making comparisons in a way that will enhance, or at least maintain self-esteem (199).

### **2.8.3 DYNAMIC HEALTH BELIEF MODELS**

A variation of the health belief model suggests that illness explanations are dynamic entities whose adequacy is determined by their usefulness within the extra-medical social environment (223). Illness explanations can be used to justify social action, either internally or externally, and may exonerate socially unacceptable behaviour e.g. stopping being a carer. The model states that patients adapt their biomedical explanation in ways that make sense in terms of particular prior understanding, and that folk explanations are more functional and resistant to change than previously thought (223).

A study of women with indeterminate symptoms shows that their understanding is an iterative process, based on prior history, ongoing experience, and the social world from which they come, and is affected by a physician's input. Women constantly try out, adjust and rework their concept of illness. The influence of the physician wanes with time and is least influential in chronic disease. Many women adopt the parts of the physician's explanation that are consistent with their own ideas and further explanations come from observing family and friends, and incorporating life circumstances. Major determinants of behaviour appear to relate to women's background and life situation. (223).

#### **2.8.4 EXPLANATORY MODELS**

This model was a response to the public perception of a crisis in medical care due to intolerable costs (in the USA), inaccessibility, and dissatisfaction with the quality of medical encounters (203, 204). This perception grew during a time where biotechnology had greatly increased its potential to make a decisive difference in individual patient encounters (203). Despite the passage of more than thirty years, and transference to a different health care system (the UK) the issues appear to have changed little.

In this model patient-doctor interactions are viewed as transactions between explanatory models (203). Generally, separate models exist for patients and doctors, and understanding is achieved through a discussion. The system is based upon the concept of disease and illness as separate entities. Patient and doctor models, however, deal with similar issues: 1) aetiology; 2) onset of symptoms; 3) patho-physiology; 4) course of illness (including type of sick role - acute, chronic, impaired – and severity of disorder); 5) treatment. Patient explanatory models deal with some or all of the issues of the doctor's model, but are not fully articulated, tend to be less abstract, may be inconsistent and self-contradictory, and based on erroneous evaluation of evidence (203). As with other models they may reflect social class, cultural beliefs, education, occupation, religious affiliation, and past experience with illness and health care.

#### **2.8.5 PRACTICAL APPLICATIONS OF MEDICAL MODELS**

Patient beliefs are correlated with their own physician's practices (224) e.g. high antibiotic prescribers see patients who expect antibiotics; in addition these practitioners are most likely to ignore current evidence-based practice.

##### **2.8.5.1 Medical models and the consultation**

Consultations run more smoothly when there is concordance of health beliefs. The extent of congruence between physicians' and patients' beliefs plays an important role in determining how patients evaluate their physicians, although satisfaction with a specific visit and overall trust may be determined differently (225). In one study of consultations, approximately 9% of the patients had one or more unvoiced desire(s), more commonly regarding referral or physical therapy. Patients with unexpressed desires tended to be young, undereducated, and unmarried and were less likely to trust their physician; physicians also evaluate these encounters as requiring more effort. Holding an unvoiced desire is associated with less symptom improvement (226).

Eliciting the patient model gives the physician an insight into the beliefs that a patient holds about his illness, as well as personal and social meanings, expectations, and therapeutic goals. In the 1970s Kleinman proposed that physicians are trained to ask some simple direct questions to elicit patients' explanatory models and therapeutic goals, and that notes should be problem-based (203). Modern primary care consultations are aided by a number of consultation models. Universally they encourage the physician to elicit ideas, concerns, and expectations, and some encourage doctors to elicit the health beliefs of their patients and to include these beliefs in their explanations.

### **2.8.5.2 Complementary medicine and health beliefs**

For many chronic problems, patients' reported improvement might be greater after encounters with 'marginal' and 'folk' practitioners than with modern physicians. This is in part ascribed to smaller social class differentials between patient and practitioner, an increased emphasis on "explanation", and a greater concordance between the explanatory systems of healer and patient (203). Folk practitioners provide personal and culturally meaningful explanations (203). Chiropractic's success over conventional medicine for back pain is attributed to a greater interest of practitioners, their skill at handling illness problems, and an ability to provide explanatory models conforming to popular health belief (227). This doesn't mean that they eschew western medicine: physical therapists, especially if younger, express a wish to learn more about evidence-based practice (228).

### **2.8.5.3 Some examples from studies of health beliefs in specific diseases**

There are no studies that concentrate on the health beliefs of women with UTI. In this section I have summarised a selection of studies on health beliefs in other diseases that illustrate concepts relevant to UTI: URTI for the concept of infection and antibiotic use; bowel problems for the impact of severity of the complaint and of the source of health beliefs; menorrhagia for the difference between illness and disease; and all for underlying worries and the triggers to consulting professionals about their problem.

#### **2.8.5.3.1 Upper respiratory infections**

Most mothers of children with otitis media hold beliefs congruent with the biomedical models of doctors. A divergence of beliefs is more noticeable when it comes to the role of antibiotics, and in some aspects of causation (229) e.g. a bacterial aetiology is a popular explanation for the common cold (230). Failure of treatment, and recurrence, can cause certain treatment options to be labelled as 'stronger' (229). Family and friends are an important source of information for parents and some ethno-medical beliefs e.g. teething



and cold weather leading to ear infections (229). Parents worry about long-term hearing problems as well as the more immediate problems of loss of sleep (parent and child) and uncertainty about how to make their child feel better (229). Adults and parents of children who seek medical care very early for an upper respiratory infection do not appear to be different in clinically important ways (231).

Mothers attending a GP about their child's cough are concerned about long-term chest damage and fear that their child will die from choking, asthma or cot death (232). Loss of sleep through worry is a common trigger for consultation, and antibiotics are seen as agents to break up phlegm rather than their actual role in bacterial destruction.

#### **2.8.5.3.2 Bowel problems**

Patients with inflammatory bowel disease construct a personal concept of 'health-related normality' and fight to maintain this as a way of coping with their illness (233).

Consulting behaviour in irritable bowel syndrome relates to perceived severity (abdominal pain and distension), and concerns about the significance of symptoms e.g. possible cancer (234). Primary care studies of beliefs in irritable bowel syndrome differ from secondary care studies, no doubt as a result of the different populations and experiences.

In a study of infant constipation, mothers report learning about stool habits from previous personal experience, written materials, and their own mothers. The impact of health-care professionals on their knowledge was minimal (235).

#### **2.8.5.3.3 Menorrhagia**

Women have a precise understanding of their complaint, so that a change in their cycle indicates to many women that they have a problem, without reference to outside criteria (236). Women attach particular importance to how they feel and their ability to function. They reject the medical emphasis on evaluating blood loss. Many are dissatisfied with consultations and think doctors dismiss their problem (236). They seek explanations for why their periods have changed and their concerns relate to their understanding of menstrual bleeding. They are unsure whether period problems could be described as illness, and what range of disturbance is normal. It is suggested that a illness model is more appropriate than a disease model for the majority of women with this complaint (236).

## **2.9 USING QUALITATIVE RESEARCH**

### **2.9.1 QUALITATIVE RESEARCH: AN OVERVIEW**

Qualitative research is a field of inquiry in its own right. It crosscuts disciplines, field and subject matters. It has separate and distinguished histories in various fields including psychology, medicine, anthropology, and sociology (237). A complex, interconnected family of terms, concepts, and assumptions surround the term 'qualitative research'. It involves a naturalistic approach to the world and encompasses a number of traditions and methods connected to cultural and interpretative studies (237).

Most qualitative research shares an operational framework with quantitative research. Both commonly start with a question, define a method for obtaining data, involve data collection and subsequent analysis, and draw conclusions, but they differ in five ways: the use of positivism and post-positivism; the acceptance of post-modern sensibilities; capturing the individual's point of view; examining the constraints of everyday life; securing rich descriptions (238). In positivism (a quantitative approach) it is contended that there is a reality to be studied, captured and understood, whereas in post-positivism (a qualitative approach) reality can never be fully apprehended, only approximated (239). Qualitative research produces multiple meanings. This challenges the basic tenet of positivism, the dominant mode of explanation for the last four hundred years or so (240). Qualitative research also uses an iterative-inductive rather than a hypothetico-deductive process (240).

Qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them (237). They are an integral part of the process, expected to reflect on their influence on data collection in stark contrast to the controlled artificial environment of experimental research, where the researcher is an apparently neutral observer, distant from the research setting (240). Interpretative analysis concentrates on understanding the views of research participants; it makes explicit the distinction between participants' views and the researchers' interpretation. It accepts that there are different co-existing interpretations of any phenomenon and attaches equal importance to each (240). Often analysis of qualitative research begins during data collection and shapes the ongoing process (241). In general, qualitative research does not seek to quantify data (241).

Qualitative research involves small numbers to allow handling the large quantity of data. It sees people as unique, each in a specific context, and takes this into account in the process

of analysis. In contrast, quantitative research investigates individuals as a member of a group, a process that diminishes the effects of individual contexts (242).

## **2.9.2 WHY IS A QUALITATIVE APPROACH RIGHT FOR THIS PROJECT?**

Qualitative research attempts to discover the detail and range of what is happening without the use of measurement, whereas quantitative research tries to measure it (242). Qualitative methods can give the intricate details of phenomena that are difficult to convey with quantitative methods (12). Qualitative research can address research questions central to primary care that are difficult to investigate by other means (243). Areas that lend themselves to qualitative research include the consultation, the doctor-patient relationship, and patients' perspectives. There is plentiful evidence about the bio-medical nature of UTI, its diagnosis and management, but very little about the perspectives of UTI sufferers and the health professionals who advise and treat them. This search for understanding in the diagnosis and management of cystitis can only be obtained by a qualitative approach.

### **2.9.2.1 The holistic nature of illness and qualitative research**

The distribution of problems presented to family practitioners differs from that experienced by our hospital colleagues. Only 15% of patients have disease that requires active treatment (244). Many health problems fit the description of 'undifferentiated illness', 'care' is seen as important as 'cure', and illness is considered in the context of family and community life (188). UTI is likely to need active intervention, but the concept that disease is more than antibiotic treatment is important and well suited to qualitative interpretation.

### **2.9.2.2 Patient perspectives**

The perspectives of patient and provider may differ on both the definition and treatment of illness (245). Professionals share beliefs but refer to them as knowledge (246). There are various sociological perspectives on why doctors think, or appear to think, like this, varying from a lack of consciousness regarding sociological perspectives to theories of medicalisation of illness, and even Marxist theories on the ulterior motives of doctors (242). Nevertheless, rational and fruitful discussion is possible even if health professionals and patients don't share a common framework of basic assumptions (247).

The ability to elicit patients' ideas, concerns, and expectations is fundamental to doctors' ability to be effective within consultations (248). Lately, the concept of eliciting patients' health beliefs has further refined this concept (249). It is important to provide explanations relevant to patients' perspectives, and to collaborate so as to increase commitment and

adherence to plans. This increases the effectiveness of therapy (250). Modern medical education embraces these values, but whilst the best may incorporate these elements into their consultations, many GPs at the end of their vocational training fail to show these skills. Despite presenting a highly selected set of consultations 14% show no ability to explore health understanding (248). In an earlier study of recently graduated students, 70% made no attempt to discover patient's views and expectations (251). An alternative method is to discover patients' ideas for individual complaints, so that medical science itself, rather than consultation skills, allows health professionals to uncover the patient perspective.

## **2.10 GROUNDED THEORY**

### **2.10.1 GROUNDED THEORY: AN OVERVIEW**

Grounded theory is a widely used qualitative research methodology that seeks to inductively distil issues of importance for specific groups of people, creating meaning about those issues through analysis and the modelling of theory (252). It is distinguished by an emphasis on method and a structured approach to data collection and analysis (253), and was devised in response to criticisms of qualitative research as impressionistic and lacking structure and credibility (254, 255). Rooted in the symbolic interactionist school of sociology, grounded theory focuses on the meanings of events to people and the symbols used to convey that meaning (256). Although clearly a qualitative method, it endeavours to integrate the strengths inherent in quantitative methods with qualitative approaches (257).

Glaser and Strauss described grounded theory as “a strategy for handling data in research, providing modes of conception for describing and explaining”. The principle aim is generation of theory from data, realised through comparative analysis (254, 258), involving both inductive and deductive approaches (259). A many-faceted process, it requires time and theoretical sensitivity to move from data to theory and back (260, 261)

All qualitative methods can be used to explore substantive areas about which little is known or about which much is known to gain novel understandings (259). Grounded theory is particularly well suited by the nature of its process, to researching areas where there is little prior information about a topic (258, 262, 263).

### **2.10.2 THE GROUNDED THEORY ‘FAMILY’**

Grounded theory is a popular research methodology that is evolving to account for a range of ontological and epistemological underpinnings (252). Just like many theories,

philosophies and religions - qualitative research methodologies fulfil the definitions of all of these - grounded theory has expanded and diversified from its original concepts.

### **2.10.2.1 What is the real grounded theory?**

There are conflicting opinions and unresolved issues regarding the nature and process of grounded theory (263), which can be viewed as a package of research methods. The use of methodology that includes the use of concurrent data collection, constant comparative analysis, theoretical sampling and memo-ing can be viewed as grounded theory (264). These mechanisms create an awareness and an appreciation of the scientific merit required and promote quality standards relating to practices in grounded theory methodology (264). Researchers adopt and adapt the methodology to fit with a variety of ontological and epistemological positions that determine the form of grounded theory that they undertake (252), and those who use grounded theory are challenged to continue contributing to its development, while justifying and debating methodological modifications (265).

### **2.10.2.2 'New or old' grounded theory**

The original concept of grounded theory included the requirement that the researcher has few preconceived ideas about the topic (266). This approach is maintained by Glaser (261). Strauss, however, takes a less purist approach in later years, suggesting that the 'grounded theory approach' can be used where there is already some knowledge about the research topic, but a new view is sought (12). Glaser argued that this new method should be termed 'full conceptual description' (267). The differences between the two versions seem to centre on the researcher's role, activity, and level of intervention in relation to the procedures used within the data analysis process (257). Both sets of protagonists, however, agree, that central to this process is the emergence of theory building (268, 269). Some studies purporting to be grounded theory, however, appear to force the appearance of theory rather than letting it emerge (270).

#### **2.10.2.2.1 Constructivism**

Constructivism is a philosophical approach to some methodologies. Constructivist grounded theory has its foundations in relativism and an appreciation of the multiple truths of subjectivism (252). Constructivists believe that scientific knowledge is constructed by scientists and not discovered from the world (271). Although implicit in grounded theory, especially the Strauss and Corbin version, this philosophy overtly allows the grounded theorist freedom to interact with participants and to take an active role in the construction of theory based on the multiple realities of their experience.

### **2.10.2.3 Being true to grounded theory- does it matter?**

Since the development and introduction of grounded theory, the number of studies that purport to be using a grounded theory method has grown enormously. While the originators acknowledged that it was entirely appropriate for the methodology to evolve and develop, some of the studies that claim to be based on grounded theory share little methodological similarity, and at times bear only a passing resemblance to Glaserian grounded theory (270). The key issues for a grounded theory study are avoiding methodological slurring, ensuring theoretical coding occurs, using predominantly one method of grounded theory, and explaining any deviation away from this chosen method. Such mindfulness and the resulting methodological rigour are likely to increase the overall quality of the inquiry and enhance the credibility of the findings (263).

### **2.10.2.4 Mixed methodologies**

To better understand the subject matter, researchers employ a wide range of interconnected interpretative practices, sometimes more than one in each study. There is no standard set of methods, and it isn't always useful to use the same technique for every step of a project (272). Each practice makes the world visible in a different way (237).

For pragmatic reasons medical research often adopts a generic approach to qualitative methodology, including elements of phenomenology, ethnography and grounded theory (273). A failure to explicate qualitative methodologies, however, may result in research that is mislabelled or is classified broadly as qualitative and subject to charges that qualitative research lacks rigour (256). A review of qualitative nursing research found that terms such as 'content analysis' and 'grounded theory' were used in non-rigorous ways and incompatibility between the underlying research approach and implementation of the method was identified in the cases of phenomenology and grounded theory (274). These two methodologies appear particularly susceptible to blurring, despite their different perspectives and origins: phenomenology, a philosophical theory, seeks to describe psychological structures; grounded theory, aims to explain social processes (256).

The similar approaches in the early stages of the research may in part explain why researchers blur the two methodologies. Listening to respondents recounting their stories is prominent during the early stages of grounded theory; later theoretical sampling based upon the emerging theory brings a sharper focus to subsequent interviews (254, 258). The Heideggerian tradition of phenomenology also demands that the researcher develops and refines their interviews as their exposure continues – similar to grounded theory!

Despite the benefits of introducing rigour, some argue that the production of a plausible story matters more than semantic arguments about methodology (275). Others suggest that to build dense, well-developed, integrated, and comprehensive theory, a researcher should use any or every method at their disposal, keeping in mind that a true interplay of methods is necessary (272). Novice researchers are encouraged to select the method that best suits their cognitive style and develop analytic skills through doing research (276).

### **2.10.3 THE PROCESS OF GROUNDED THEORY**

Traditionally, a research process is imitated by identifying the phenomena and by naming the research problems. After the data has been collected and analysed, the results and conclusions are reported. When the grounded theory approach is used, however, the research does not necessarily follow the chronological stages of the traditional research process (269). Rather than begin with theory and setting out to test it, grounded theory begins with an area of inquiry and allows whatever is theoretically relevant to emerge (12). Researchers may not know what the essential matters are in the early stages, and the research question may even change during data collection (268). The procedures of making comparisons, asking questions, and sampling based on evolving theoretical concepts are essential features of this methodology (269).

#### **2.10.3.1 Data management and the development of theory**

Data collection, analysis and the formulation of theory often take place at the same time. This can be a problem for researchers, causing difficulties in shaping the research process as a whole (260). Sampling is theoretical: themes and categories emerging during analysis drive the selection of participants and data. A conceptual framework is verified by further data collection and the process continues until each concept is saturated (256). Emerging substantive theory should be readily modifiable and relevant to the people concerned (261). Further development of substantive theory leads to the creation of formal theory.

#### **2.10.3.2 Sampling**

##### **2.10.3.2.1 Theoretical (or purposive) sampling**

This is the process of data collection employed in grounded theory whereby the researcher collects, codes, and analyses data, and decides what to collect next and where to find it in order to develop the emerging theory (254). It also enables validation of concepts and hypotheses as they are developed. Those found not to 'fit' can then be discarded, revised, or modified during the research process (269). Thus sampling decisions evolve during the research process itself (12).

Some suggest that theoretical sampling is a term interchangeable with purposeful sampling (263), and in the early stages of a study theoretical sampling does involve the purposeful selection of a sample (277), or it may be directed by the literature. Others believe the two are different: purposeful sampling involves the calculated decision to sample according to a preconceived set of dimensions, whilst theoretical sampling involves no such decisions (263). Perhaps, the practice of mixing methodologies has led to this confusion.

#### **2.10.3.2.2 Width of sample**

The choice of a wide and diverse sample or a more ‘focused’, narrow, concentrated sample should be directed by the conceptual level of the theory (254): this is dictated by the wish to generalise findings, or to apply it only to the type of groups studied. Some degree of selective sampling, however, may be desirable, as it may be impossible to address the whole research phenomenon (260). In initial interviews, researchers choose interviewees with a broad general knowledge of a topic (278). Initial data collection requires full coverage, but subsequently, it requires only collecting data on categories, for the development of properties and propositions (279). The first set of data can set the tone for further theoretical sampling (280), but an initial group with too narrow a (or an unusual) focus will inhibit the emergence of early theory. Purposeful sampling may be useful, therefore for both the first and second interviews, with theoretical sampling thereafter (263) to ensure that a broad overview is available before theoretical sampling is applied.

#### **2.10.3.2.3 Sample size and theoretical saturation**

Whereas selection of participants is a function of the emerging hypotheses, sample size is a function of theoretical completeness (256). The criterion for judging when to stop sampling is theoretical saturation. Saturation occurs when no additional data is being found where the researcher can develop the properties of a category (or theory) (254). A theory is saturated when it is stable in the face of new data and rich in detail (279). Additional cases should serve specific purposes within the overall scope of the project and may be: chosen to extend the emerging theory; chosen to replicate previous cases, thus testing the theory; or chosen as an opposite view to extend the theory (281).

#### **2.10.3.3 Maintaining objectivity**

The objectivity and detachment of the original grounded theory approach was described as a ‘smash and grab’ approach (252). However, Glaser advises that preconceived ideas risk introducing bias to the interpretation of data (261), and previous knowledge may direct the research and make it more difficult to find a new point of view (282). Having few



preconceived ideas may create a sense of detachment from the research, which may be difficult for novice researchers (260), and presumably, also, for experienced researchers new to the research topic.

Self-reflection may prevent the blurring of boundaries between notions rooted in the researcher's knowledge and experience, and those communicated by research participants (283). Researchers may use reflexivity to identify areas of potential bias and to 'bracket' them (suspending their ideas) so their influence on the research process is minimal (284). The researcher may also keep a diary of personal responses, build in time for discussion with other members of the research team, and incorporate individual responses into documents associated with data analysis (theoretical memos/ analytic notes) (283).

#### **2.10.3.4 Data collection in grounded theory**

Data collection usually involves 20 to 30 interviews with informants theoretically selected (255). Grounded theory embraces all manner of data collection (266). Different kinds of data allow different perspectives, which enhance understanding and develop its properties. Often researchers will predominantly use one technique but theoretical sampling allows a multifaceted investigation (254). Combining different types and sources of data can be synergistic and increases reliability. Interviews and observations may be supplemented by documents, videotapes, or data quantified for other purposes (269).

Sensitising questions help researchers tune into data and its meanings: theoretical questions for process, variation and connections among concepts; practical and structural questions to direct sampling and to help to develop evolving theory; guiding questions for the interviews' observations and analyses - these change over time based on evolving theory, generally becoming more specific and less open-ended as the research progresses (269).

#### **2.10.4 ANALYSIS OF A GROUNDED THEORY PROJECT**

Analysis is the interplay between researchers and data (12). It is a balance between science and creativity. Researchers can try to be as objective as possible, but in a practical sense it isn't entirely possible (269). Experience and knowledge sensitise researchers to significant problems and issues in the data, facilitating alternative explanations and recognizing properties and dimensions of emergent concepts. Experience acts as data itself, but researchers need to employ considerable self-awareness when using it in their analysis (269). In grounded theory, data analysis has a well-defined process that begins with basic description and moves to conceptual ordering and then theorizing (285).

#### **2.10.4.1 Coding**

Coding is an iterative, inductive, yet reductive process that organizes data, from which the researcher can then construct themes, essences, descriptions, and theories (257). The ‘schism’ in grounded theory is also apparent in analysis. The disconnect between Glaser and Strauss lies in their different perspectives regarding the data analysis process, specifically the procedures used (257). The traditionalists approach analysis in a structured manner, whereas Strauss and Corbin state that techniques and procedures are tools of analysis but should never drive the analysis (269).

##### **2.10.4.1.1 The Constant Comparative method of analysis**

This method of analysis is integral to grounded theory methodology, characterised by a free-flowing and creative process in which analysts move quickly back and forth between types of coding (269). It involves drawing information from the data collected and comparing it to emerging categories i.e. periods of data collection alternate with periods of analysis. Theoretically, every new piece of information received should provoke a review of strategy, but in reality data collection inevitably occurs in blocks, whether the data is in the form of focus groups or a piece of text.

##### **2.10.4.1.2 The three stages of coding**

Traditional grounded theory moves in a step-by-step process through different stages of coding: axial coding, representing core categories, follows the initial stage of open coding. The final step is selective coding, where the researcher identifies a ‘story’ and writes a narrative that integrates all the categories in the axial coding (266). Theory generation is associated with selective coding. The first two stages, whilst specific to grounded theory, bear similarity with other forms of qualitative analysis with significant iterative processes. The level of development and specificity clearly distinguish coding in grounded theory from other qualitative methods (257). The earlier stages of coding may be divided into the sequential activities of description, conceptual ordering, and theorising (269). The third stage, selective coding, leads to the formation of hypotheses. Researchers may relate the analysis to social, economic, political, and historical factors of influence. This latter stage of analysis is not often seen in grounded theory work from primary care.

##### **2.10.4.1.3 Microanalysis**

A new concept in grounded theory analysis, microanalysis is most suited to the beginning of a research project to uncover the relationships among concepts. It involves scanning interviews for interesting or relevant analytical materials, rather than coding every bit of

data (269). It involves listening closely to what the interviewees are saying and how they are saying it. Analysts consider the plausibility of data and suspend judgements whilst it is broken apart and reconstructed in an interpretative way.

### **2.10.5 OUTCOMES OF GROUNDED THEORY PROJECTS**

The outcome of a grounded theory study is the production of a plausible relationship between concepts or groups of concepts. This is presented in the form of a narrative statement, a visual picture, or a series of propositions or hypotheses (269). When the data collection and analysis are complete, the literature can be used to confirm findings and findings can be used to illustrate previous theories. Bringing the literature into the writing demonstrates scholarliness and extends, validates, and refines knowledge in the field. Researchers shouldn't feel insecure about their discoveries, and checking the published literature, to validate or negate every finding, hinders progress and stifles creativity (269).

### **2.10.6 WHY IS GROUNDED THEORY RIGHT FOR THIS PROJECT**

It is essential that the particular methods chosen are consistent with the research question being asked and that they are clearly defined in the research report (256). Grounded theory is ideally suited to elucidating behaviour as the participants understand it, learning about their world, their interpretation of self in the interaction, and sharing their definitions (286).

#### **2.10.6.1 Grounded theory suitability to health care**

Grounded theory studies have been conducted in a wide range of disciplines including sociology, nursing, anthropology, health science, business and management (263). The epistemological underpinnings of grounded theory make it valuable in the study of nursing, which is based on an interpersonal process between nurses and clients (262). This focus is on understanding, explaining, and/or predicting human behaviour, allowing exploration of human responses to health problems (287). Nursing research, perhaps, has embraced qualitative research and grounded theory to a much greater extent than other medical disciplines, but the same concepts apply.

#### **2.10.6.2 Grounded Theory application**

With specific previous knowledge of the subject, it could be argued that grounded theory is an inappropriate choice. Constructivist and 'modified grounded theory' perspectives are, however, comfortable with this position if objectivity is safeguarded. Certainly, I had well-formed ideas about the management of UTI, but despite my medical experience, only a superficial knowledge of patient perspectives. I hadn't used the Internet for information sheets or advice on UTI, and had been intrigued as to why some doctors rejected emerging

evidence. Thus, I was studying areas of relative personal ignorance. Previous studies on symptoms (3) and beliefs (4) produced predominantly descriptive outcomes from generic methodologies, allowing scope for more interpretative studies. Objectivity was maintained through the use of independent interviewers, 'bracketing' to limit personal influence on data collection, and multiple analysts from different backgrounds. My aims were to produce minimally biased original data, and to rely on the structured nature of grounded theory analysis to maintain this balance. Unusually for a grounded theory project, I have provided more raw data for the reader to independently draw conclusions. The complex, sometimes contradictory, views we collected necessitated many revisions of the analysis before I could reach the point of substantive theory.

## **2.11 DISCOURSE ANALYSIS**

### **2.11.1 WHAT IS DISCOURSE ANALYSIS?**

Discourse analysis is a way to make sense of the ways in which people make meaning (288). It can be subdivided into three groups: formal linguistic, empirical, and critical discourse analysis (CDA) (289). I used CDA in the study of metaphor in order to draw meaning from women's use of language when describing their experiences.

### **2.11.2 TYPES OF ANALYSIS**

Formal linguistic discourse analysis, involves a structured analysis of text in order to find general underlying rules of linguistic or communicative function behind the text (289). It involves microanalysis of linguistic, grammatical, and semantic uses and meanings of text. Researchers using empirical discourse analysis do not use highly structured methods to code individual words and utterances in detail (289), whilst scholars who situate themselves within the CDA tradition often separate their work from other forms of "non-critical" discourses analyses by arguing that their analyses move beyond description and interpretation of the role of language in the social world, toward explaining why and how language does the work that it does (288).

Analysis in CDA is more formal than the other two varieties. Fairclough's analytic framework (290) is constituted by three levels of analysis: the text, the discursive practice, and the socio-cultural practice. The analysis of text involves the study of the language structures produced in a discursive event. An analysis of the discursive practice involves examining the production, consumption, and reproduction of the texts. The analysis of socio-cultural practice includes an exploration of what is happening in a particular socio-

cultural framework (290). In our project we didn't formally use Fairclough's framework but embraced the concepts of CDA. We sought in particular to compare linguistic content and structure to the socio-cultural context of women with UTI.

### **2.11.3 QUALITY IN DISCOURSE ANALYSIS**

The mark of a high quality study is clear documentation of the sources of information used and delimitation of data sources, including a description of decisions made with regard to selection of groups or individuals for interviews, focus groups, or observation, and, importantly, a description of the context of the study (289). The method of analysis should be clearly explained, including assumptions made and methods used to code and synthesise data. It is important that researchers describe the ways in which their own individual socio-cultural roles as they may influence their perspectives (289).

## **2.12 CONTENT ANALYSIS**

Content analysis has been defined as a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding (291). I used this method of analysis in the studies of Internet information.

Content analysis is a well-established technique on its own, but also forms the basis of other specific methodologies such as grounded theory. It has various applications, one of which is to examine trends and patterns in documents (291). Studies in health care research have used content analysis to identify themes in newspapers (292) or on the Internet (293).

There are two approaches to coding data that operate with slightly different rules: emergent coding, and a priori coding (291). With emergent coding, our method of choice, categories are established following preliminary examination of the data. Two people independently review the material and come up with a set of features that form a checklist. Next, the researchers compare notes and reconcile any differences on their checklists. Thereafter, the researchers use a consolidated checklist to independently apply coding and regularly assess the reliability of the coding (291). Rigour in content analysis is judged in the same way as other qualitative methodologies.

## **2.13 FOCUS GROUP RESEARCH**

### **2.13.1 DEFINING FOCUS GROUPS**

Focus groups are a form of group interview that capitalises on communication between research participants in order to generate data, and explicitly uses group interaction as part of the method (294). They involve a relatively homogenous small group of individuals

purposefully selected by the researcher to address a specific topic (295). The presence of a moderator to probe and clarify responses (296) is integral to the composition of focus groups (297). They are used as a methodology as well as a means of collecting data (298).

### **2.13.2 PURPOSE OF FOCUS GROUPS**

Research using focus groups is usually exploratory or explanatory (295). They are particularly useful where investigators wish to establish quickly a range of perspectives on an issue of importance among different groups (299). Focus groups have the “potential to uncover important constructs which may be lost with individually generated data” (300), achieving powerful interpretative insights through synergies (301). Researchers encourage participants to talk to one another, ask questions, exchange anecdotes and comment on others’ experiences and points of view (294), creating an audience for one another (302).

Focus groups are said to be stronger on breadth than depth (299), reproduce community attitudes and patterns of practice, and explain the reasons behind findings (295). The format allows insights into subjects’ perceptions to emerge which are not evident in individual interviews (303), and are an ideal way to explore beliefs and attitudes. In contrast individual interviews are more suited to documenting knowledge and practice (295). The exception to this rule is that focus groups may be useful for topics which are habit-ridden or not thought out in detail (297). Biographies and learning about individual informants are not features of focus groups.

Focus groups are also ideal for exploring peoples’ experiences, opinions, wishes, and concerns. Questionnaires are a good way to quantify such data, but focus group research is better for exploring how points of view are constructed and expressed (302).

### **2.13.3 DISTINGUISHING FEATURES OF FOCUS GROUPS**

Focus groups are a “broad umbrella” that include many variations (297). Focus groups are structured and are, therefore, more formal. Formality implies that the researcher’s power is enhanced; however, focus groups function to decentre the role of the researcher (301). Some focus groups defy these criteria; their degree of formality is determined by the nature of the research topic (297). As well as general formality, they are distinguished by inviting participants, and the distinctive role of the moderator (304, 305). Other suggested criteria include the size and use of specialised facilities for the interview (306).

### **2.13.3.1 Group size**

There seems to be no hard and fast rule on this. The size of group is determined not by any pre-set formula but is determined instead by the ability of a group to maintain adequate discussion, and by the amount of detail that researchers need to hear from participants (297). Eight appears to be the median number for quotes of ideal size (294, 297, 299, 302, 307). Groups of three and groups of twenty have been convened for different purposes (297) and some researchers prefer to work “with five or six participants, or as few as three” (302). Lately, the concept of mini-focus groups has become more established, generally taken to mean four to six participants (308). Some medical studies use less than the ideal numbers of interviewees (309). The group size may vary depending on its nature: fewer for homogenous groups; more participants when looking for disconfirming evidence (310).

Larger groups may fragment more easily, may require greater moderator control, and can be difficult to document. Moderator involvement is necessarily high in larger groups (297); this may not suit all research styles or aims. Small groups lend themselves to situations where the participants are highly involved in the topic, and are respectful of other members of the group (as interpersonal dynamics are more disruptive when groups are smaller).

### **2.13.3.2 Group structure**

Focus groups may be run in a structured, unstructured, or intermediate manner (297). Structured groups are most useful when research questions are already well developed. Moderator involvement is high (308), standardised interview schedules are used, and group discussion is likely to be comparable from one group to the next. Tangential issues are unlikely to be addressed. The structured approach is useful when it is deemed necessary to make consistent comparisons between groups (more likely in divergent groups), or where a new set of participants are being compared with a previous set of groups (297).

### **2.13.3.3 Group types**

Focus groups may be comprised of different participants e.g. strangers and friends, or involve diverse group tasks, e.g. brainstorming, consensus (302). Hybrids of the various group types on offer may be developed, using them in multi-method studies as well as refining stand-alone group methods to address a wider range of issues (302).

#### **2.13.3.3.1 Strangers or friends?**

Market research texts insist on groups being held with strangers to avoid ‘pollution’ and ‘inhibition’ (302). Acquaintances may rely on assumptions, rather than voicing potential

differences (311). Thus, the rule of thumb prefers strangers to acquaintances (297). Not all projects are held in circumstances where participants can be strangers and issues around self-disclosure may be easier to deal with where there is prior acquaintance (312). Unless a particular group dynamic is critical to the research, then practical concerns on availability are more important than decisions based on participants' prior acquaintances (297).

#### **2.13.3.3.2 Pre-existent groups**

Social science researchers prefer to work with pre-existing groups (302). The naturally-occurring group is a most important context in which ideas are formed and decisions made (302). Pre-existing groups may share attributes of participant observation groups (an ethnographic tool) (297): such groups allow observation of fragments of interactions that approximate to naturally occurring data (294). Other advantages of participant observation may also be realised: collection of data on a wider range of behaviours; a greater variety of interaction with the study participants; a more open discussion of the research topic (297); the ability to fit the research session into established meeting slots (302), which might reduce the loss of participants, unable to fit around a researcher's schedule.

#### **2.13.3.3.3 Homogeneous (or heterogeneous) groups?**

Participants are more likely to share experiences and feelings with people whom they perceive to be like themselves in some way (313). Most researchers aim for homogeneity within groups to capitalise on these shared experiences (294). Diverse groups explore more perspectives within the group setting (294), but group dynamics may be a problem.

#### **2.13.3.3.4 Brainstorming groups**

Brainstorming is frequently used in medical education to generate ideas and discussion on new topics (314). They produce exploratory information (304) and are often informal, less directed by interviewers or unstructured, and may need little in the way of preparation (302). Limited research, however, suggests that groups do not generate better thoughts than individuals (315). They may be most effective for aiding consistency and reliability amongst individual responses, as participants are more thoroughly challenged by their peers (307). Brainstorming groups may provide a good introduction for novice researchers as they tend to be fun and are easier to moderate (307).

#### **2.13.3.4 Sampling**

Imaginative sampling is crucial (294). Participants are selected to reflect a range of the total study population or to test particular hypotheses and specific groups of people who



possess the characteristics relevant to the phenomenon being studied are identified (316). An initial mixed group may be useful: subsequent segmented groups can be compared and if the differences in perspectives are insignificant, then fewer groups will be needed (297). ‘Samples’ shouldn’t be mixed across status or authority lines for ethical reasons as well as the fact that the discussion tends to be uncomfortable or even conflict-ridden (317).

#### **2.13.3.4.1 Segmentation**

Homogenous sampling may be segmented e.g. sufferers of a particular condition may best be divided into different gender, age, race, social class or lifestyle-groups to promote maximum discussion (297). Under-segmentation may be inhibitory, but over-segmentation may lead to flat discussion. The goal is homogeneity in backgrounds, rather than in attitudes (297). Multiple segmentation strategies are more complex, and capture a wider range of distinct perspectives (318) and are similar to an experimental design (319). The guidance on focus groups, however, overemphasize the extent to which researchers can control for all characteristics of participants which are likely to be relevant; some details are likely to emerge only once discussion has been initiated and the precise composition of groups will often be the product of circumstance rather than planning (302).

#### **2.13.3.4.2 How many groups?**

The rule-of thumb is three to five, based on the claim that more groups seldom provide meaningful new insights (297); this concept of saturation is also integral to grounded theory (266). Each focus group tends to have unique characteristics and it is best to include enough groups to balance the idiosyncrasies of individual sessions (320, 321). These idiosyncrasies may consist of unusual participants or unusual group dynamics (321). Formats that bring together more heterogeneous groups, thus generating greater diversity of opinion, will require more groups. Two focus groups of eight participants are said to be equivalent to ten individual interviews (315). Availability of participants will affect either the number of groups, the size of the groups, or both (297).

#### **2.13.3.5 Recruitment**

Inadequate recruitment efforts are the single most common source of problems in focus group projects (322). Locating participants and recruiting them to the project is only half of the story; actually getting them to turn up on the day is equally important (322). “No-shows” can be neutralised by over-recruiting by 20% (297). Over-recruitment should take into account who the participants are, where the research takes place, whether they are

being paid, and how critical the size of the group is to the success of the task (297). Inherently, smaller groups are at the mercy of one or two individuals not turning up.

### **2.13.3.6 Specific issues in focus group research**

#### **2.13.3.6.1 Sensitive issues**

The close and trusting relationship engendered by qualitative research, which isn't present in the anonymity of quantitative research, is well suited to the study of sensitive topics (243). Focus group research has been used for topics such as AIDS research (323), advanced directives (324), and domestic violence (325).

Traditionally, researchers considered focus groups inappropriate for handling sensitive issues (313), and preferred one-to-one interviews and questionnaires. Groups, however, can encourage open conversation about embarrassing subjects and facilitate the expression of ideas and experiences that might be left underdeveloped in an interview (318) although this may be dependant on the group composition and topic (326). They allow for 'safety in numbers', and may encourage the participation of those who are wary of the interviewer or who are anxious about talking (294). Sometimes less inhibited members break the ice for shyer participants (294). Homogeneity of the group may help as it is not productive to ask people to talk with discussion partners with whom they are not comfortable (297).

When focus groups are used to research sensitive issues, an exaggerated response may be observed: participants may be more, rather than less likely to self-disclose and share personal experiences (313, 317). The group identity may allow greater candour (326, 327), and provide a more dynamic atmosphere than individual interviews (326). The balance of power may shift away from researchers in groups, facilitating discussion of awkward topics. The tendency to report only socially desirable thoughts or behaviours in one-to-one interviews is counterbalanced by peer support in the group format (326). Over-disclosure can lead to a serious invasion of privacy that could be regretted at a later date, without the ability to retract (317). There are no specific strategies to avoid this ethical problem (297).

#### **2.13.3.6.2 Gender and focus groups**

Gender may be important in determining success. Women are used to sharing thoughts, a process which translates naturally to focus group interviews (318). Men, in contrast, are more sensitive in individual interviews (328).

#### **2.13.3.6.3 Feminist perspectives**

Women's experiences are important, and to understand them, women's lives need to be addressed in their own terms (329). The aim of a feminist inquiry must be to provide explanations of women's lives that are useful as an instrument to improve their situations. Focus group research is unusual in feminist research though it should be well-suited (330).

There is no 'correct' persona for focus group facilitation although some facilitators will be more appropriate for some topics and for some research populations (302). There is often an assumption that the facilitator for feminist research will be female (329).

#### **2.13.3.6.4 Negative feedback**

Focus group discussion is also more likely than interviews to uncover negative feedback (294), including comments about medical professionals (331, 332). In addition focus group participants may develop a more trusting relationship with the researcher, as they can both develop and express their own agendas as well as challenging that of the researcher (333).

#### **2.13.4 RUNNING FOCUS GROUPS**

The drawback to the researcher new to these methods is that there is no longer one standard format, which can be followed. Instead, research design for focus groups becomes a subject itself (322, 325, 334, 335). Thus, each focus group project is unique, and the research task will provide all the necessary clues for the design (307). There are four phases of qualitative research: planning; observation; analysis; and reporting (242).

##### **2.13.4.1 Planning focus group research**

Planning is more important for focus groups than other forms of qualitative research (297). Researchers produce an interview format, bring together participants, and ensure the right mix of people. Ethical concerns (e.g. consent, confidentiality and the use of audio-tape), budget issues, and time constraints should be addressed before starting (297). Time constraints may be a greater problem where the focus group work is part of a larger project, though when focus groups are the sole source of data, there may need to time built in for a return to the field to collect further information (297). Researchers need regular reflective time in-between data collection exercises to check on focus, and if necessary, to change the research question depending upon emerging themes (243).

##### **2.13.4.1.1 Venue, setting and timing**

Sessions should be relaxed: a comfortable setting, refreshments, and sitting round in a circle helps to establish the right atmosphere (294). Traditional focus groups in marketing research may operate to a stricter format (308). Hotels have neutral associations (335), and

may make participants feel considered and respected (317) but their geographical position may be a barrier to recruitment (242). Evenings may be better for working women, daytime for shift workers, and those with children (242). Presumably, neither is good for working women with children!

#### **2.13.4.1.2 Incentives and financial arrangements**

Executive focus groups often offer higher-value cash incentives; marketing groups from community samples usually accept less (297). Monetary incentives may be replaced by meaningful sponsorship (320) e.g. taking part for a community organisation.

In medical research, there is little scope for incentive payments, and the ethical background is an altruistic desire to further knowledge. Generally, incidental expenses attract payment, but incentive payments are not usually encouraged. Fortunately, people seem ready to participate in medical research despite the lack of direct incentives. The opportunity to learn more about one's own illness and to further the current research in that field for one's own or fellow sufferers future benefits may be reward enough. Informant interviews on the subject of recruitment may help before commencing the project itself (297).

#### **2.13.4.2 The facilitation process for focus groups**

In market research a 'moderator' has an authoritarian role to ensure the efficient running of a group (308). Medical focus groups are likely to be less researcher-centred and include more social interaction, compared to individual interviews. Facilitators must understand group dynamics and approaches to open questioning, as they are unlikely to be able to exert control in a way that would be possible in individual interviews. Though facilitators require substantial inter-personal skills such as the ability to listen and to facilitate without becoming so involved as to bias discussion, facilitator effects on the quality of focus groups are not well understood (317). There is a tension between active participation and passivity by a facilitator, particularly, when they share group characteristics (313).

Small group work is now common in medical education, managing change, and health promotion. There are significant similarities between these facilitators and those engaged in research activity. Key attitudes and behaviours of facilitators have been identified as the abilities: to remain neutral, to keep groups focused, to encourage participation, to protect individuals and ideas, and being positive and non-evaluative (336).

All sessions, whether structured or less structured, should begin by introducing the topic in an honest but general fashion, in order to prevent a lack of understanding and over-

direction, which in combination, can lead to restricted and channelled discussion (297). On the other hand, lengthy introductions create an expectation of autocracy. Starting questions can take the form of ‘discussion-starters’, ‘ice-breakers’, personal introductions or discussing unrelated topics. They should be easy to respond to and interesting to all (297).

#### **2.13.4.2.1 The facilitation process when researching sensitive issues**

Facilitators of focus groups involving sensitive issues set the tone and manage the flow of discussion (337). Sometimes, this may involve the use of warm-up exercises (though adults may not appreciate these), the establishment of ground rules, and a gradual move from less sensitive to more sensitive areas during group discussion (313). External facilitators bring two assets to group-based research: objectivity and the ability to emphasize that personal disclosures are solely for the purpose of improving general understanding of a topic; the other is the ability to feed participants’ views into appropriate channels (338). Whilst group cohesion and interaction is a positive process during the research phase, it is possible for this reaction to induce expectations of future action by the researcher or by the group itself (338). While the subject of cystitis is unlikely to lead to expectations that are difficult to accommodate, independent group leaders may still have an advantage.

#### **2.13.4.3 Data handling**

##### **2.13.4.3.1 Recording**

Tape recording and transcription is recommended (294). Taking careful notes and identifying key issues on a flip chart may be a substitute. Most people have few problems understanding the researcher’s need for taping to create a record of the discussions and quickly settle into a discussion that ignores the microphones and the recorders (297).

The moderator should produce field notes after each session. Sometimes administering questionnaires is useful to provide feedback on group composition e.g. social class (297).

##### **2.13.4.3.2 Analysis**

Analysing focus groups is basically the same as analysing any other qualitative self-report data (294), apart from the need to indicate the impact of the group dynamic and to analyse in ways that take full advantage of the interaction between research participants (294, 339). Researchers may focus on content rather than the process of interaction (330). One review found no examples of analysis concentrating on the conversation between participants and very few that even included any quotations from more than one participant at a time (318).

### **2.13.5 INDIVIDUAL INTERVIEWS**

Whilst there is plenty of advice about the use of different techniques or perspectives in focus group interviews, there is very little about the specifics of undertaking one-to-one semi-structured interviews. Perhaps, this is because the technique is the well-established default method of qualitative data collection, on which all other methods are based, or perhaps, it is because interviewing is almost as old as civilisation.

The main method for obtaining data for qualitative analysis is by interview (243, 299). Interviews are a flexible method of gathering data, allowing investigators to respond to the individual way in which respondents interpret and answer questions (299). They are more effective for tapping into individual biographies (302), creating a greater depth of response than questionnaires and allowing discussion of the reasons and perceptions behind statements (299). As they are more controlled, they provide a greater depth of information from each participant than focus groups (297). The dynamics of individual interviews put a greater burden on informants to explain themselves to an interviewer, so that elaboration of points requires less (or more subtle) intervention from the interviewer (311).

Interviews may be characterised as ‘structured’, ‘semi-structured’, or ‘unstructured’ (or ‘in depth’) (243, 299). Structured interviews usually take the form of interviewer-administered questionnaires; semi-structured interviews are conducted on the basis of open-ended questions around a fixed set of topics; unstructured interviews have very broad objectives and they are usually led by the respondent’s priorities and concerns (243, 299).

#### **2.13.5.1 Consultation skills or qualitative research skills?**

Practising clinicians routinely interview patients during their clinical work, and they may wonder whether simply talking to people constitutes a legitimate form of research (243). Modern, relaxed and patient-centred consulting styles, have many transferable skills, but the qualitative researcher’s orientation is fundamentally different from that of the clinician (243). The differences come in the power of expertise, and in structure: in a consultation, there is a structure leading to a certain set of behaviours and potential outcomes, whereas in a research interview it is the interviewee’s perception of structure that is important; in a consultation, doctors also retain power over explanation and interpretation, but this is the function of the interviewee in the research interview (243). It is best not to interview one’s own patients for research purposes, but if this cannot be avoided, patients should be given permission to say what they really think and shouldn’t be corrected if they disagree with doctors (243). A common problem is that facilitators are likely to be asked questions by

interviewees during the course of an interview (243). This may undo earlier efforts not to impose their own concepts on the interview. One solution is to answer such questions at the end of the interview, although this not always a satisfactory response (340).

### 2.13.6 COMBINING INTERVIEW METHODS

Focus Groups can be used as a single mode of qualitative enquiry, or mixed with other methods, quantitative or qualitative (297). Focus groups provide direct evidence about similarities and differences in opinions and experiences, and help people to explore and clarify their views in a way that would be less accessible in a one-to-one interview (294).

**Table 3: combining interview techniques**

Based on Morgan (297). Predominant methods are in normal type.

Type	1st method	2nd method	Purpose
1	<i>Focus group</i>	Interview	Devising interview schedules in uncharted territory. Surveying multiple different populations
2	<i>Interview</i>	Focus Group	Generating group discussion guides where piloting is deemed necessary. Assessing compatibility of participants from different backgrounds/ cultures
3	Interview	<i>Focus Group</i>	Exploring issues and confirming differences from interviews
4	Focus Group	<i>Interview</i>	Providing depth and detail on topics superficially discussed in group interviews

Group discussions allow less structured interviews, an advantage where the interview's direction is harder to predict or where there are no, or minimal, pre-construction of interview guidelines (297). Group-work may, however, taint subsequent interviews (341).

#### 2.13.6.1 Are focus groups better than individual interviews?

Focus groups are different but not better than individual interviews. Group interviews do not produce more or better ideas than an equivalent number of individual interviews (315), yet focus groups are often only used to get hold of a bigger sample (342).

As well as substituting for interview, focus groups have been seen as a substitute for participant observation, an ethnographic tool. They can bring together in an unforced manner people with similar conditions and a higher degree of shared experience. This can create special bonds, especially where the condition is disabling, making such groups well suited to participant observation (297). Shared illness experience leads to the quick establishment of group identity, cohesion, and enhanced interaction. Those with varying illness experiences, less complex, or acute illnesses (e.g. occasional cystitis) may not create

such strong feelings (297). Discussion of the topic is enhanced by the presence of an active facilitator, and group pressure may inhibit misleading responses (326). Attitudes and decision-making, however, are less well suited to observational techniques (297). Focus groups are also the preferred method of observing private or habit-ridden behaviours.

### **2.13.7 INTERVIEW METHODS AND THE PHD**

The original plan was to use focus groups as the predominant data collection method in both interview studies, so that multiple diverse views could be obtained. Pragmatism, however, influenced the methods.

#### **2.13.7.1 Are patient views about cystitis a sensitive issue?**

The concept of sensitive research refers to the potential to raise strong feelings and opinions, or to pose a threat to those involved, whether researchers or participants (343). All research related to sexuality is seen as sensitive (313). Sexual activity is thought to be a common trigger for cystitis, though susceptibility is very variable amongst the population, but such an association inhibits communication between patient and clinician (4).

#### **2.13.7.2 Patient experiences**

The original plan was to use predominantly focus group research, with interviews to fill in gaps and provide depth on selected issues (see Table 3). The switch to individual interviews occurred earlier than planned due to a high number of participants failing to 'turn up on the night', and, therefore, we moved from a Type 4 to a Type 1 approach. As the subject matter is largely uncharted, either approach was suitable, and the brainstorming and non-UTI groups had ensured a good spread of views before we altered course.

#### **2.13.7.3 Professionals views**

Unlike patient experiences, medical knowledge is charted territory, though the underlying drivers of actions are poorly documented. We successfully employed a Type 4 approach. Many groups were pre-existent and simple to recruit. Registrar groups provided cultural heterogeneity and other groups were selected for certain characteristics determined by theoretical sampling. We undertook a few individual interviews to clarify specific issues with selected professionals, often those with executive or supervisory roles. These interviews were a significant source of divergent views.

## **2.14 ACADEMIC RIGOUR AND THE PHD: PROSPECTIVE CONSIDERATIONS**

In all forms of research the basic strategy to ensure rigour is systematic and self-conscious research design, data collection, interpretation, and communication (316). The research



design should be detailed so that it can be fully understood and, if necessary, reproduced. The report should also carry sufficient conviction to enable someone else to have the same experience as the original observer and appreciate the truth of the account (344). Extreme relativists hold that every research perspective is unique and equally valid in its own terms, but this position means that research cannot derive any unequivocal insights relevant to action and commands little support (345). All research is selective - there is no way that the researcher can in any sense capture the literal truth of events - and depends on collecting particular sorts of evidence, each of which has its strengths and weaknesses (316).

#### **2.14.1 BIAS**

Professional experience is a potential source of sensitivity, enabling a researcher to move into an area more quickly as they are familiar with the surroundings or events, but it can also block perception (269). Reflexivity may limit the effect of prior knowledge on the analysis of data (346). Researchers should compare perceptions with what is actually stated i.e. the analyst uses experience without putting their experience into the data; and they should concentrate on how research participants see events (269). Ultimately, high quality data analysis depends on the skill, vision, and integrity of the qualitative researcher (241).

#### **2.14.2 REPRODUCIBILITY AND RELIABILITY**

Purposive or theoretical sampling strategies maximise reproducibility by minimising bias that arises from the selection of samples on the basis of convenience (316). Meticulous records of interviews or observations and documenting the process of analysis in detail ensure retest reliability (316). Computer programs, or using more than one analyst, may improve the consistency or reliability of analyses, but the appropriateness of inter-rater reliability in qualitative research is contested, except where researcher bias is especially likely to be perceived to be a problem (241). Good qualitative analysis documents its claim to reflect some of the truth of a phenomenon by reference to systematically gathered data; poor qualitative analysis is anecdotal, unreflective, and descriptive without being focused on a coherent line of inquiry (344). Data should illustrate rather than dominate the analysis and the most reflective and insightful analyses use quotations sparingly and lists of data extracts indicate under-analysis (240). On the other hand, fully complementing textual analysis with data ensures that readers can judge the reliability of outcomes for themselves. The solution of making full transcripts available would be cumbersome (316), and might breach the conditions for ethical approval. A partial solution is to present extensive sequences from the original data followed by a detailed commentary (316).

### **2.14.3 VALIDITY**

Validity is improved by triangulation, respondent validation, and deviant case analysis. Comprehensiveness may, however, be more important than internal validity (345).

Triangulation compares the results from either two or more different methods of data collection (e.g. interviews and observation) or, two or more data sources (e.g. members of different interest groups). Some consider that triangulation is an alternative to, rather than a tool of validation (347). It is controversial as a genuine test of validity because it assumes that weaknesses in one method will be compensated by strengths in another, and that it is always possible to adjudicate between different accounts (345). Triangulation may be better seen as a way of ensuring comprehensiveness and encouraging a more reflexive analysis of the data than as a pure test of validity (345). Whilst feasible in theory, in practice the types of data gained from different qualitative methods may not be entirely compatible. The production of similar findings provides corroboration and reassurance; the converse, however, that the absence of similarities refutes a theory is not true (345).

Respondent validation, or 'member checking', compares the investigator's account with those of the research subjects to establish the level of correspondence between the two sets. Study participants' reactions to the analyses are then incorporated into the study findings (316). Alternatively, interviews or focus groups are re-run with the same people so that their reactions to the evolving analysis become part of the emerging research data (316).

### **2.14.4 RIGOUR IN GROUNDED THEORY**

Constant comparison relies on fluid and skilful application of analysis rather than rigid adherence to procedures (269). A safeguard in support of rigorous analysis is attention to observations inconsistent with the previously developed sensitised theory (283). Such conflicting findings (divergent or disaffirming views) contribute to a more detailed and comprehensive understanding of the phenomenon under study (283). In contrast to quantitative research, consistency over time can be a threat to validity of findings within an interpretative paradigm, where multiple realities exist (348). Bland data may reflect different perceptions from lay and medical perspectives (269), and grounded theory shouldn't force a position. Discrepancies between a researcher's data and the findings reported in the literature should stimulate the researcher to ask what is going on; to check if they are overlooking something important; and to consider whether conditions are different in their study. They should consider how differences affect what they are seeing (269).

Triangulation uses complementary sampling strategies (e.g. typical and deviant cases), complementary methods of data collection (e.g. observation and interviews), and multi-disciplinary involvement and review of data analysis to prevent one set of interpretations to dominate (349). Triangulation is inherent in grounded theory research projects, which use several methods of data collection. Researchers look for patterns of convergence to develop or corroborate an overall interpretation (316). Triangulation allows the researcher to obtain the varied meanings and interpretations of events, actions, interactions, and objects that can be built into theory (269). Grounded theory, however, just needs credible theory rather than respondent validation (256); occasionally it fits the concept of grounded theory, when participants are also the intended recipients of the final theory (270).

#### **2.14.5 PITFALLS IN QUALITATIVE RESEARCH**

Ideally, research is planned, designed, and neatly carried out, but in reality it is a messy affair (269), involving a lot of going back and forth and around before finally reaching one's goal (272). This doesn't reduce the validity of the research but means that it rarely proceeds completely as planned (269). Data collection may further be affected by errors such as equipment failure; environmental hazards; and transcription errors (350).

#### **2.15 HOW WAS RIGOUR APPLIED TO THE PHD?**

At the start of the PhD I was idealistic about incorporating rigorous processes, but at times pragmatism prevailed. I have outlined my background and starting bias in section 1.5 p4.

Grounded theory itself is characterised by well-defined processes with inherent rigour and objectivity. Its suitability and contribution to the quality processes of this PhD is discussed earlier in this chapter (2.10.6 p.51 and 2.14.4 p.66). I tended to a constructivist approach, which allows flexibility of methods as long as theoretical principles are maintained (351). We adjusted our plans for data collection, originally balanced focus groups and individual interviews, according to emerging theory, but allowing for recruitment opportunities and problems. For constant comparison we sometimes used summaries and field notes rather than full transcripts, especially when appointments for one-to-one interviews came in quick succession. Full transcription could take weeks. A team of independent researchers from complementary backgrounds helped me throughout, providing balance and ensuring that reflexivity was addressed at an early stage. Axial coding was undertaken separately and meetings between analysts convened in order to negotiate agreement on selective coding. Substantive theories also emerged from these meetings. We presented interim findings to

academic groups – academics, primary care clinicians, anthropologists, and methodologists - and incorporated feedback in our analysis.

To increase objectivity during interviews, we employed ‘bracketing’, a process which behoves the facilitator to suspend their thoughts on the subject matter (269). This was felt to be particularly relevant for ‘expert’ interviewers, and for interviewers who were also acting as analysts, and once they had become fully immersed in the data. To compensate for the impersonality of this process we offered discussion after the taped interviews were complete. When a lay interviewer offered this in one-to-one interviews, they reported back to myself before re-contacting the participant with feedback.

To maximise validity we decided to use complementary sampling techniques, multiple methods of data collection and non-traditional sources of data (e.g. popular media), and a multi-disciplinary panel for data collection and analysis. Informal triangulation through clinical interactions occurred throughout the project. Constant comparison and the consequent development of theory appear incompatible with respondent validation, since the research output is further from the raw data than in other qualitative methodologies. Studies that return to the original participants to validate theory are operating beyond the boundaries of grounded theory (270). We used respondent validation to compensate for a technical hitch in our first focus group (re-inviting members to a later group) and as part of iteration for the (two) individual doctor interviews, but it contributed little.

When analysing data, qualitative researchers are faced with a dilemma: to remain true to their methodology by emphasising interpretation or to openly demonstrate reliability and reproducibility through extensive reporting of original data. I chose the latter course, since connections between data and grounded theory outcomes are less obviously linked than in other disciplines and rely on the reader’s trust in descriptions of the processes.

The Internet and metaphor studies use simpler methodologies appropriate to the subject matter and available data. We declined to apply generic methods in order to increase objectivity and rigour. A systematic application of a multi-disciplinary analytical process was a key element of both studies.

Metaphor in doctor-patient communication was for me a novel concept. The study was conceived during an analysts’ meeting, and it subsequently became clear that this was a separate line of enquiry rather than substantive theory. Sampling used the patient groups, and the analysis was largely retrospective, so there was little opportunity for introduced biases. Later interviews with patients and all with health professionals addressed metaphor prospectively, providing a degree of triangulation.

The Internet study used a purposive method: the first twenty sites were chosen on the basis that patients were unlikely to search beyond these unless they were looking for something specific. The Internet study also included a quantitative scoring system based on an internationally recognised quality statement. I employed binary scoring agreed by both analysts for all but two criteria, minimising the potential for bias. The scoring for the remaining criteria related to a computer-generated score for readability and the number of years from the last update of the site, both objective. The scoring for these criteria was decided upon before the calculation of the total scores and ranking of the sites to prevent contamination.

## **2.16 SUMMARY OF THE RATIONALE FOR THE PHD**

UTI is a common condition that has significant personal and economic costs. It took many years for streamlined management of UTI to be well-accepted and embodied in a national guideline (10), but increasing concerns about antibiotic resistance have caused a rethink of these policies. In order to decide on future management strategies it is most important that we consider patients' and doctors' ideas, as these will be crucial to policy change.

Social science research is increasingly recognised as relevant to general practice (188), and there is an awareness that doctors' own feelings and values will influence the way in which they practice medicine (352). Patient ideas (250, 353) are central to the consultation. Research on concerns and health beliefs in UTI will help doctors to understand women's' rationale for seeking care.

## CHAPTER 3 PATIENT EXPERIENCE OF UTI

*Creating a new theory is not like destroying an old barn and erecting a skyscraper in its place. It is rather like climbing a mountain, gaining new and wider views, discovering unexpected connections between our starting point and its rich environment. But the point from which we started out still exists and can be seen, although it appears smaller and forms a tiny part of our broad view gained by the mastery of the obstacles on our adventurous way up. (Albert Einstein)*

### 3.1 INTRODUCTION

In previous chapters, I found support for the idea that symptoms of UTI could be more important in the diagnostic process than tests. It is important, therefore, that we understand patients' views of their illness, their reasons for consulting, as well as their expectations of management.

In this chapter, I will present the aims, background, methods, results, discussion and conclusions of my first project – a qualitative study of patient experiences. This, the first of three related studies, began with the sole purpose of validating patients' symptoms. I hoped to provide evidence that properly validated symptoms and disease descriptions could be used as specific pointers to the presence of UTI. Previous studies had suggested that they were helpful, but no single symptom or combination of symptoms was sufficiently reliable for accurate clinical diagnosis. During the PhD, emerging evidence reduced the need for proof that symptoms predict UTI, and I soon found that we were capturing a greater depth of patient experience than previously published in the medical literature, no doubt due to the more intensive qualitative nature of our work. After discussions with my research support team, we expanded the remit of this study, continuing it to the natural conclusion of a full qualitative study, the point of saturation of data for all the main themes rather than our original narrower aims of a supporting study.

Women's use of metaphor in their narratives was a new and unexpected avenue of enquiry. Our handling of this observed phenomenon, its background, and its underlying academic basis all differ significantly from other patient experience data. I have, therefore, accorded it a chapter of its own.

This study uses grounded theory methodology and a range of interview techniques to uncover the wealth of data on patient experience of UTI. This chapter deals with themes identified from the breadth of patient experience, from the recognition of symptoms, through patients' interpretation of their illness, to their interactions with health professionals and their disease management.

### 3.2 AIMS

A qualitative study to obtain women's views on symptoms that suggest to them that they have cystitis and to find out what would make them consult. The study aims to discover women's ideas and beliefs regarding cystitis, its symptoms, management and untoward effects, and to compare their ideas with common health belief models.

### 3.3 BACKGROUND

Two papers (3, 4) had provided information on women's ideas and experience of UTI before I began this study. During the later stages of the PhD the qualitative section of an HTA project (7) also published relevant findings.

A questionnaire-based study (3) used a narrative technique to provide descriptions of the symptoms of cystitis and the natural language that women use. A cohort of 196, average age 44, but including some older women (range 19-97), was recruited from a primary care setting in Norway. The selection method is unclear, but most likely convenience sample based on consultations for cystitis. The nature of the questionnaire and analysis is also unclear, apart from the inclusion of an open-ended question about symptoms. The authors categorised responses according to narrative descriptions, probably from this one question. Three categories relate to classical symptoms: dysuria is represented by "*a terrible scorch when the bladder is nearly empty*"; frequency and urgency by "*frequent need to void, although just a few drops will come, sometimes so suddenly that it may go wrong*"; back and suprapubic (lower abdominal pain) by "*constant ache in the low back, belly and the genital area*". The authors list another two categories that fit less precisely into standard medical models: "*symptoms localised elsewhere in the body*" and "*miserable and no good in the whole body.*" As the study was conducted in Norwegian, it is possible that translation may have influenced the descriptions and use of medical jargon.

In a study from the UK, 99 women were interviewed over the phone, and 14 responded to a questionnaire (4). Women were asked one open question on the cause of their symptoms, and a further closed question on risk factors, though there appears to have been room for some individual responses. Analysis appears predominantly quantitative and the sample selection appears opportunistic. Almost half the women thought that their UTI happened by chance ('just one of those things'). Around 10% considered that stress, childbirth or operations, and sexual intercourse were causatory. 5% or fewer considered that menstruation, food and drink, or a chill had caused their illness. In response to the second

question, 39% thought sexual intercourse was a risk for UTI, 28% drinks (coffee/ tea, alcohol, fruit juices acidic drinks equally), 27% hygiene, 19% clothes, and 8% foods. Perhaps, women attribute their UTI to risk factors only if they can see a definite connection. When freely responding some women mentioned the risk from wiping back to front, tight jeans, bubble baths, cross-infection from a partner, reduced fluid intake, over-spicy or yeasty foods, and 21 cited nylon tights or underwear. Contraception was considered a cause but the Pill was blamed as much as barrier methods.

Only a fifth of women reported that doctors asked about the aetiology of their UTI. Women rejected some explanations, as there was a lack of detail or a mismatch with their beliefs e.g. honeymoon cystitis (in a married woman); a 'short urethra' and many couldn't remember what had been said. A third of women felt that talking to their doctors about UTI was embarrassing, but a fifth thought their doctor was embarrassed or diffident.

A nested qualitative study (7) identified the journey from 'person to patient' that begins with symptom onset, continues with symptom recognition, action or waiting, and often ends with seeking medical help. The focus of this study was the validity of a proposed strategy of delayed prescribing for UTI in the light of women's symptom experiences and health beliefs. 20 women were opportunistically sampled (five with first-time infection) from a cohort assembled for the quantitative study. The study team used analytic induction, an ethnographic tool, which, like grounded theory, is an iterative method that approaches data analytically, searches for 'deviant cases' (though not in this study), and seeks to generate theory. Analytic induction, however, concentrates on causation, and tests as well as generates theory that is universally applicable, and, is therefore more precise and limited (266). Researchers define provisional theory early in the analytical process, and data saturation is not used as the end-point.

In this study, women recounted experiencing multiple symptoms and signs concurrently, and drew on previous experience to decide on their significance. The authors categorised women's response according to Schumann's Illness Model and identified the triggers to consultation: no alleviation of symptoms; escalation of symptoms or long duration; disturbance of normal social or vocational functioning; concern that this was, or could become, a serious illness. Women worried about spread of infection to the kidneys and the appearance of blood in the urine. The key to the success of a delayed prescription strategy was considered to be addressing women's concerns about a 'watch and wait' strategy,



though the study found that many already tried to put off treatment with antibiotics and preferentially used self-care methods, especially fluids and or cranberry.

All three studies provide limited information. The two that pre-date my PhD used simple questionnaire or telephone interviews, techniques unlikely to uncover the full qualitative richness of women's views and experiences of UTI. The subsequent HTA study uses individual interviews and more complex methods but is limited by its subjugation to a larger quantitative study and the focus on verifying an a-priori theory about the use of delayed prescriptions. There is, therefore, ample scope for more definitive research.

### **3.4 METHODS**

#### **3.4.1 RESEARCHERS**

Focus group moderator: Mrs. Audrey Dougall (AD);  
Individual interviews: Mrs Nicky Hall (NH);  
Data analysis: Dr James Larcombe (JL); Dr Iain Edgar (IE); Mrs Nicky Hall; Prof. Pali Hungin (PH).

#### **3.4.2 PARTICIPANTS**

Most of our participants were women with a history of one or more UTIs. One focus group included women with no history of UTI. The brainstorming groups involved a wide spectrum of participants, including men and women with no prior history of UTI.

#### **3.4.3 DATA COLLECTION METHODS**

I planned to use focus groups of women to provide the majority of the information.

In-depth individual views were planned, either to resolve ideas coming from the focus groups, or in case the focus group method was inappropriate or inhibitory.

Initial focus groups were intended to represent a cross-section of the population of women with a history of UTI. Later sampling was theoretical, either recruiting from under-represented groups or backgrounds, or recruiting participants who were deemed most likely to help in theory development.

#### **3.4.4 INTERVIEW SCHEDULES**

We began by meeting the brainstorming group; its large size and interactive nature necessitated a more structured approach. The initial interview schedule comprised questions on current knowledge of infections; who it affects; its importance; and expected management. The results from this group helped to inform our later questions. Further changes to questions occurred in the manner of constant comparison dictated by grounded

theory. We relied on field notes and initial summaries rather than full transcript analysis for this process. The reasons for this were two-fold: firstly, interviews were scheduled to meet both interviewer and interviewee availability; secondly, transcription and analysis couldn't be guaranteed in the intervening time.

The schedules included warm-up and warm-down questions: women's feelings about attending the group/ interview and having attended, and questions on social and illness background to provide feedback for our sampling strategy. Questions became progressively more searching, starting with agreeing definitions and terminology, before progressing to narrative descriptions on experiences, addressing understanding of symptoms, effects (both what and whom), perceived causes, fears and concerns, and actual and expected management.

### **3.4.5 MODERATORS AND INTERVIEWERS:**

I took some initial soundings from adult women patients attending my surgeries. These suggested that discussing UTIs in detail would not pose a problem or cause embarrassment, despite suggestions that UTIs were a potentially sensitive subject. These soundings were undertaken prior to the production of the research protocol, and application for ethical approval. However, we decided to be cautious until further proof was forthcoming from our initial interviews and began with same-sex interviewers/ moderators rather than myself. We also felt that experience in biomedical qualitative research, but without particular knowledge of UTI would be an advantage, though grounded theorists debate the necessity of this.

### **3.4.6 RECRUITMENT AND SETTING**

Our initial recruitment strategy for the focus groups was based on our experience with brainstorming group and from previous literature.

A 50% response rate to an invitation to attend a focus group has been suggested as usual but we allowed for as little as a 30%, in keeping with a colleague's experience (242). The response was still poorer than expected, causing us to alter strategy and to rely more heavily on the semi-structured interviews that were scheduled to follow the focus groups.

#### **3.4.6.1 Focus groups of women with a history of UTI:**

##### **3.4.6.1.1 Identification of potential participants**

We identified potential participants in a number of ways, appropriate either to available information sources in the three collaborating practices, or to the needs of the theoretical

sampling strategy. Staff at each surgery received training to identify women from computerised disease registers or clinical notes.

We thought that few women would be erroneously identified as having had a UTI. An indication that the request to participate could have been made in error (due to the inadequacies of the search) was included in the invitation letter, and an apology given. The consent form included a section for return if this had been the case.

Surgery A: A part-dispensing practice with accurate links between diagnostic information and therapeutic interventions. All women aged 18-64 recorded as having a UTI in the last three years, or having ever received trimethoprim or nitrofurantoin on the computer database were invited to participate (n= 52). Trimethoprim was used almost exclusively for UTI in this surgery; nitrofurantoin was little used but is exclusive to UTI. We used diagnostic data for only three years as the information management system had changed. The low numbers identified (approximately half the expected numbers) highlighted that the change in computer supplier had caused significant data loss, the extent of which the practice were previously unaware.

Surgery B: Patients at this surgery live in a deprived area, in contrast to most of those at surgery A, enabling us to invite a different cross-section of UTI sufferers. It was staffed by a salaried service at the time of the searches and the computer records were not well advanced. One member of staff was instructed in how to manually search records for evidence of a diagnosis of UTI or a relevant antibiotic prescription. We applied no time limit for the documentation of a diagnosis. Evidence of UTI was deemed to be a prescription for nitrofurantoin alone or a combination of a relevant antibiotic (trimethoprim or cephalosporins) and recorded diagnostic terms (UTI, cystitis, pyelonephritis). This maximised the specificity of the search to avoid inviting patients inappropriately. The searches identified plenty of potential participants despite excluding women with questionable diagnoses. One woman wrote expressing concerns regarding her invitation, though we were able to confirm a correct diagnosis.

#### **3.4.6.1.2 Invitation to participate**

Eligible patients were sent a letter of introduction on host practice notepaper and signed by a partner (surgery A) or manager (surgery B), an information sheet, a consent form, and a stamped-addressed envelope for the reply. Interviewers contacted potential participants, using telephone numbers supplied on returned consent forms to organise focus group

sessions. We did not make particular attempts to achieve homogeneity, and the low response rate further precluded this. We relied on cohesion from shared illness experience rather than social homogeneity.

#### **3.4.6.1.3 Setting**

The Focus Groups were held on 8/7/02 and 23/9/02 in a specialised meeting room at the surgery in Sedgefield. This room is separated from the clinical areas, and was available if necessary during the day as well as on evenings. The group gathered around an irregular octagonal table. Non-alcoholic drinks and biscuits were provided.

### **3.4.6.2 Focus group of women without a history of UTI:**

#### **3.4.6.2.1 Identification of potential participants**

Surgery C (my own surgery) was used to recruit to this group. Some years previously, 43 patients had previously agreed, after random selection from our patient database, to be part of a joint 'Patient Participation Group' and research source (consent to be approached about research was included in the initial invitation to join the group). 12 were women aged 18-64. Of these, seven had no previous UTI and three were happy to be contacted. This was insufficient so I conducted a whole database search of women aged 18-64 with no diagnosis of UTI or relevant prescription. I randomly selected ten records and checked pre-computerised records for adherence to the entry criteria. A further three participants provisionally accepted the invitation to participate on the set date of 20/11/02.

#### **3.4.6.2.2 Invitation to participate**

We approached women in the same way as for those with a history of UTI. Altered (and ethically approved) letters of introduction, information sheets, and consent forms were sent to potential participants. Replies came through an audit clerk at the practice. Despite the pre-arranged date and agreement to participate, only three of the six attended the group.

#### **3.4.6.2.3 Setting**

The setting was the same as for focus groups of women with UTI.

### **3.4.6.3 One-to-one (semi-structured interviews):**

#### **3.4.6.3.1 Identification of potential participants**

Two groups of women were approached for this part of the study. Women who accepted an invitation to participate in the focus groups, but who were unable to attend were contacted again to see if they would be happy to participate in one-to-one interviews. This was a sizeable group. We felt that this approach was beneficial from a number of perspectives:

from an ethical point of view, women who respond positively, should where possible be given the opportunity to contribute; it reduced the burden on the practices for further searches or extensive individual invitations. These women did not form a homogenous group, and offered us some scope for theoretical sampling.

Clinicians at all three surgeries (two successfully) were asked to recruit a second group of women, who met criteria determined by theoretical sampling, at the time of a diagnosis of UTI. A further two surgeries picked for theoretical reasons, agreed to be involved at this stage but failed to recruit any women: one at a distance from the original three surgeries to check for geographical peculiarities; the other served a large south Asian population.

#### **3.4.6.3.2 Invitation to participate**

For women transferring from the focus group list to one-to-one interviews, an additional phone-call was made to request the use of the alternative strategy. Five interviews took place between 2/5/03 and 27/5/03. Two women were interviewed individually when a focus group (18/11/02) was severely affected by low recruitment and ‘no-shows’.

Newly invited women received verbal explanations from their clinician, information sheets and consent forms. They returned positive replies to designated boxes placed in host surgeries whereupon the interviewer telephoned to arrange dates, times and venues. To eliminate any risk of coercion the two women that I approached were invited to participate by a research facilitator after an interval of one month. One woman originally invited to the non-UTI group suffered from an infection and agreed to be interviewed in her new capacity. Women recruited for having acute and non-recurrent UTIs were interviewed between 9/4/03 and 9/10/03.

#### **3.4.6.3.3 Setting**

Participants had a choice of venues. Invariably, they chose their own home as the preferred setting. This was agreed where requested, though alternative venues (surgery or university) were available if the interviewer had for any reason felt unsafe.

#### **3.4.6.4 Brainstorming sessions:**

##### **3.4.6.4.1 Identification of potential participants**

Students at the University of Durham, Queens Campus, Stockton-on-Tees were included in both a pilot study and a session as part of the main study. The students were in their first, introductory year of a broad-based health and social science curriculum. None had come straight from school, and their ages ranged from 21 to 54. They were predominantly

female. This group were chosen for likely interest in participation, convenience and accessibility, and the ability to merge the research session into a planned seminar.

The students were split into several groups: an all-male group, a group of students with some previous experience in health-related work (e.g. nursing, care assistants), and two groups of female students (one of which had no-one with prior experience of UTI, and one with two members who volunteered that they had suffered from a UTI).

#### **3.4.6.4.2 Invitation to participate**

A week prior to the brainstorming sessions, students were given information sheets and consent forms. This was repeated immediately prior to the session (as no completed forms were received). 23/32 in the group attended (a normal attendance rate).

#### **3.4.6.4.3 Setting**

The group session was held in a large seminar room, commonly used and familiar to the students on Queens Campus, University of Durham.

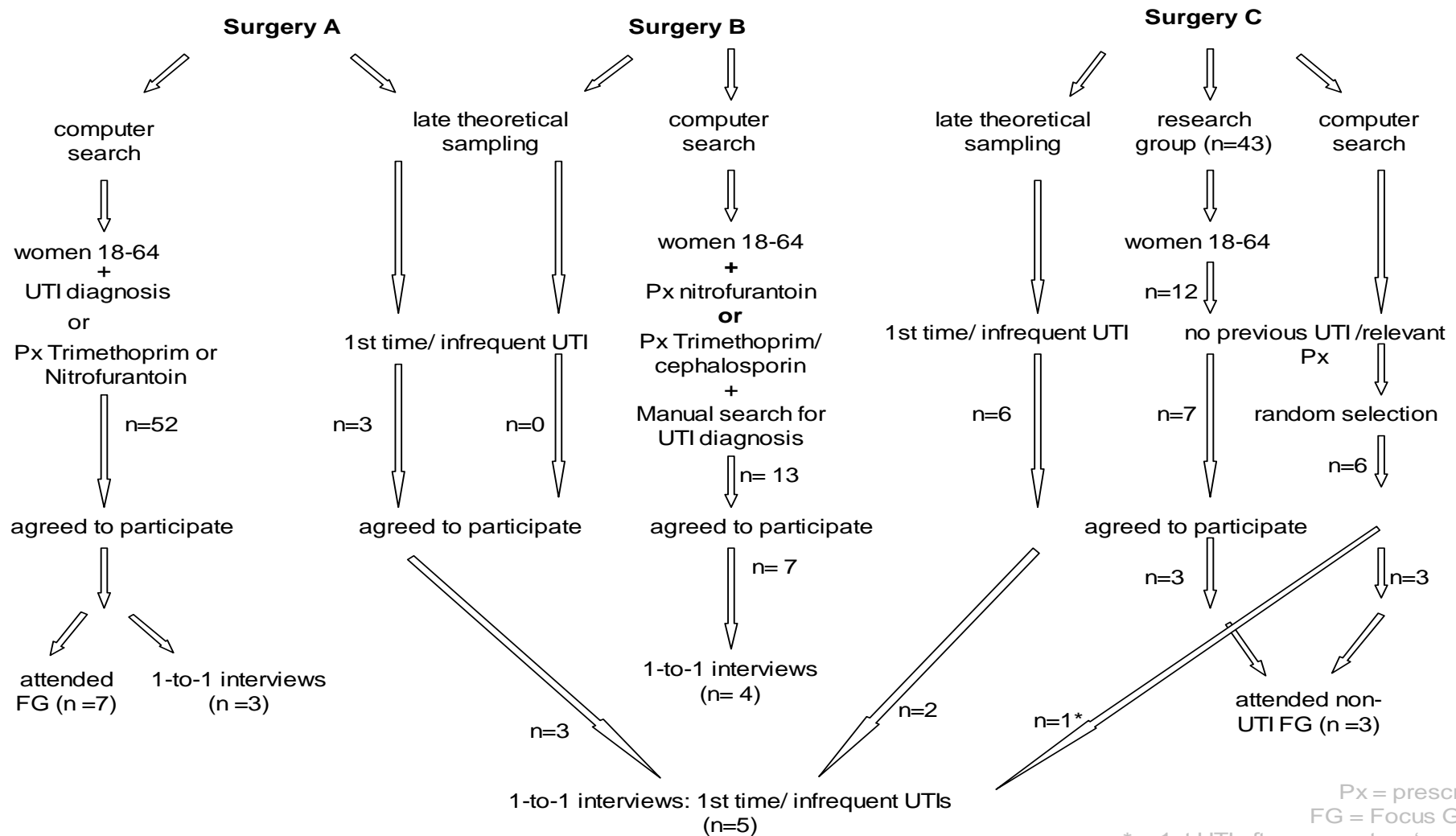
### **3.4.7 SAMPLING**

Our initial strategy was determined by the outcome of the pilot brainstorming session. This showed that moderately heterogeneous groups did not adversely affect discussions on UTI, though we did not know if the medical knowledge of our participants led to fuller discussion than expected. This suggested that a reasonable strategy was to use focus groups supplemented by individual interviews.

We sampled practices to reflect different demography and methods of working. The focus group participants, whilst representing these differences, were otherwise self-selecting. After the initial focus groups we convened a group with no history of UTI to look for divergent views. We changed to individual interviews to maintain theoretical sampling. The focus groups suffered from the combined effect of a poorer than expected response to invitations to participate and the numbers of 'no-shows' (around 30%).

Some of the early individual interviews involved women who had expressed interest in the focus groups. They were picked for ethical rather than strictly theoretical reasons. We selected further participants from previously under-represented populations. We achieved saturation through triangulation and by obtaining further divergent views. Most women in the focus groups suffered from multiple recurrences of UTI, were usually social class ABC1, and were often older. We selected later interviewees for different perspectives: they were younger, had fewer episodes of UTI, and were more often social class C2DE.

## RECRUITMENT AND SAMPLING: PATIENTS



### **3.4.8 DATA AND ANALYSIS**

#### **3.4.8.1 Data collection and transcription**

##### **3.4.8.1.1 Brainstorming groups**

Their regular tutor and I led the process. After initial explanations to the whole group and discussion on UTI we separated the participants into five groups and asked them to record their responses to the questions on flip-chart paper. The whole exercise took just over 30 minutes, excluding feedback after the session.

##### **3.4.8.1.2 Focus groups**

A medical anthropologist experienced in leading focus groups, moderated each session. I was present as an observer to capture non-verbal communication, insights into group dynamics, and to familiarise myself with the raw data. To minimise my impact (as a male and a doctor) I adopted a position outwith the group, joining them in discussion only at the end, to discuss points of fact or opinion requiring clarification. The groups were scheduled to last up to 90 minutes, though only the non-UTI group fell within this time-period.

##### **3.4.8.1.3 Individual interviews**

These were undertaken by an experienced qualitative medical researcher and audio-taped. The interviews were scheduled for one hour and lasted 45-75 minutes.

The interviewer made both field-notes and a précis of each interview so that constant comparison could occur before receiving full transcriptions. The field notes also served as records of views that weren't likely to be immediately obvious from the transcriptions. Further management was the same as for the focus groups.

#### **3.4.8.2 Data analysis**

In keeping with grounded theory analysis followed the 'constant comparative' method: open coding, proceeding to axial coding then to selective coding. In reality the stages overlapped: the methodology caused us to assemble and reassemble theories, even at a very late stage, and themes reached saturation at different points in the iterative process.

The minimum time between focus groups was one month, allowing me to perform preliminary analysis. AD and I debriefed after each session and discussed interview plans in the light of initial analysis and before the next planned session. NH and I discussed the field-notes and summaries from individual interviews in order to pick up new or developing themes and to decide on saturation. For pragmatic reasons a few of the early



interviews were undertaken in quick succession. Later interviews, when we were planning to test theory were held on dates further apart to allow prior analysis and discussion.

At least two researchers independently undertook the analyses. AD provided feedback from the focus groups; these were formally analysed by IE and me. NH and I analysed the individual interviews, immediately and more formally at a later stage. IE provided two sets of analyses at different stages in the process. All three analysts met on one occasion to plan the strategy for the final interviews. I undertook the final analysis and coding, incorporating further ideas from the overall project supervisor, PH.

Quotes were chosen because they expressed common experiences, attitudes or topics or because they showed the breadth of experiences of participants.

### **3.4.9 ETHICAL CONSIDERATIONS**

#### **3.4.9.1 Ethical approval**

Co. Durham and Darlington local research ethics committee granted ethical approval, and agreed an amendment to allow the use of individual interviews. We obtained additional approval from the University of Durham ethics committee for the brainstorming sessions.

#### **3.4.9.2 Consent**

We produced information sheets and consent forms to standard formats, and agreed by the ethics committees. Consent forms have been retained in locked cupboards.

#### **3.4.9.3 Confidentiality**

We addressed this issue in the information sheets and re-iterated it before an interview or group session. We placed particular emphasis on participants' responsibility to maintain each other's confidentiality during and after focus groups. We maintained participants' anonymity during analysis and removed potentially identifiable data.

#### **3.4.9.4 Sensitivity**

Shared illness experience was felt to be an effective method of reducing discomfort (a perception shared by participants). We made a conscious decision to tread carefully around sensitive subjects (e.g. sexual histories). However, we encountered one or two instances of over-disclosure due to the conviviality of the participants' discussions.

*"I am going to be horribly embarrassed at what we talked about, particularly as \*\*\*is \*\*\*. I am going to blush and look the other way." (FG239p21)*

Individual interviews were felt to be a more appropriate method to discuss in-depth sensitive issues, should they arise.

#### **3.4.9.5 Safety netting**

We outlined a pathway for dealing with medical, psychological, or criminal (e.g. rape) concerns but our interviewees uncovered no such matters of concern during the project. Management would have been at the discretion of the individual unless such a path was deemed to be unsafe. The participant's GP would have been informed, following appropriate consent and discussion with myself (in cases of serious concern, no consent would have been necessary).

#### **3.4.9.6 Data collection**

We audio-taped each interview and focus group after obtaining written, and just prior to the session, confirmatory verbal consent. Tapes were marked and passed to a transcriber at the University of Durham with no known connections to recruiting sites who produced electronic and 'hard copies' of the interviews as soon as practicable.

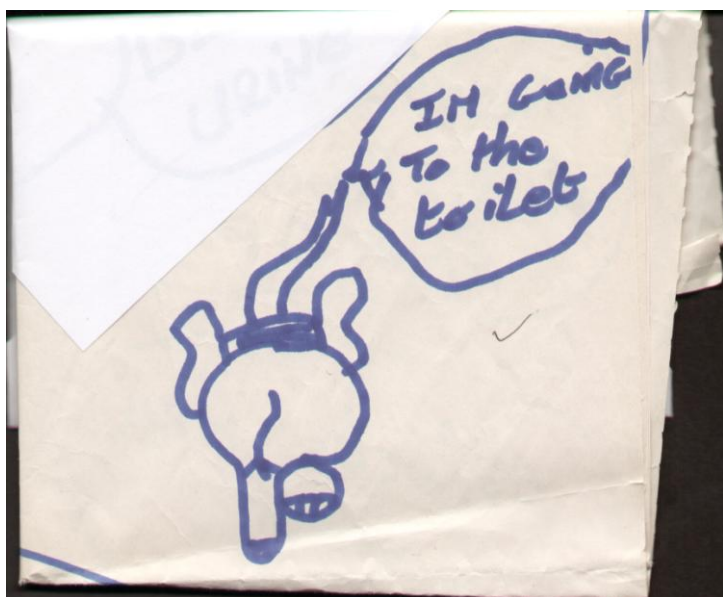
#### **3.4.9.7 Data storage**

Tapes and hard copies are kept in locked cupboards at the University of Durham and Sedgefield surgery and electronic material is stored on password-protected computers. As agreed with the ethics committees, we will keep all data for one year after publication.

#### **3.4.10 CONCLUSIONS: METHODS**

This qualitative study embodies rigorous methods, and attempts to remain true to the ideals of grounded theory. Practical constraints, however, meant that strict adherence to theory were difficult to maintain. A number of initial plans have been revised, some extensively, to respond to the needs of the research as well as barriers and problems that arose during the course of the project. Flexibility in approach was maintained, in keeping with a constructivist approach (252) so that the primary aim of discovering both the depth and range of patients' beliefs, and coming to conclusions as to how these had developed, remained an achievable goal.

## 3.5 RESULTS



### 3.5.1 HOW DO WOMEN DESCRIBE THEIR SYMPTOMS?

Medical professionals put symptoms into neat categories using medical terminology e.g.: dysuria, frequency, urgency. Women's descriptions of their symptoms can often be easily mapped to these medical terms, though their language is usually much more colourful. A feature of women's descriptions was their tendency, not surprisingly, to describe their symptoms in a more holistic or generalised way.

#### 3.5.1.1 Terminology and women's understanding

##### 3.5.1.1.1 A water infection or cystitis?

A number of women preferred to use lay terms such as “*water infection*”, “*something wrong with the waterworks*” or “*something in your water*”. Some used these terms interchangeably with cystitis; sometimes this was in response to their audience, inferring the use of a different terminology if younger and female:

*“Girls together - we all know what we are talking about type of thing, but if you go the chemist and you see a young guy behind the counter you say water infection”* (121208p3)

*“I would normally say cystitis. I wouldn't say urinary tract infection - not to a friend. Maybe water infection if you were talking to an older relative or something. It is probably an old fashioned way of talking about it isn't it - something wrong with the waterworks”* (121189p10)

Even so, most, but not all women appear comfortable with the term ‘cystitis’:

*“Water infection. I don't think many people know what cystitis means”* (12125p1)

but this participant viewed the two terms as synonymous. One woman considered a urine infection to be an acute situation and cystitis a recurrent or chronic condition:

*“a urine infection because there is some sort of bacteria in your water system. Cystitis I think is sort of an ongoing water problem”* (FGDAp1)

another describes the differences in terms of internal or external bacteria:

*“I think a water infection is something you get from a bug that shouldn't be in your body and it has got in and caused a water infection...whereas cystitis to me is the bug that should be in your body, it is just in the wrong place”* (12195p11)

#### **3.5.1.1.2 Upper or lower UTI?**

Cystitis (lower UTI) and an upper UTI are associated with different treatments and prognoses. Most women experience different symptoms:

*“you know when it is cystitis because it is that painful”* (12194p3)

*“With the kidney infection you're not dribbling...you go to the toilet properly. With cystitis it won't start, it's just dribbling backwards and forwards a thousand times”* (121274Ap25)

Experiential learning may be a significant factor in recognition as women with no previous history or only occasional episodes of UTI, seem less aware of the differences as this exchange in a focus group shows:

*“I didn't know there was a difference between a kidney infection and a water infection...I think it is much higher up... It comes from there though doesn't it...It's inflammation of your bladder I think”* (FGNp1)

#### **3.5.1.1.3 Cystitis or thrush**

Confusion between symptoms, and their causes, was common and led to many instances of misunderstandings, and in muddling of descriptions:

*“so I was confused about - if that's the case - is it because of the irritation to the area or is it because of the transmission of some sort of bacteria or bug or whatever, or is it a combination of both or what - so I am not really sure about that”* (121189p6)

Quite a few women experience both of these infections at the same time- most commonly during antibiotic treatment of UTIs:

*“When I have a urine infection I ache all over, my whole body feels it...you worry about getting it, because I hate thrush as well after taking antibiotics. It’s a vicious cycle”* (FG239p5)

Symptoms can be very similar; though some women think they can tell the difference:

*“Thrush is like an itchy feeling, like a burning; with cystitis you’re running to the toilet but you’re not passing the water and you have a throbbing feeling and painful”* (12185p12)

Discharge is a ‘giveaway’; without this women find it difficult to tell the difference:

*“if you have thrush and a cystitis..it gets a bit confusing. I went to the Chemist and bought Canesten tablets or cream - if you don't know the difference between them you don't know what you're treating”* (12125p6)

### **3.5.1.2 Individual symptoms**

Since UTI can be diagnosed on the basis of symptoms alone, the purpose of this section is to map women’s narratives to symptom descriptions. All women appeared to suffer from the classical symptoms of dysuria and frequency. They recognise these as markers of UTI and reliably describe them, albeit in a variety of ways. Urgency of micturition often forms part of the symptom description of frequency. Strangury is a quaint medical term that seems synonymous with a combination of dysuria and frequency. Women suffer from generalised symptoms, affecting their abdomen or whole body, more commonly than is usually appreciated, but their descriptions are variable.

#### **3.5.1.2.1 Descriptions of ‘dysuria’**

Dysuria is a medical term meaning painful urination (354). It is classically thought of as a burning pain when passing urine. A recent paper on the subject of language in consultations suggested that doctors talked of ‘burning pain’ more than patients (355) but we found the opposite: women almost universally describe a burning (or stinging) sensation as a cardinal symptom of cystitis:

*“oh it’s an awful burning feeling, always wanting to go to the loo - you can never do anything when you get there and it burns”* (121189p5)

The headline from another study described cystitis as “peeing barbed wire” (3). Whilst burning was the commonest way to describe the pain of cystitis, women found a number of other analogies:

*“the only way I can describe it is as if there was glass inside you”* (12194p1)

*“The worst point is going to the toilet and passing water, because that really hurts - it is like knives” (FG239p8)*

*“ I have always likened it to broken glass, not knives” (FG239p8)*

*“I mean that is the best description is burning. The razor blade analogy” (12195p5)*

### **3.5.1.2.2 Descriptions of ‘frequency and urgency’**

The symptoms of ‘frequency’ and ‘urgency’ often go hand-in-hand and describe, respectively, a need to go frequently, and to go with little warning, to the toilet:

*“God I need to dash to the loo every 30 seconds” (12195p1)*

*“I think that is absolutely the worst thing. You know, if you were on the point of thinking ‘right you are going to wee now’ sitting there in your chair, that is what it is like 24 hours a day” (FG239p8)*

Frequency is invariably associated with passing only small amounts of urine:

*“I mean you are backwards and forwards to the toilet and you are only passing a spoonful at a time” (12194p2)*

So little may be passed that women describe the sensation as an inability to pass urine. This could be misinterpreted as urinary retention, a condition rarely affecting women:

*“You feel as though you need a wee, but you know for a fact nothing is going to happen” (121208p3)*

*“ I have just sat on the loo for hours and just dripped, for want of a better description” (12195p2)*

Women don’t urinate frequently on purpose. This is an involuntary symptom:

*“your brain saying hang on a minute, I know I don't really need to go for a wee, but my body is telling me that I do” (12195p1)*

### **3.5.1.2.3 Descriptions of ‘strangury’**

Urine passed painfully and in drops (354) is strangury.

*“It's a trickle, a burning trickle” (121189p10)*

*“the feeling of oh/ouch and not much urine coming out” (121189p3)*

*“You felt as though you didn't want to let the water go out of your bladder” (121910p1)*

The effects of treatment (acupuncture) further describe the reality of these sensations:

*“I felt a happiness and emptiness as if there was no more pressure from the bladder. I do not go so often to the toilet.”* - quoted from another study (356).

In medical papers, strangury rarely appears as an individual symptom. Perhaps, because it is so closely associated with other more discriminatory symptoms, it has little diagnostic value. It forms, however, an important part of women’s descriptions:

*“oh it’s awful isn’t it, that awful burning feeling, always wanting to go to the loo - you can never do anything when you get there and it burns”* (121189p5)

Frequency is associated with passing small amounts of urine, so the combination of frequency and dysuria is virtually synonymous with strangury:

*“You just constantly want to go to the loo. There is nothing there to wee, apart from the odd dribble and it burns, it just burns so badly and when it gets really bad, you believe that you are going to the loo, which has happened to me”* (12195p1)

#### **3.5.1.2.4 Descriptions of abdominal discomfort**

Many women describe unpleasant sensations in their lower abdomen: “pain”; “bearing down”; “blowing up”; “pulling”; “dragging”; “heavy sensations”. Some are likely to represent distinct symptoms:

*“My whole stomach seems to contract”* (FGD2p11)

*“the pressing feeling is like someone standing on you”* (12185p14)

*“I felt really heavy, I felt as though everything was hot and wanting to drop out actually - I felt as though I had something there that wanted to fall out you know”* (121274Bp1)

Other descriptions may represent different perceptions of dysuria:

*“you feel like somebody is pulling inside at you - you know when you go to the toilet - like a bearing down – it’s awful pain”* (121275Ap2)

It was not uncommon for these sensations to predict the onset of a UTI:

*“The day before I get stomach pains and slight cramps and a bit irritable and feeling a little bit run down and then my waterworks start”* (FGD2p10)

A few women suffered a sudden onset of symptoms, but more commonly cystitis developed gradually. Prodromal symptoms often took the form of feeling generally unwell or irritable. This phenomenon isn’t often described.

#### **3.5.1.2.5 Generalised symptoms**

Generalised, sometimes vague symptoms are not often recognised as a significant part of the symptom complex of UTI, but feeling generally unwell, feeling weak and tired, or feeling irritable and restless occurred in 68%, 67% and 53% of women in a questionnaire survey (357). These symptoms predominantly affected women aged 50-64. Our participants suffered a range of generalised symptoms:

*“You cannot settle yourself - you cannot get any comfort at all”* (12185p5)

*“I feel all to pot. I feel bad. You cannot get a resting place”* (12185p8)

including specific pain phenomena or a combination of both:

*“it is just like a little trickle and then the pain shoots up inside you”* (12185p13)

*“shuddering pain all the way through your body and the pain goes down to your fingertips”* (121145p5)

*“it is the most horrible feeling because you sort of get all clammy and you get this pain, which goes right through your body”* (121145p1)

Even though cystitis is an internal inflammation, a number of women find that it hurts them when walking. There is no indication that these women muddle cystitis and thrush, so it seems like a real effect from cystitis:

*“when it was at its worse, when you were walking sometimes, it was like rubbing, it was that sore”* (12194p3)

*“But when you were walking sometimes you could feel an uncomfortableness”* (121910p3)

Another woman mentioned more generalised effects on her demeanour:

*“When I went onto the antibiotics my husband would come in and say: 'by you look much better today' because my face looked a bit brighter and I would you know, feel like smiling at him when he came in and I would feel like putting makeup on and looking good because I felt good, but that's what cystitis does for you, it makes you feel really down and depressed and you don't want to look wonderful because you feel awful”*.(FG87p7)

### **3.5.2 HOW SERIOUS ARE UTIS?**

Women don't see UTIs as life threatening, but the severity of their symptoms varies. For many, UTI is worse than flu. Women are often concerned about debilitating symptoms, but some feel the lack of outward signs mean they aren't taken seriously:



*“How serious is it to me - it is very important - it really is. It really is serious. I don't think people take it seriously enough.”* (121145p7)

*“It isn't copable - you just cannot cope because you cannot physically sit on the loo and do everything else that you need to do at the same time and be in agony when you go to the loo”* (12195p4)

Women empathise with friends, relatives and colleagues who have UTIs, even if they haven't themselves experienced the same symptoms and take their views seriously:

*“She said it was the worst feeling she has ever had.”* (12185p7)- of a relative

*“There was a lady at work who suffered with cystitis on a recurrent basis. We used to say ‘poor sod's got cystitis again’”* (FGN p1) - of a woman with no history of UTI

The words ‘horrible’ and ‘awful’ are common threads in women's descriptions:

*“It is not a very nice feeling for a lady I don't think. It's horrible”* (12185p5)

*“Just all to pot and you feel like drained going backwards and forwards to the toilet, you don't know where you're at. It's an awful feeling.”* (12185p9)

### **3.5.2.1 Why do some women feel UTIs are trivial?**

Severe symptoms are not universal; some women either suffer milder symptoms, or become accustomed, and almost accepting of them. We don't know whether they have a more pro-active approach to the treatment of UTI:

*“It's like any everyday nuisance - if your sink got blocked every six months – it's that kind of oh bloody hell this has happened again type attitude to it.”*(12195p6)

Perhaps, women look back and minimise the symptoms if they recover well:

*“Talking about it now it sounds trivial, but it is serious at the time when it happens to you”* (121208p6)

*“it's something that women get and they get cured from it and then they totter off until they get it the next time...so I don't think it is classed as important”* (12195p12)

This may be due to competing priorities, whose importance increases as the symptoms of UTI recede, rather than a process of trivialising illness. The following is an excerpt (from another study) where a woman blames her younger self for carelessness, but justifies it as her role as a busy young mother prevented her from looking after herself properly:

*“I think it was just a case of getting cystitis and neglecting it, you know. I might have got something from my doctor and taken part of the treatment, and once the pain had gone, just stopped - which most people do, really. But when we’re young we don’t think about it the same”* (195)

Some women apologised for returning a consent form: they felt frauds as they hadn’t had cystitis often and were currently well. This reaction is predictable: these women consider UTI to be a ‘normal illness’ in the same way as chickenpox is a ‘normal illness’ (358) of childhood, whereas those who suffer recurrent UTI might be considered to have ‘real illness’, which is something to moan about. Women also trivialised their illness as they lacked outward signs:

*“Like I say, you are sat there thinking to yourself am I being trivial - because it is cystitis... I don't think I am wasting their time? Like I say, there are people sat there coughing and spluttering and you always feel someone is worse off than me and that's the way I feel”* (121208p8)

*“I think people would take it more seriously if you had 'flu, or cold settled on your chest with phlegm, than with cystitis”* (12125p6)

### **3.5.2.2 Comparison of severity with other diseases**

Women spontaneously offered comparisons with other painful conditions such as toothache, headaches (including migraines) and earaches:

*“worse than toothache or earache”* (12185p9)

*“like a headache that won’t go away”* (121910p7)

One woman suggested that it was equivalent to an episode of toothache but less severe than a migraine (though the symptoms of a UTI are likely to last longer). Some women compared the symptoms of cystitis to period pains and pregnancy:

*“It was a lot like that sort of pain that you have when you have a really bad period”* (121274Bp18)

An inability to control symptoms effectively may influence the perception of severity:

*“It was worse than childbirth. It was really severe pain. It was awful. I mean I have got quite a high pain threshold anyway and I know I can take quite a lot of pain, but this was something I could not control.”* (FGD1p5)

Some women have very consistent symptoms, but others experience differing severity of infections. One woman used her experience of treatment success to reflect this:

*“Sometimes the over-the-counter remedies must work, which means that sometimes you must get it worse than others”* (12195p6).

#### **3.5.2.2.1 Is UTI worse than flu?**

To come to a better understanding, we specifically asked women to compare cystitis to other illnesses. We asked if cystitis equated to an episode of flu, pneumonia, or something ‘in-between’. Usually women placed the severity of UTI in-between flu and pneumonia, though one woman felt flu was more severe as it caused her to be bed-bound. If women suffered more severe symptoms they rated UTI more significant:

*“Compared to a lot of things, it’s probably like a minority where it becomes troublesome, but I think for those people then it’s very important, because it can have a huge impact on their lives”* (FG87p1).

#### **3.5.2.2.2 Thrush or UTI?**

All but one participant who compared thrush to UTI felt that thrush was less troublesome, particularly as it causes less pain and urinary frequency.

*“Thrush I would wish on my worst enemy - cystitis I wouldn’t.”* (12195p11)

There seems to be agreement on what is reasonable to wish on your worst enemy!:

*“I cannot express to you how horrible this pain is and I wouldn’t wish it on my worst enemy”* (121145p6)

Even if thrush is seen as more troublesome, UTI is seen as more worrying:

*“The thrush is worse. It’s awful, it’s hot and burning, and you know you just want to writhe at yourself”...(So what would be more serious for you, the kidneys or the thrush?)... “The kidneys”* (121274Ap21)

### **3.5.3 THE UTI CAREER**

Many women have long histories of UTI, frequently starting in teenage years, and occasionally earlier. Their symptoms differ as they age. Many, but not all, find mechanisms to ameliorate regular symptoms. They gain experience not only from their own illnesses but also from those of friends, relatives and work colleagues. Other information sources in the media or the internet appear less important, but may be useful for women with no previous UTI especially if there is no family history. As a result of

previous experience, women may present with a ready-made diagnosis of cystitis, but clinicians need to be aware that the use of this term may be imprecise.

### **3.5.3.1 Experiences of UTI at different times of life**

Most of the women in this study first suffered a UTI in their teens or early twenties:

*“I first started getting it when I was 18 or 19 and I have had it on and off ever since. I couldn't possibly tell you how many times”* (12195p3)

A previous questionnaire survey suggests that the pattern of symptoms changes with age: women aged 18-35 suffer most from ‘distressed bladders’ whereas women aged 50-64 suffered significantly more generalised symptoms (357).

*“You know you drink gallons of water when you're younger and you just jump up and get on with it, you don't always bother I think. You take more notice as you get sort of older. If it becomes more persistent, which it has done in my case, but it wasn't as bad as what it is now”* (FGD2p14)

On the other hand, women who have suffered many UTIs in early adulthood, are more likely to actively seek solutions and find ways of reducing the frequency of UTIs or their symptoms. A few develop UTIs later in life, or suffer an increased frequency of UTI after events such as abdominal surgery, pregnancy, cancer, or the menopause.

### **3.5.3.2 Recognising cystitis: women sufferers as expert diagnosticians**

Most women become experts of their own illnesses. Many know someone who suffers from cystitis, so their symptoms could be checked against others’ experience; rarely, is there a suggestion that doctors have a role in diagnosis!

*“I have had it that many times over so many years - that you know you become a bit of an expert on it from your point of view and you get this sort of feeling in your stomach and you think this is it, I am going to start with cystitis”* (12195p1)

*“I started in my teens, called the doctor out in the middle of the night because I didn't know what it was”* (FG239p4)

#### **3.5.3.2.1 Recognising a bout of cystitis**

Recognition that their symptoms represents an episode of cystitis doesn't pose any apparent problems for most, but not all, women that we interviewed:

*“I just thought oh here we go again”* (FG87p4)

*“I just couldn't distinguish between when there was an infection there and when there wasn't” (FG87p3)-a participant with recurrent UTIs*

*“It is difficult to say, I am terrible at self diagnosis” (121189p3)*

Symptoms, and women's definitions, as no doubt in many other illnesses vary from person to person. It is important to understand that there is a range of experience:

*“To me it is like going to the toilet for a thimble full and then the smell - when I was talking to this other girl she said mine's not like that. She said she was just back and forward to the toilet, but she didn't have the smell” (121208p9)*

#### **3.5.3.2.2 Presenting with a ready-made diagnosis**

Women may present with a diagnostic label rather than symptoms. To make this step, they usually draw on either their own or someone else's previous experience. Women recognise that their diagnostic labels may reflect different interpretations:

*“ the girls in the office say 'I think I've got cystitis because they're going back and forwards to the toilet; you put a label on it whether you've got it or not” (121208p2)*

*“maybes because I have had cystitis, I know what it is. Whether this girl I am talking about whether she thinks its cystitis and it may not be, she might just have diagnosed herself and not gone to the doctors” (121208p9)*

#### **3.5.3.2.3 When do women become experienced?**

Women with less experience of UTI don't always view themselves as “sufferers”

*“I was surprised when she gave me this to fill in you know. Because it wasn't as though I was there often for the cystitis” (121910p2)*

Some women find that variable symptoms mean that they never become expert diagnosticians, but others with typical symptoms each time quickly become experts:

*“once you have had it you know when you have got it again” (12185p7)*

#### **3.5.4 HOW DO WOMEN FIND OUT ABOUT UTI**

*“I think really that's how people get to know about these things. Women talking about common experiences” (121189p12)*

Women with a previous history of UTI draw heavily on personal experience for their knowledge of UTI. Relatives, often mothers, and female friends, who have suffered the same problem, form a reservoir of accessible expert opinion. Information from work

colleagues, and from people (or animals) they look after, is more important for women with little or no past experience of UTI. Information from published sources such as information leaflets from health professionals, magazines, television or the Internet appear to be less important sources of knowledge.

#### **3.5.4.1 External sources of information**

As UTIs are so common, it's not surprising that many friends, colleagues and relatives are sufferers and are on hand to offer advice. Health professionals don't seem to be particularly important sources of information. Since many women attend doctors, especially male doctors, with the express purpose of obtaining treatment, and without entering into potentially embarrassing discussions, this is not too surprising. A few women had received leaflets from their doctors, but these had a mixed reception.

##### **3.5.4.1.1 Women with little or no previous experience**

Women have no prior experience to draw on for their first bout of cystitis, and were unsure of the significance of their symptoms:

*"It was a new one on me, because I hadn't had cystitis before either. So I didn't know what that was like either. It was new and it was uncomfortable, very uncomfortable, and you know you sort of don't know what is going on"* (121274Bp1)

Sometimes, they discover, when relating their symptoms, that relatives have had similar experiences:

*"Then I explained it to my mam or my older sister, and I don't know if they had had it before, and then they said they had had something like that, but I had to go to the doctors"* (12185p17)

Single episodes may not provide sufficient information on UTI. Women use external sources to supplement knowledge gained from personal experience:

*"I have only had it once before in my life...but I recognized the symptoms...partly from having experienced it myself, partly from reading about it, talking to other women about it"* (121189p2-5)

Leaflets are seen as useful for people who have recurrent but infrequent UTI.

##### **3.5.4.1.2 Media**

Magazines were a source of information for a few women:

*“I buy the Women’s Weekly all the time- the things I have tried that are there that other people have tried, to get rid of it...I keep all the articles for next time I get it and I will try those things out” (FG87p1)*

and, especially those from the USA who featured ‘clever’ American doctors:

*“you get some good tips in magazines - from America – it’s always American doctors you know” (121275Ap7)*

but don’t expect those in doctors’ surgeries to be useful!:

*“I don’t read many magazines – just in the Doctors’ Surgery...they are usually three years out of date and the front cover is missing and somebody has done the crossword” (FGNp13)*

Perhaps health professionals ought to consider the quality of waiting room information as a misunderstanding about the side effects of cranberry was shared by two women (interviewed separately) and came from a commercially produced health magazine.

Adverts and television documentaries are sources of information – but there’s little directly relevant to cystitis:

*“the infection had gone to my kidney. Actually, I had heard about it before on the TV one day. Just coincidentally somebody on television was talking about it on one of those hospital programmes” (121189p9)*

*“the Yakult advert isn’t it - our body is full of good and bad bacteria and they are all alright when they are in the right place, it is when they get in the wrong place that there is a problem” (12195p12)*

*“You see adverts on the TV for Canesten cream for thrush, but you don’t see anything for cystitis” (12125p9)*

Only one woman mentioned books:

*“I am the sort of person that looks in medical dictionaries and things and tries to find out for myself” (121189p2)* but she later cautioned:

*“then you tend to go and have a look yourself and get the wrong answers” (121189p13)*, a feeling echoed by two other women:

*“I do these sort of things and you know end up worrying myself sick - it is best just to see a professional straight away, which is what I did” (121189p4)*

*“I tend to look into it myself and read about things and think ‘oh yes, I know what it is’ and then worry about it. Sometimes it is better not to know and just go and find out straight away”* (121189p13)

Only one woman with no personal history of UTI, mentioned the Internet as a useful resource: she had used it for information about a young pupil’s illness. The upsurge in Internet use, however, might invalidate this finding.

#### **3.5.4.1.3 Health care environments**

A few participants worked in the fields of health care, and received advice from colleagues. Much of this was similar to the advice other women gained from friends, relatives, and experience. Some information could also be categorised as medical myths. One worked in veterinary care and drew a parallel with animal disease:

*“it can be associated with them coming into season as well, so whether it is related to us having periods and what have you”* (FGNp6)

#### **3.5.5 WHAT DO WOMEN THINK CAUSES THEIR UTIS?**

Women’s beliefs about triggers may be associated with their choice of self-treatments, or avoidance. They are linked to illness representations, which may be shaped by past experience and current medical conditions. Women appear curious rather than unduly concerned about the cause of their UTI. Most associate triggers of one sort or another though a few can’t put it down to anything, or haven’t considered this question before:

*“I have never thought about it. It is just something that happens and that's it. I have never thought about anything ever setting it off”* (12194p4)

*“it hasn't been like a set pattern. There is no method to what is causing it”* (12185p10)

#### **3.5.5.1 Beliefs about anatomical causes**

##### **3.5.5.1.1 A woman’s problem**

Everyone, including men and women with no history of UTI believe this to be a woman’s problem. Female anatomy was only occasionally mentioned as a cause, and more by non-sufferers: *“short urethra close to the anus”* (BGBA). Perhaps, women accept anatomical causes without question, or with experience they feel other causes are more important:

*“It’s our anatomy unfortunately. There is too much room for infection to go up”* (FGNp2)

##### **3.5.5.1.2 Cultural practices**



Women brought up in parts of the world where this is accepted, can be victims of a cultural practice, female circumcision, which mutilates and leaves them susceptible to UTI:

*“They sewed everything together and then leave just a little hole the size of a match so that you can have a wee, but then you sat there for hours because it took forever to come out”*  
(12125p4)

### **3.5.5.2 Beliefs about infective causes**

#### **3.5.5.2.1 Lay microbiological explanations**

The concept of an attack by an uninvited micro-organism was commonly cited:

*“I think a water infection is something you get from a bug that shouldn't be in your body”*  
(12125p11)

The idea that an infection that ascends through the urethra was generally accepted:

*“my understanding of cystitis is that the good bugs that live in your back passage travel to the front part and get into a bit where they are not supposed to be and cause the problem”*  
(12195p8)

but as this later quote from the same interview shows, uncertainty reigns:

*“where you have eaten something or your have just breathed something in and it has caused a water infection”* (12195p11)

Chance associations may muddle the mechanism of infection (e.g. respiratory illness):

*“I had a period where every time I got a cold I got cystitis. I didn't get any cough or any problems with my throat, but I got cystitis immediately”* (FG239p4)

#### **3.5.5.2.2 Moisture**

Women often view moisture (and dampness) as a cause of UTI, and the association appeared to be that moisture provides a breeding ground for infection:

*“with the trauma that goes on and the amount of other fluids that come out, that you know, something is bound to track up in that respect”* (FGNIp4)

The idea that ‘bugs’ track upwards aided by moisture or fluids is quite a common idea

*“bugs..they do that travelling through moisture”* (12195p8)

*“we used condoms and that's a lot better from a cystitis point of view, because of the lack of liquid, for the want of a better description”* (12195p6)

One woman inserted tampons after sex to reduce her exposure to moisture.

### **3.5.5.3 Beliefs about physiological factors**

Women recount a range of physiological factors that appear to trigger their UTIs. Commonly, they blame hormonal changes (especially the menopause and periods), though stress, both physical and mental, and, occasionally, surgery are cited.

#### **3.5.5.3.1 Stress**

A number of women cited stress as a trigger:

*“I think stress can cause a lot of things and it manifests itself in different people in different ways”* (FGNp4)

But some considered stress in a broader way- physical stress as well as mental stress:

*“If I was worried about something or if I had been poorly”* (FGD2p15)

or merely being at ‘a low ebb’

*“I think lifestyle upset as well. Because you said about stress didn’t you...I think lifestyle has a lot to do with a lot of our problems these days”* (FGNp3)

#### **3.5.5.3.2 Pregnancy and hormonal changes**

Pregnancy is a well-recognised risk factor for UTI, and for complicated UTIs, yet surprisingly our participants rarely mentioned it. Perhaps, in the absence of any serious episodes, they view it as ‘business as usual’ as regards their urinary tract?

*“that would be related to sort of muscle weakness after having a baby or whatever”* (FGNp3)- a woman with no history of UTI

The brainstorming group contributed proportionately more on this subject, citing the *“side-effects of the pill”* (BGA5), *“having a smear, and having a baby”* (BGA1) as causes of UTI.

Some women feel that their periods are associated with their UTIs:

*“sometimes before my periods or after my periods and sometimes every couple of months”* (12125p10)

One woman felt that cystitis was more likely after her period if she used tampons.

Some women associate the menopause (either naturally or after surgery) with an increase in UTIs. This is a well-recognised association, and is probably related to the loss of local immunity with the reduction in hormone levels:

*“I have put it down to the change - I don't know. I have had it more frequently since I stopped my periods” (121274Ap1)*

*“I had a hysterectomy and had my ovaries out and with being sort of dry down below, that I went through a phase where I really had it quite a lot then” (121145p3)*

On the other hand, one of the women who attributed her cystitis to her periods had benefited from the menopause.

### **3.5.5.3.3 Other physiological changes**

A couple of women recounted the onset of, or an increase in the frequency of, cystitis, to abdominal (rather than gynaecological) surgery. It is quite possible that the women had been temporarily catheterised and that this had acted as the trigger.

### **3.5.5.4 Beliefs about familial factors**

There's a suspicion, but no medical evidence, of specific hereditary components to UTIs in adults, but nevertheless many mothers had suffered similar problems.

#### **3.5.5.4.1 Heredity**

Whilst women describe members of their families (especially their mothers) as suffering from similar problems, they themselves don't usually consider this as evidence of a hereditary component of UTIs:

*“my granddaughter has started - she is only three - with the same thing...so I don't know whether it is a family thing” (121145 p4)*

Some felt a genetic component unlikely even when suggested as a possible trigger:

*“They say different diseases and complaints could come back from parents, but I don't think so” (121275Ap12)*

### **3.5.5.5 Beliefs about environmental factors**

Most women consider drinking extra water to be a treatment for cystitis (see later), whereas poor hydration is seen as a cause of UTI prevented by normal fluid intake. Diet is only viewed as a possible cause where women have special restrictions. Information sheets carry a plethora of warnings about clothing types and tightness but most women haven't found any benefit from adhering to this advice, though more appear to agree with the advice on soaps, bubble baths and perfumed products.

#### **3.5.5.5.1 Hydration**

Drinking insufficient fluid is almost universally believed to be a cause of UTIs:

*“not enough fluid in your system” (BGBB)*

*“My mum sometimes has urinary infections. If she doesn't drink a lot she sometimes gets cystitis” (FGD2p13).*

There is some evidence that poor hydration may contribute to recurrent UTI in children, but there is little about this in adults. A number of women commented on the necessity to maintain hydration in the elderly in order to prevent UTIs:

*“Older people don't drink as much ..it's a job for them to get to the toilet, so they think if they drink less they'll pee less and they won't have to get up and down out of the comfy armchair so many times” (FGN2p5)*

A good fluid intake ensures regular toileting, which is seen as inhibiting cystitis:

*“I know from the past I will get cystitis if I don't go to the toilet regular” (121145p4)*

One woman observed that dehydration through fluid loss (rather than poor hydration through lack of drinking) might cause UTIs:

*“Women get it more often in the summer than the winter, when it's hotter, when they're sweating more” (12195p9).*

#### **3.5.5.5.2 Dietary factors (including acids)**

Women occasionally consider dietary factors, especially ‘junk food’, as a trigger for UTI, but also some specific associations such as highly salted or flavoured foods:

*“if you abuse your body with eating all this rubbish and different stuff - I suppose it can cause complaints can't it. I try to be sensible and try to keep fit”(121274Ap19)*

*“so I don't know what causes it. Poor diet? Not enough liquids? I don't know – it's just something that you get” (FGNp2)*

*“I avoid food with salt and a lot of herbs” (FG239p18)*

One woman, who for medical reasons had restrictions on her diet commented:

*“It maybe's been starved of some nutrients it does need”(FGD2p19)*

A number of women associate the burning sensation of dysuria with acidity (of the urine). Only some of these make an association with acidic food or drink:

*“I don't have any lemons and oranges etc. with a lot of acid in, so I think maybe that helps” (FG239p18)*

*"I cannot drink white wine. I don't know if it's the acid in the wine or whatever"* (121145 p5)

### 3.5.5.5.3 Clothing and hygiene

*" don't wear trousers and don't use smellies and don't put bubble bath in the bath"* (12195p8)

Tips on a wide range of clothing factors and bathing are common in information sheets provided by medical professionals. There is no scientific basis for all of these statements, and many, but not all, women come independently to this conclusion:

*"It is just telling you not to have a hot bath and things like that and iron your underwear, wear cotton underwear and not wear tights - things like that. You try all that, but nothing works"* (12125p10)

*"I always wear cotton...you think of these thongs and things - well I couldn't wear them"* (121274Ap12)

*"I used to try and look at what I wore but that didn't make any difference, so I just went back to wearing jeans or what have you"* (FG239p16)

Many women don't express a specific opinion on bath and cosmetic products. Soap gets a mixed reception and some women wash with water alone. On the few occasions where they express an opinion, they are in agreement with the advice sheets:

*"talc definitely brings it on; definitely different kinds of soap I wouldn't use"* (121145p3)

Women sufferers don't consider poor hygiene as a cause of their UTIs and those that have tried further preventative measures are equally sceptical:

*"My mum...she said always wash yourself well after you have had intercourse, but I didn't think it was doing any good really"* (FG239p12)

As infections can make women 'feel dirty' they find it hard to drop the association and don't completely rule an effect out:

*"I didn't know what was causing it. I really honestly did not know, because my personal hygiene is very good"*(FGDp2)

*"I suppose cystitis - the old wives sort of tale - oh its because you are not clean, or you haven't got washed or you are sweaty and all that sort of thing, there is still that slight misconception I suppose of it"* (12195p8)

*“down and outs, living on the streets whatever, their hygiene would be an issue”* (FGNp6)

One exception to this rule is ‘wiping front to back’ which appears generally accepted as a sensible thing to do, and even if it doesn’t work, has no downside. Sometimes illnesses are attributed to over-cleanliness and a few women appear to associate UTIs with an imbalance created by excessive hygiene:

*“I am not trying to be overly clean and using feminine deodorants or bubble bath in the bath, I just couldn't understand it”* (FG239p2)

### **3.5.6 MYTHS, FOLKLORE, AND OLD WIVES’ TALES (AND REMEDIES)**

Women recognise many pieces of advice as “old wives’ tales” but, at the same time, these form the basis of many illness beliefs. It is a fascinating feature that worries and beliefs are intertwined with folklore and myths.

It is difficult to discover why some myths start up, why they persist, or why they disappear. ‘Catching a chill’ and the dangers of the dirty toilet seat are remarkably persistent, whilst drinking barley water seems to be disappearing as a home remedy. Perhaps, folklore changes when new ideas appear - in the case of barley water there are proven alternatives, not only antibiotics, but also home or over-the counter remedies such as cranberry.

It is difficult to gauge how widespread is the belief in folklore. Perhaps, the test is whether it is common enough to be dismissed:

*“I cannot put it down to anything - it is not strange toilets and I don't use bubble bath”*  
(121208p1)

#### **3.5.6.1 Catching a chill**

One of the commonest pieces of folklore is the concept that infections are caused by over-exposure to cold. Perhaps the double meaning of the word ‘chill’ - as a term for a feverish illness and as a description of coldness – has a part to play. Two areas of the body in particular are thought of as being related to the onset of UTIs when they are subject to cold: one is the ‘kidney area’, the other is the feet.

*“cystitis is just as likely to be caused by a chill as by excessive consumption of a particular kind of alcohol. An attack occurs when the urethras - tubes that lead from the kidneys to the bladder - become inflamed. Infection also can be communicated to the kidneys from the colon.”* -a ‘holistic’ internet site (359)

##### **3.5.6.1.1 Kidney chills**

*“Just a bit of chill around there - getting cold in my back - and then it's gone to my kidneys”* (121274Ap2)

Mothers warn of ‘chills on the kidneys’ if youngsters don’t wrap up warmly. This narrative series shows how folklore passes from generation to generation:

*“My mam used to always say: get them long jumpers on and vests – you’ll get cold in your kidneys. We were told that from being bairns...I keep saying to our \*\*\* - no wonder you’ve got cold and cystitis, you’ve no clothes on hardly....when you get older a lot of these things do come back true - because you do get all these complaints - you know. You don't listen when you are younger”* (121274Ap11)

The myth of the adverse effects of getting cold is seen in a wider context as well:

*“If you are sitting on a cold step - you think are you getting cold that way - you're not getting a cold, but are you sending cold into your body”* (12185p10)

One woman thought her kidney infections were seasonal. Personal experience appeared to confirm the myth of cold as a trigger, but medical fact contradicts this: kidney infections are commoner in the summer.

#### **3.5.6.1.2 Cold and Feet**

The association between the feet and UTIs is an unexpected theme. It occurs in three ways: firstly, reflexology uses the feet for diagnosis and treatment- a few women had tried this, and their experiences are discussed later (complementary medicine); secondly, the feet may be associated with symptom relief:

*“sitting relaxing with my feet up. Whether it eases the pressure off my stomach I don't know”* (FGD2p18)

*“The first thing I do is take pain killers then...put me socks on - keep my feet warm”* (121145p1)

Warm socks are considered preventatives as well as a treatment, as thirdly, the feet are seen as the portal of entry for cold, a (mythical) trigger for UTI:

*“I sometimes think if you are out and you have no socks on and I think have I got cold and has that started it off. Is it a weak spot inside you, I just don't know”* (12185p9)

*“my son had a urinary infection, having stood in a river for three hours doing some research in cold water. He got a desperate urine infection”* (FG239p2-3)

*“There were a lot of draughts, so you got cold and unless you had very good shoes and very good underwear on, you were very exposed to the draughts and the cold and I started the first time (cystitis) at about 14 to 15 years old” (FG239p3)*

### **3.5.6.2 Home remedies**

Barley water is a traditional ‘home’ remedy, its use handed down from mother to daughter. There is no objective evidence of benefit. Cranberry, on the other hand, appears as a recent method of self-treatment, advocated by some professionals and information leaflets. It is backed by some scientific evidence, and is, therefore, considered elsewhere.

#### **3.5.6.2.1 Barley water**

Barley water, usually home-made, is a common remedy from the past:

*“You used to boil the barley and they used to use the water that you boiled it in for your kidneys.. that was an old fashioned way” (12194p9)*

Frequently mothers or grandmothers had offered this to our participants:

*“My mum knows all these old remedies and if I say 'oh mum, I am unwell' she says you shouldn't be doing this and you shouldn't be doing that - in my day we did this. That is when I started drinking barley water” (121208p2)*

A modern form, though probably not equivalent, is now widely available:

*“I get a bottle of lemon barley - but my mam used to do the proper barley you know and we used to drink the juice. It was horrible. Caster oil was horrible but we had to have that too” (121274Ap16)*

#### **3.5.6.3 Other old wives’ tales**

We uncovered a few other old wives’ tales, though none of these were widely cited:

*“put an old sheet on the bed ..... and I found that helped as well” (121910p4)*

*“I only use white toilet paper. Again it is maybes an old wives’ tale. Coloured toilet paper is supposed to aggravate infections and things, but whether or not there is any truth in it or not, I have no idea” (121208p1)*

Salt is still used occasionally for its antiseptic effect on superficial injuries. In UTI, there is no logical reason for any benefit, and may be considered part of folklore:

*“I put salt in the bath. I don't know whether that is any good or not. I think it is because it heals stuff” (121910p11)*



#### **3.5.6.4 How do myths evolve?**

Thrush and UTI cause similar symptoms and have similar warnings about clothing and hygiene, so it isn't surprising that women use yoghurt, a relatively new home remedy, for both. Another utilised yoghurt for its generic effect on burning sensations:

*“one of my friends said, because she'd been abroad and got sun burnt, one of the Greeks told her to cover herself with yoghurt for sunburn and they said it was good for burns and soreness. So I thought right, I'll give it a try which I did do”* (12194p9)

In another example, one woman theorised about her experience of developing UTIs after sex, and linked it with her personal belief about moisture being a cause:

*“so on a morning after a wild night of passion or quick five seconds of passion or whatever, the next morning you are very damp aren't you? Sorry I am asking you questions now! Then I would get cystitis - I am not saying every time, but I suddenly thought - even with my very limited intelligence - is this connected?”* (12195p7)

*“I think probably it was handed down - like Chinese whispers and a bit keeps getting added on each time..but the thing is I know I do the same with my two daughters - if they've got problems. Whether rightly or wrongly things get passed down”* (121208p2)

Once our interviewer exclaimed *“well you learn something every day”* in response to what we recognise as a myth. How they are perpetuated!

#### **3.5.6.5 Medical myths**

Medical myths appear to be a complex mix of: folklore, no different from lay perspectives; 'noble myths'; and misunderstandings of medical information. Although some women maintain a healthy scepticism, others are affected by medical nonsense.

The worry is that some women may be unable to distinguish bad from good, hopefully evidence-based, advice...but that is really the doctor's responsibility, isn't it?

##### **3.5.6.5.1 Myths in leaflets and advice**

Some of the advice that professionals hand out has no discernible benefit and appears to be a form of medical folklore. Women receive it with a degree of scepticism:

*“They gave me leaflets saying don't have hot baths and don't use fabric conditioner and things like that and have cold baths”* (12125p7)

*“It is just telling you not to have a hot bath and things like that and iron your underwear, wear cotton underwear and not wear tights - things like that. You try all that, but nothing works”* (12125p10)

Despite trying these measures this woman’s infections hadn’t abated, and rather than question these myths, she considered that she might have another illness.

#### **3.5.6.5.2 Noble myths?**

Originally defined by Plato, ‘noble myths’ create benefit by encouraging people to do something sensible. A few women had been told about the rarely important interaction of antibiotics and alcohol. These myths may be seen as factual by both sides:

*“The nurses say ‘well she’s been drinking and she’s on these antibiotics and it says don’t drink with them because they counteract each other. That’s just why I thought you know when it said don’t drink with them, I thought ‘God, I’m only away for a week’ and if I’m not going to have a drink, so maybes it’s my own fault”* (121910p3) - a health care worker reflecting on why a UTI had been prolonged.

#### **3.5.6.5.3 Medical misunderstandings**

One woman misunderstood the list of interactions quoted in a magazine and thought that it was the cranberry itself rather than the interaction that had an effect on the heart:

*“It has got like digoxin in it - you know the stuff you take for your heart - warfarin - it contains something to do with warfarin”* (121274Ap6)

She still used cranberry, intermittently and with caution, as she had a healthy heart, but one can see how ‘Chinese whispers’ could lead to the birth of a myth.

A muddling of vaginal infection and UTI probably led to the following quote:

*“I think of tampax and things like that - they can cause infections”* (121247Ap12)

In this next quote, a health care worker had correctly understood the association of skin changes and the application of direct heat, but had misunderstood the process:

*“They always say you should never put a hot water bottle on anything because it can cause a bleed - that’s what we were taught at work”* (121274Ap17)

#### **3.5.6.5.4 Medical myths and infectivity**

Muddling of thrush and UTI doesn’t seem to be exclusive to patients:

*“The doctor gave him some Canesten and they said I should go and give a water sample”.*  
(121910p1)

Another variation on this theme, was the implication that bugs can be transmitted by underwear (or perhaps, this was due to a mixing of myths):

*“Yes - I iron my underwear. They say ironing kills any germs”* (12125p10)

Reportedly this idea came from a hospital information sheet. Some women, however, view over-cleanliness as a risk factor for UTI; this may have its origins in the aetiology of some vaginal infections and the effects of antibiotic resistance. There is no evidence either way in UTI, but here a doctor endorses a potential myth:

*“My doctor told me it could cause damage - you can be too clean so you can remove the bacteria that would fight”* (FG239p14)

#### **3.5.6.6 Dirty toilet seats**

The idea that UTIs are caught by sitting on toilet seats is quite common. Women, whilst sceptical of this idea, would avoid dirty toilet seats ‘just in case’:

*“I am always very careful when I go to the toilet when I'm out, you know. I make sure the seat is clean - I don't actually touch the seat you know”* (121274Bp11)

*“Whether or not you can pick up infection from some toilet seats I don't know”* (121208p5)

The source of this myth is uncertain in most cases. Some cite parents:

*“it is probably from being a child, again from my mum and dad, ‘you cannot use those toilets they are dirty - you might get an infection’”* (121208p11)

but doctors were also cited as the source of this myth on more than one occasion:

*“A doctor told a friend of mine that urinary infections are contagious and can be caught from toilet seats, is this true?”* (BG1)

*“My GP told me - I had been on holiday the first time I got it - it was probably from sitting down on public loo seats, but I got cystitis - not that I was ever aware of having sat down - I always try to hover in public loos. He definitely said that that was the cause and certainly I had just been on holiday and had been bed and breakfasting, so you know I had covered an awful lot of loos and area in that time”* (FG239p15)

### 3.5.6.7 Sex as a trigger for UTIs

In medical circles, sex is considered a major cause of UTI and children are managed differently when they are sexually active. However, sex as a trigger for UTI seems for some women to be a random association: (UTIs) “*come out of the blue*”(BGAV). Many women find that UTIs are variably associated with sex:

*“I get cystitis - after sex unless I am very careful. I am sure I get it for other reasons as well, but I am sure sex is one of them”* (12195p6)

*“You just wonder whether that has set it off, but it cannot, because sometimes when I was poorly and you still get it, well it cannot be that”* (12185p9)

One woman with very frequent exacerbations found that many were triggered by sex but even when she abstained as a result, she could suffer recurrences:

*“there have been times when I have had it in the past and I didn't have a partner, so I can say that yeah that probably could cause it, but there are obviously are other reasons why it happens”* (FG239p16)

Women were fairly evenly split on whether they had an explanation for sex causing UTIs. Most, but not all, blamed friction and trauma if sex brought on a UTI:

*“I think it is because everything is so closely connected inside your body, whether the friction from it would sort of stimulate something to move inside - whether that would be the reason why I really couldn't answer that”* (FGDp6)

*“Also is it just a case of a sort of bruising aspect and contact, then there is a likelihood that it might happen again, I would have thought”* (121189p7)

Others considered it to be a purely microbiological explanation:

*“(sex)- it is injecting something foreign to our bodies, so there is no reason why it shouldn't or can't cause an infection”* (FGNp6)

*“my doctor actually drew me a diagram of like how it is connected to sex and that kind of thing and how you can get it through sex, and she actually drew me a diagram of you know what bits were infected and what have you”* (FG87p8)

#### 3.5.6.7.1 Honeymoon disease

*“Honeymoon disease-too much sex”* (121189p6)

The association with sex is well established in folklore as honeymoon disease. In this instance, there is medical fact to back up the belief:

*“My grandmother told me that because she used to suffer from it and she said - we were talking about it one day and she said it was always known when she was young - I mean she died last year at 90, so 60 years ago whatever, it was known as the honeymoon disease because women got it on honeymoon after they had had sex for the first time”* (12195p6)

### **3.5.7 WORRIES AND MEANINGS OF ILLNESS**

Women’s concerns reflect underlying health beliefs, cues from health professionals, and previous experience, either their own, or those of relatives or friends. The level of concern voiced by women varies quite markedly, but some of this may reflect comfort with the interview, the type of interview, and personality traits.

#### **3.5.7.1 Worries about progression**

Whilst most women are aware that UTIs can cause more severe illness, surprisingly few express concern. Only one of our participants had suffered a long-term complication, though a few had suffered severe episodes or prolonged illness. Despite this, most women seemed reassured about the generally benign nature of UTI.

##### **3.5.7.1.1 Will it get worse?**

Many women are relatively unconcerned about the progression of their illness as either they do not perceive their symptoms to be particularly severe or they are confident of the therapeutic effect of antibiotics.

*“Just how long it's going to last, but apart from that no. Do you mean worried what it could lead to? No. No.”* (121208p7)

*“I didn't actually worry about it getting any worse because I always knew that even though it was really unpleasant, ultimately it would get better”* (FG87p4)

Even if they have had concerns about progression of their illness in the past, women may become desensitised to this fear with repeated episodes of UTI that clear without leaving any residual problems:

*“It didn't bother me really. I have had that before”* (121274Ap4)

##### **3.5.7.1.2 What might it lead to?**

Women, who express concerns, mostly worry that UTIs could lead to renal failure. In the main this is theoretical as they are confident of the benign nature of their illnesses:

*“you hear of all sorts don't you.. kidneys packing in, or maybe one is not working as good as the other...if they packed in, I mean if your kidneys don't function you can get all sorts of things can't you...kidney dialysis and things like that”* (121274Ap14/21)

*“if you damage your kidneys you don't get them two a penny do you, once they have been infected and you know their function becomes less and less efficient”* (FG87p4)

Some women had a generalised anxiety towards their symptoms and possible effects:

*“It could escalate and make things a lot worse for your body”* (121274Bp12)

*“it feels like it's taking the lining off the inside of my stomach sometimes”* (FGDp14)

#### **3.5.7.1.3 Lack of knowledge – help or hindrance?**

A lack of background knowledge has an effect on women's level of concern. Women with no history of prior UTI or only occasional episodes feel less certain about the likely outcomes, and concern is greatest in those with least experience:

*“I feel if it wasn't treated, I don't know - I have no idea what it could lead to, but that is one of the things - you know, if it gets worse, what can it cause?”* (121275Bp12)

*“I mean I would presume it would get worse and worse until something horrendous happened, but I suppose a minor shot of it may go away itself”* (FGNp7)

*“I would worry about it spreading to other places...everything must be connected. It goes in here and out of here, so it's got to stop at all these places on the way hasn't it”* (FGNp8)

One woman who regarded herself as a 'worrier' felt that things might be easier if she could follow her mother's advice that 'ignorance is bliss':

*“My mum actually said that to me - you can know too much you know. Then you can sit and worry about things”* (121189p14)

#### **3.5.7.1.4 The effect of previous severe illness**

Women's concerns appeared heightened if they suffer severe acute symptoms rather than chronic problems. One woman, who was sure to treat her infections promptly, was concerned by the experiences of two people who had ignored their symptoms - one a relative, and one, whose story she had seen on a TV documentary

*she did ignore it I think and she ended up in hospital with a kidney infection, so I have heard of people that it has happened to.”* (121189p9)

Others may not have given it great thought until asked to reflect on their experiences:

*“So no, to me it is an inconvenience, it is a nuisance, it is a pain in the arse and I wouldn't worry about it any more than that, but I suppose...you don't know, it is like anything - what effect does it have in the long term”* (12195p9)

### **3.5.7.2 Worries about cancer**

It is unusual for women to associate the possibility of cancer with simple cystitis:

*“Cystitis is not something I would think about - God is it going to cause something drastic like the big C or something like that”* (12195p9)

On the other hand, previous experience of cancer predicts worries about the diagnosis. Two women we interviewed had themselves suffered from cancer (both unrelated to their cystitis) and both admitted to worries about the significance of any recurrent symptoms. However, they managed their own anxieties in different ways:

*“Everybody thinks of all sorts that could be the matter, but you cannot think like that or you would drive yourself mad”* (121274Ap14)

*“I think with having the cancer, everything would make me think is it the cancer again? Everything that I have now I tend to go the doctors, every pain I get”* (12194p6)

A relative of the second interviewee had recurrent cystitis. Although rare, and furthermore, we don't know the precise circumstances, this turned out to be a marker for an underlying cancer. The different approaches of the two women may reflect personality differences, or the effect of external experience, or a complex mix of both.

### **3.5.7.3 Worries about specific symptoms**

Seeing blood in the urine (haematuria) is the symptom that most consistently triggers women's anxiety about their diagnosis. Dragging sensations, incontinence and frequency also appear to create anxiety about their underlying significance.

#### **3.5.7.3.1 Haematuria**

Haematuria is most commonly seen as a marker for severity:

*“If I am weeing and it's red then to me it is severe – that it is doing some sort of permanent damage I suppose. Because it is obviously burning the lining”* (12195p9)

However, many women were unsure as to what precisely it signified:

*“because of the blood, I wasn't sure whether it was anything more or anything to worry about...I hadn't heard of bleeding before”* (121189p1-2)

*“It is hard to put it into words really, what exactly your fear is, but you just feel that as I am bleeding there must be something not quite right” (FG239p10)*

One woman with a previous (non-urological) cancer feared the worse when she had haematuria with cystitis. Other women consider cancer, but generally dismiss it as a serious possibility. An exchange in a focus group illustrates the concerns and uncertainty, which lead women to seek help earlier:

*“You think of five different sorts of cancer...you think it is something more sinister than a urinary infection... there is something different, that's dangerous, so I think you associate it with it being two different things. I would immediately go to the doctor if I had blood in my urine” (FG239p10)*

Others think that blood is a marker for the site of infection:

*“If you get blood in your urine - it is coming from your kidneys isn't it?” (121274p20)*

As expected, many women had microscopic evidence of blood picked up on dipstick testing for possible UTI. The lack of a visible abnormality contributes to a phlegmatic attitude to this finding, but sometimes women's attitudes are coloured by the particular significance attributed to the symptom by health professionals:

*“when they saw blood in it, when the nurse did it, she said you will have to go back in and you know see him (the doctor)” (121274Ap3)*

### **3.5.7.3.2 Incontinence**

Some women worry about incontinence. This is either due to urgency:

*“if you didn't go, you are frightened that you would wet yourself” (121208p4)*

or in one instance, arose from observing the effects on older women:

(incontinence and UTI)... *“I'm not overly concerned about it, but it does become a concern when I do see my mum trying to struggle with the two” (FGD2p19)*

The same participant worried that her bladder irritability was caused by repeated UTIs

*“I cannot hold on for a long time and I always wondered whether the damage from the water infections can cause something like that” (FGD2p20)*

Poor access to toilets leads to worries about (urge) incontinence:

*“You know you're walking about on your job and you're dying to go the toilet and you think you're going to wet yourself, but when you go it is just little trickles” (12185p5)*



### 3.5.7.3.3 Bearing down sensations

Dragging and bearing down are sensations may accompany UTI; as well as being unpleasant women worry that they signify an impending prolapse:

*“You know you can cope with going to the toilet more, but if something does come out, what would I do. You know it is impossible you know, and telling yourself there is nothing can actually fall out of your body.....you know this fear that something is going to fall out. I couldn't make sense of that feeling”* (121275Bp7)

### 3.5.7.4 Worries about immunity and infectivity

Women are worried that their immune system may be less effective after UTI, especially after courses of antibiotics. They are less concerned about passing infections on, possibly through an elementary understanding of the aetiology of UTI.

#### 3.5.7.4.1 Worries about general immunity

Women are concerned about the effects of cystitis on their general immunity:

*“it would worry me that if I did have an infection and it didn't go away and then your body is working on an infection, so it is like you're susceptible to other things because your body is fighting an infection”* (FG87p4)

Some worry about the effects of antibiotics on their immunity, particularly where they need repeated courses:

*“I don't want to get into that spiral of taking antibiotics again...it seemed the more I took them the more I needed them - I don't know whether that was the case, or whether it was just my immune system was so low by that point that it was not fighting things off quite so well”* (FG87p12)

#### 3.5.7.4.2 Worries about the spread of infection

A few women, uncertain about how UTIs develop, are concerned about contagion:

*“They say you cannot pass it on, but you don't know with infections do you?”*

(12185p6)

This uncertainty is further illustrated by this discussion in a focus group:

*“Well it's inside isn't it...It's nothing contagious...if she said I have got a terrible infection on my hand, then I might move seats, but it is inside – it cannot get out can it. Is it contagious?”* (FGNp10)

Interestingly, women appear to have no concerns about passing UTIs sexually to their husbands. On the occasions where it was mentioned, our interviewees seemed aware that they may be confusing thrush (which is contagious) and UTI (which is not):

*“when you have intercourse you are frightened you are passing it on and then you get it back again - you just don't know do you”* (12185p6)

#### **3.5.7.4.3 Hand washing**

*“If I have been to the toilet I always wash my hands thoroughly - because I know it can spread if you don't do that like”* (121910p8)

*“have I picked germs up - touching yourself –you know- that's the only thing I can think of....or was it my cleanliness. Have I not washed my hands”* (121274Bp11)

The possibility of transmitting infection (to oneself) was an occasional fear, perhaps because women recognise that UTIs arise from the body's own bugs. Some mention this fear, however, alongside concerns about dirty toilet seats (other people's bugs).

#### **3.5.7.5 Worries about work and home**

Whilst pain and/or dysuria (in its various perceptual guises) may be the symptoms women complain most about, frequency of micturition seems to be the symptom that has the greatest effect on social or occupational interactions.

##### **3.5.7.5.1 Effects on work**

This varies from the adverse effects of symptoms on women's ability to work at normal capacity to the perceived, probably more than actual, problem of smell associated with the infection that might be noticed by work colleagues.

The worst problem for work was the need to visit the toilet regularly. Apart from disturbing the flow of work in an office situation:

*“I have never had one, but I assume it is embarrassing and uncomfortable and stops you just getting on with things”* (FGNp2)

it was embarrassing to be seen to go the toilet often:

*“You think are the guys thinking - is she going again - maybes they are not thinking that, but you feel that they are thinking that”* (121208p4)

Proximity to toilets and the inability to 'excuse' oneself is a worry:

*“I had to drive to \*\*\*\* every morning, knowing the whole journey that I was desperate to go to the loo, but you are not really desperate to go to the loo, but you are and that's a nightmare”* (12195p2)

*“If you were a check out assistant at Morrisons or Asda it must be purgatory knowing that you have cystitis”* (121208p6)

Two women recounted planning their toilet routine around home visiting schedules:

*“I did say to one of my friends - I hope somebody is going to be in your house when I go to \*\*\*\* - because I might have to call in you know”* (121274Bp16)

These problems translated into concerns, real or imagined, that work colleagues would be inconvenienced, or would question the respondents' work commitment:

*“she had to supervise these day long \*\*\*\* exams and members of staff had to run in every half hour to let her go to the loo”* (FGNp2)

*“I just say to the girls at work if I am at the toilet I am not skiving”* (121208p4)

One woman with more serious infections and an underlying abnormality recounts feeling frustrated that she couldn't return to work because of her condition (one episode entailed four months off work). Most women, however, could work whilst ill, though a few found that their symptoms made it difficult for them to continue:

*“You are getting all hot, you are getting all clammy, you've got this going on in your lower abdomen and it's really hard to concentrate on anything else... I would prefer to come home because you cannot concentrate or anything with the symptoms of it.”* (121145p8-9)

#### **3.5.7.5.2 Social events**

Whilst many women worry about the effect of UTIs on their work, they have fewer concerns about the effect on their social lives. Perhaps, the flexibility of many social activities means that women can tolerate the effects of their symptoms better than when they are at work. Cystitis, however, still reduces women's activities, and acts as a general dampener on their mood and motivation:

*“you don't really want to be with anybody, to talk to anybody and your social life and everything gets affected”* (FG239p16)

*“you could be on a night out and I would have to definitely come home”* (12195p10)

Daily rituals such as picking up the children from school are a greater problem, presumably due to poor access to toilets and an inflexible schedule.

Holidays are a source of concern, especially the difficulties of accessing care:

*“If you were away on holiday I think I would probably die...I know there are doctors abroad, but it must be horrible for people who get it on holiday.... I think I would probably have to go to the rep to see who you had to get in touch with to get a prescription. You just don't know what they would give you abroad”* (12185p10-11)

### **3.5.7.6 Embarrassment**

Most women feel some embarrassment about their UTIs and this may affect their consulting behaviour. They are embarrassed when their illness is uncovered, at work, at home, or whilst accessing health care:

*“when you're out you've to ask people if you can go to their toilet. It's embarrassing. Some people let you go to their toilet and some people don't like it”* (12185p5)

*“It is also very embarrassing if you are in company. You are jumping up and down all the time and everybody keeps looking”* (FG239p8)

*“if you go the chemist and you see a young guy behind the counter you say water infection or maybes just even look on the shelves yourself”* (121208p3)

*“you have to come back through the waiting room, go to the toilet with this bottle and back through the waiting room again - so everyone knows”* (121208p7)

One woman with no previous experience of UTIs also cited the embarrassment of children when they had constantly to ask to be excused at school. Historically, UTIs were stigmatised through a prevalent belief that they are sexually transmitted:

*“I remember her being embarrassed about it and not wanting to tell anyone and not wanting to talk about it. She said her mum had told her not to tell anybody you know, that she had cystitis. So there is a stigma attached to it and I didn't know why...whether it was because her mother realized there was a stigma attached to it from when she was girl you know, and that the only way you could contract it was by sexual contact or whatever, or you know, and she didn't want people to think that about her daughter”* (121189p5)

#### **3.5.7.6.1 Sexuality**

Most women find that sex is the last thing on their minds with a UTI, and others admit that their fears of recurrence affect their sex life even when they are free of infection:

*“the thought of having it is so awful and I know that well, it depends on how vigorous or what position is going to bring it on, so we adjust our sex life accordingly and frequency is less”* (FG87p12)

*“sometimes it is in the back of my mind, will I be alright. It does take away a lot of the pleasure”* (FG239p11)

In a survey of sufferers of the related but more severe condition, interstitial cystitis, one third blamed the break-up of their last relationship on the condition, and their partners commonly noted that women were depressed as a result of persistent symptoms (360).

Some women feel the smell from infected urine lingers; this puts them off sex. The spontaneity of responses in our interviews suggest that this was a major concern:

*“I won't have sex if I have cystitis. You don't feel clean - this odour - because you can smell it you think someone else can smell it”* (121208p10)

Occasionally husbands avoid sex, guilty at their (perceived) part in the illness:

*“he was shocked about the bleeding and I think he felt a little bit guilty that he might have caused it you know”* (121189p7)

Sometimes, anatomical misunderstandings can act as a dampener:

*“if you are getting sort of foreign bodies in your tubes then that cannot be a very good idea can it” ... “that's enough to put you off sex for life – foreign bodies in your tubes”*(FGNp6)

#### **3.5.7.6.2 Feeling dirty**

Some women associate UTIs with feeling dirty, some express no particular opinion, and one participant associated vaginal infections (such as thrush) with feeling dirty, but not UTIs. The brainstorming group, however, put this concept succinctly:

*“bum factor”*; *“thought to be dirty”* (BG1)

*“You do feel like you are unclean really and you do tend to go in the bath”* (121910p11)

Perhaps, the association originates from the role of faecal organisms in the aetiology of UTIs, or from the (unproven) trigger for UTIs, ‘wiping the wrong way’.

#### **3.5.7.6.3 Smelly urine**

Infected urine can be smelly, though not all smelly urine is infected. A fishy smell, in particular, may be associated with infection, but not many women recount having such strong-smelling urine; one describes it as a *“strawy smell”* (FGDp1).

Women, unsurprisingly, are embarrassed when their urine smells strongly:

*“the smell and cloudy urine. It is embarrassing...if the girls were at home and their boyfriends or husbands and they go to the toilet after me I would be embarrassed”* (121208p3)

*“the most upsetting thing I find about urinary infection is that when you do go to the toilet, there is a very strong smell”* (FG239p2)

Smelly urine is an unfortunate, but not debilitating part of their illness for many, but some worry that the smell is more obvious than they think:

*“When my friend said ‘oh it smells’ - and I thought ‘oh can you smell me’ - no, no - you just can yourself”* (121274Bp15)

*“Well I think it smells quite horrible and I think it smells like very strong. I probably don't smell to the outside world, but I am concerned”* (FG87p6)

On the other hand, for women who experience severe urgency and dribbling, the worry can be a reality. Only one participant mentioned this.

### **3.5.8 A HIDDEN ILLNESS: SHARING OR SECRECY?**

*“it is one of those diseases between the waist and the knees”* (12195p12)

#### **3.5.8.1 Is UTI a suitable topic for open discussion?**

Women vary in their approaches to discussing UTI, reflecting their overall approach- whether ‘open’ or ‘closed’ on the subject.

*“but no it isn't the sort of thing you talk about”* (121910p11)

*“it could be a sensitive subject to discuss...I find it a bit uncomfortable sort of talking about my own problems”* (FG87p7)

There appear to be unwritten rules about discussing cystitis:

*“not quite proper to talk about over dinner”* (12195p13)

For some, the ability to talk about UTI in certain circumstances suggests that there is an element of embarrassment but nowadays a reduction in stigma as characterised by an earlier quote from schooldays:

*“Some people might go to the doctors and not give it a second thought explaining their symptoms and other people feel a little bit embarrassed”* (12185p15)

### **3.5.8.2 Recognition of illness by others**

Some women mention that as UTI had no outward signs, it means that there is no recognition of illness. Others mention that they feel a lack of empathy from others (or a lack of understanding) because understanding comes from personal experience:

*“The only people that really understand is the ones who have it as bad as you and you know you don't go round with a sticker saying have you got cystitis as bad as me!”*  
(FG87p7)

Moreover, some feel it is ‘hidden’ because men didn’t suffer from it (and don’t understand it); others because it wasn’t seen as a priority compared to other diseases:

*“but because it is a female orientated disease - there is maybes not so much done on it”*  
(12195p12)

*“You go to our surgery and everything seems to be about diabetics, but there is nothing about water infections or symptoms you should be looking out for.”*(12125p9)

### **3.5.8.3 Who do women talk to about UTIs?**

Mostly, and preferentially, they talk to other women, normally relatives or friends

*“Thrush and cystitis, women know quite a lot about those things, down below type things”*  
(121189p5)

#### **3.5.8.3.1 Relatives**

Women appear willing to confide in female relatives and in female doctors, and especially (female) relatives who are medical professionals! Most would confide in their husbands or partners, but not with other male relatives, either perceiving that men wouldn’t understand a predominantly woman’s illness, or out of embarrassment:

*“I mean it wouldn't bother me if it was a male nurse, but I wouldn't like to talk to males in the family, like my father or anything like that, I think I would feel embarrassed”*  
(12185p7)

*“if you talk to a man they don't have a clue - like what are you on about?”* (12125p8)

Male relatives may react with indifference as this ‘Venus and Mars’ scene suggests:

*“Well my brother was there when I was telling my sister in law, but he wasn't taking any notice because he was too busy with his computer, asking me what to do with it....so I don't think he heard a blind thing!”*(121274Bp6)

Some purposefully hide their illness through embarrassment, some to avoid worrying family members unduly in the presence of potentially serious symptoms.

*“If I was out of fettle and you cannot be bothered, I would try to make a different excuse for what I had - I wouldn't like to say I have got so and so”* (12185p7)

This concern increases when a face-to-face explanation is impractical:

*“she isn't up here - she is a hundred miles away. I wouldn't like her to worry unduly about me. If I phoned her and said I had been passing blood, she might worry unduly about it”* (121189p13)

#### **3.5.8.3.2 Friends and work colleagues**

Friends are the next most important confidantes:

*“You are not made to feel ashamed about things any more like you used to be and women feel comfortable talking about these things with their best friends and they are able to open up quite easily about things”* (121189p12)

The workplace is a common source of discussion as well. Some women would *“sort of have a laugh and a joke about it”* (121910p6) with female colleagues at work even though they felt it inappropriate for discussion with men: none of our respondents suggested that they would confide in male work colleagues:

*“I talk to the girls about it no problem - I don't find it embarrassing”* (121208p9)

*“This is the coffee morning scenario you see. It is the sort of thing women talk about”* (121189p11)

On the other hand, men's diseases are seen as fair game for everyone to discuss:

*“I get funny stories at work about men's experiences of vasectomy. You don't have funny stories about cystitis and I think women's diseases in that sense are a bit less talked about”* (12195p12)

#### **3.5.8.4 Generational differences**

Almost universally, women believe that there is greater openness about UTI (and other previously 'hidden' problems) than in the past:

*“years ago I think, like anything, it wasn't talked about, was it?”* (12195p13)

and a few women go as far as suggesting such discussion was previously frowned upon, and that this is caused by a different upbringing:



*“I think it is like most things in this day and age that things are less taboo than they were”*  
(12195p12)

*“the younger ones are more open...we were brought up a different way”* (12194p7)

Many women recall that their mothers didn't talk to them about problems, generally explaining this as a generational issue:

*“She was quite old fashioned. She couldn't talk you about things”* (121274B21)

One woman explained this as a personality issue, though, the impression given is that her mother was a 'woman of her times', and that such an attitude was common:

*“My mam is not the type - when they are old they don't talk about things...my mam never told me nothing about anything”* (121274Ap10)

Some women compare their mothers' attitudes to their own with the next generation:

*“I can talk to my daughters (about UTIs), but I couldn't talk to my mother” ...“they say to me - oh mam I am itchy down below or I have a pain and they can talk about it, where I couldn't with my mother. It was a different attitude then”* (12194p8)

Of course, current generations may find their mothers relatively inhibited as well (or perhaps, embarrassingly open), but we are unable to test this out.

In the workplace or in friendship groups, participants suggest that younger women are generally more open about potentially embarrassing topics, including UTIs:

*“I think people generally now talk much more openly about things. It is not so much swept under the carpet. You are not made to feel ashamed about things any more like you used to be and women feel comfortable talking about these things with their best friends and they are able to open up quite easily about things”*(121189p12)

*“it has become a lot less taboo than it used to be. It is the same as rape, or child abuse, or whatever - but all of these subjects are talked about a lot more openly than they used to be”*(12195p13)

#### **3.5.8.4.1 But what about experience?**

One twist in this tale, however, is that some women feel that experience, in particular, serious illness and childbirth and all their ignominies cause them to unshackle inhibitions and become more open. This contradicts the generational concept, but perhaps prevailing taboo is stronger than the effect of experience:

*“But once you’ve had an episiotomy, you no longer give a toss about anything”*  
(Winkleman,C) (361)

*“they do this radiotherapy with you all bare and that, so I don't think anything would upset me now in that way, talking about anything now.”*(12194p7)

General life experience, specific experiences related to work or previous health care, or age itself leads to less embarrassment:

*“Maybe when I was younger I might have been (embarrassed), because I didn't have much understanding about it”* (121189p11)

*“I don't get embarrassed by many things - because of the people I have worked with and the places I have been”* (12195p14) – a non-health care worker

*“I cannot see why it is embarrassing. No - not when you have worked in a hospital...you lose your dignity anyhow so”.* (121274Ap22)

### **3.5.9 TREATMENT**

Women report a need for immediate relief, antibiotic treatment, and the wish to ‘flush out’ the infection. Their need is determined by the presence of pain and discomfort, and sometimes by a fear that the symptoms will get worse unless acted upon. Such early action may take the form of self-treatment or trips to the chemists or doctors.

#### **3.5.9.1 Self treatment**

Women vary in their attendances to doctors: some visit for nearly every infection, some for very few. Their expressed reason for this is severity of symptoms rather than any other aspect of consulting behaviour. Women use self- or over-the-counter (OTC) treatments early in their illness and when they adjudge their infections to be less severe but they perceive that such treatments are less effective and something to tide them over till a doctor’s appointment:

*“The over-the-counter remedies obviously don't cure it, but they hold it at bay”*(12195p2)

*“You get all of this sort of 'mixey' up stuff, mix with water and drink this and all that sort of thing from over the counter.”* (12195p2)

However, they seek medical help and antibiotics for more severe infections or if the OTC treatments fail to improve symptoms:

*“but I think at the end of the day you still need to go to the Doctors and get antibiotics, because I don't think any of that other takes if off.”* (12185p4)

Despite this, women are keen to manage their own illness if the means are available:

*“I think you should be able to buy something over-the-counter, better than what you can.”* (12185p2)

They may propose a graded response depending on the severity of the infection:

*“Drink lots of water and if it starts to get a little bit stronger, that's when I will start to drink cranberry juice and take the bicarbonate of soda and usually about a pint of water every three hours or something, and usually I find that it doesn't develop into anything else, or if it does, it just lasts for a few days and then eventually clears up”* (FG87p4)

Remoteness from services may determine women's choice of treatments:

*“you are not round the corner from the local Chemist, so I always have something in the house and I just start treating myself”* (12195p2)

The most common forms of self-therapy are drinking plenty of water, cranberry juice, and OTC remedies, especially cystopurin (Mist.Potassium Citrate). Analgesics are also used as well as the many self-treatments previously mentioned. One woman mentioned camomile tea, whilst another mentioned tea tree oil, but it is unclear how the latter was used.

#### **3.5.9.1.1 Cranberry**

Women considered cranberry preferable for a UTI in certain circumstances. One considered it whenever her urine became smelly or dark, but would then use antibiotics if cranberry was ineffective; others saw it as a treatment of mild infection; one woman wanted to avoid adding to her medicine list:

*“The last time I had it I didn't go to the doctors I just got some cranberry juice and I drank a lot of that and a lot of water, because I was on that many tablets, I didn't want to take any more tablets”* (12194p1)

#### **3.5.9.1.2 Prevention**

Some women link good health and healthy lifestyles with reducing the risk of UTIs. Many women, as we have seen, have difficulty in pinpointing triggers to their UTIs, so unsurprisingly, they didn't feel able to take preventative measures:

*“I haven't figured out how I got it, so I cannot figure out how I can do anything different you know”*(121275Bp13)

Some women identify triggers, but they are often inconsistent, and women only take avoidance action if they feel it is an easy option. Common examples are avoiding bath additives and soaps, or actions to reduce infection after sex:

*“but I am always getting a shower or a bath or make sure that I go to the toilet afterwards, so that it doesn't sort of leave any chance of infection really in that sort of area, but it doesn't always work.”* (FGDp16)

As detailed in earlier chapters, cranberry is mildly beneficial as a preventative treatment, but it can be unpalatable (unless mixed with orange juice). Perhaps, this reduces its appeal, and women who opted for this generally used it intermittently:

*“I don't drink cranberry juice all the time - I should really have a glass every day - with having problems with my kidneys - but I don't.”* (121275Ap6)

#### **3.5.9.1.3 Drinking more fluids and ‘clearing the system’**

Many women believe that drinking large amounts of water can flush infections out of the kidneys and bladder, but it seems to be taken with a good dose of scepticism:

*“You are supposed to drink eight glasses of water a day...maybes it will flush my kidneys out and get rid of the infection a bit more”.* (91003p4)

A number of women had found with experience that drinking extra fluids appeared to have no beneficial effects, and had given up on this ‘treatment’. One interviewee’s belief in the benefits was strengthened by a slimming clinic, which encouraged clients to “flush the system”. Some women do feel that passing large volumes of water reduce painful symptoms but just as many are sceptical:

*“Everyone says you have got to drink, drink, drink, but the more you drink the more you need to go to the toilet, so the more you have to go through the shudder of this pain and it is really a vicious circle.”* (121145p2)

*“The more you drink the more you’ll flush things out and the better it’ll be, you know - but it didn't work. I just spent more time on the toilet altogether.”*(121274Bp2)

*“It is just hearsay: if you drink more you flush the infection out. How it works I don't know, but you’ll try it thinking it could help...it could be more comfortable”* (121208p7)

#### 3.5.9.1.4 Physiomechanical means

Some women, and their doctors, considered that bladder emptying rather than urine volume was the key:

*“You are supposed to pee after sex aren’t you to clear everything out”.* (FGNp6)

*“One doctor said to me that if you feel you don't empty the bladder, stand up a little bit so you are not actually sitting down and then you get the rest out and I have been doing that and I think that has really helped me.”* (FG239p15)

and some considered that failing to empty their bladder would prolong the symptoms:

*“I think sometimes I prolong the cystitis because I don't go as often as I really should do because it is really painful every time I go”* (FG239p8)

#### 3.5.9.2 Medical Treatment

Although some women self-medicate as a first step, they turn to antibiotics when the alternatives fail. Few women use antibiotics as an immediate first line treatment in all cases; instead they save this strategy for when their initial symptoms are more severe. Some women suffer from thrush with antibiotics and this significantly affects consultation behaviour. Expectations in an era of rapid medical advances, however, may be high:

*“You’d think they’d find something better now to cure it altogether. That's what I feel. Like a better medication - once you have took it, that's it gone.”* (12185p9)

##### 3.5.9.2.1 Antibiotics

Quite a lot of women find that antibiotics give them immediate relief:

*“It kicks in and it sorts it straight away.”* (12195p7)

*“You get this horrible pain to go to the toilet, but until you go to the Doctors to get whatever tablets he gives you to relieve the infection...I need something there and then – it’s urgent... (what happens once you have got the antibiotic?)..well it will only take two hours”* (121145p2/9)

As a result, women suffering more severe and more acute illnesses, and women with recurrent UTI who ‘know what’s going to happen’ will seek immediate relief. One suggestion was a ‘rescue dose’ of antibiotics, which is used in some other illnesses:

*“I would like to think I had some antibiotics in ready. That means you don't have to go to the Doctors. There are a lot of people more poorly with illnesses than cystitis, but cystitis*

*still has to be treated because it is an awful feeling and it would help to have something in the house ready” (12185p14)*

#### **3.5.9.2.2 Empirical treatment**

A few women commented on doctors’ prescribing habits, which can be variable - a different length of antibiotic courses, and the use or otherwise of empirical treatments:

*“You're bad - then they say see how you go or sometimes the doctor would give you something until the results came back” (12125p16)*

With empirical treatment women receive antibiotics at their first contact, and prior to or without the results of investigations. Most women are very happy with this approach, but others are concerned about the imprecision, though the following quote suggests that communication of an effective management strategy was lacking:

*“They weren't sure if they were the right ones that were to cover the water infection that you had. Hit and miss. Very hit and miss” (FGD1p2)*

On the other hand, one participant recounted a very informative discussion about the reasons for false negative tests and the benefit of symptomatic treatment:

*“He said some ladies could just be under that barrier and you'd still need treatment for it. It doesn't say because they say she is under, she shouldn't need anything. We know they tend to go off the symptoms you tell them as well” (12185p16)*

#### **3.5.9.2.3 Delayed treatment and spontaneous regression**

A number of publications suggest that UTIs regress spontaneously, but no one in the interviews had consciously ‘sat it out’. One woman who had never suffered a UTI wondered if minor illness might regress. Someone with very frequent UTI mirrored this thought, but it is a situation that may be infrequent:

*“I mean I would presume it would get worse and worse until something horrendous happened, but I suppose a minor shot of it may go away itself” (FGNp7)*

*“I could maybe's count on one hand the times that I haven't and it has cleared up with drinking plenty and it has just been like a touch of cystitis” (FGDp17)*

A delayed treatment strategy per se, or due to a policy of treatment based on results may only be acceptable to women with mild symptoms:

*“sometimes you would either really suffer for two days, while there was nothing done in between, or if you were lucky they would prescribe some antibiotics” (FGDp16)*

#### **3.5.9.2.4 Side-effects**

Thrush is a common complication of antibiotic treatment. For some women, the symptoms of thrush are worse than the symptoms of UTI and can inhibit them from seeking treatment or can lead to non-compliance:

*“I don't like going to the Doctors to get antibiotics because I always get thrush afterwards” (FG239p2)*

*“Sometimes I explain that it isn't worth it because of the thrush, but they say it is the only way they can treat it” (12125p2)*

*“Sometimes I might not finish the antibiotics. Because thrush is more uncomfortable than cystitis” (12125p11)*

Women appear to have few concerns about other side effects, and none of our women had suffered from allergic responses to urinary antibiotics:

*“If you read the side effects on some tablets you would never take anything would you?” (12195p10)*

#### **3.5.9.3 Complementary Medicine**

One might expect herbal (non-vitamin, non-mineral, natural) products to form the majority of alternative medical therapies tried by our participants as up to 1 in 5 people in the USA use these (362). Perhaps, due to the availability and acceptability of simple over-the-counter or home remedy measures such as Cranberry Juice, Potassium Citrate, and barley waters, which may be viewed as both mainstream and alternative, there seemed to be little demand for complementary medicines. Most considered complementary medicine as supplementing rather than supplanting conventional medicine:

*“I hate people who say alternative, because it's not an alternative – it's complementary - you use it to boost conventional medicine” (121247Bp9)*

Complementary medicine is considered better for prevention than cure

*“I like to think that if there is a way of preventing things, I am not so sure about treating and curing things, but certainly prevention” (121189p4) – about ‘holistic therapy’*

Women use complementary medicines for chronic problems, rather than acute relief, sometimes citing that they needed a quick and reliable response. Women who used complementary therapies were positive about their effects but when they were observers there was much greater scepticism:

*“I don’t know whether it works or not, I think half of it is psychological”* (FGNp12)

### 3.5.9.3.1 Reflexology

The commonest alternative therapy for UTI in our sample was reflexology. Three women had experienced this therapy and all were positive, two extremely so. In two cases, the reflexologist had impressed our participants by diagnosing their urinary problems from feeling their feet and without any obvious prompt or prior discussion of symptoms:

*“I could feel a very strong sensation in the bladder region which you know I thought was a bit funny when she was just manipulating my feet”* (FG239p6)

One woman had viewed reflexology as a relaxation technique rather than an alternative method of managing disease and was initially sceptical:

*“I just went because I thought it would be a treat to go and get pampered and have my feet rubbed”* (FG87p9)

but was impressed by a spontaneous and unprompted diagnosis:

*“Without going into my medical problems...I didn't mention cystitis, I didn't think it was relevant and it was when she was going over the different points in my feet...she said – ‘oh, do you have any problems with your bladder?’ And she hadn't really picked up anything else, and I said I do actually”* (FG87p9)

Two women with frequent recurrences of UTI had gone for regular reflexology. One felt that reflexology had helped strengthen her immune system, the other had been told of ‘irreversible changes in her bladder’ but felt that reflexology had benefited her more than prophylactic antibiotics, or surgical intervention:

*“for years and years it was there more than it wasn't - it interfered with all aspects of my life and then as I say since I have been having the reflexology all I can say is that it has been so much better, it just seems too big a coincidence”* (FG239p5)

One woman who had tried complementary therapies for another condition in the past (and was still positive about their use) was wary about taking them now as she was on number of different tablets:



*“I wouldn't take anything else or try alternative therapies even now because I don't want to upset things” (12194p3)*

#### **3.5.9.3.2 Other forms of complementary medicine**

Our sampling strategy is unlikely to have led to saturation on this subject so we cannot be sure of the breadth of use of complementary medicine. One acquaintance of an interviewee used homoeopathy, and one woman tried both Reiki, which she used as a daily pick-me-up, and ‘crystals’

*“I tried making elixirs with the crystals - because they are supposed to help like kidneys and things - it has something to do with the water” (121274Bp9)*

Whilst neither was effective, she felt that the calmness induced by Reiki had enabled her to manage her painful symptoms more effectively:

*“I feel as though I can deal with pain and I cope with it a lot more easier than people who don't do Reiki - that's what complementaries do. They help you deal with you know things easier - you know - you don't go down the depression route” (121274Bp10)*

#### **3.5.9.4 Temperature as a treatment**

Temperature change or taking hot or cold fluids is common method of combating symptoms. Heat could be applied in a variety of ways- hot water bottles, putting socks on, or soaking in a bath (or on a bidet), a method that had a strong following:

*“Have a nice warm bath and just feel warm and cosy and hide away to relax” (FGDp18)*

*“I cannot tell you what it is about the bath, I don't know if it makes me relax or whether it is the heat that takes the tummy ache away, I don't know what it is - but I must get in the bath” (121145p11)*

One variation on this theme, passing urine in a warm bath, appears to have quite widespread following, and this advice was later quoted in a national newspaper (360).

*“I did read once... if you pass urine under water, have you read that, it helps. I did try that and it did help, though it didn't get rid of it” (FG87p6)*

Mostly heat is applied externally, but some thought warm drinks helpful:

*“When the infection has set in, hot tea. I don't know why” (FGD2p17)*

Women more commonly cited heat rather than cold as helpful. Logically, if heat helps, then cold should make things worse, though a substantial minority found the application of cold helpful – either externally, or through cold fluids:

*“I am always in the bath when I have got that ... just a cool bath”* (121910p11)

*“When I have finished the tablets, I just keep drinking loads of cold water - that’s all I stick to”* (12185p5)

### **3.5.9.5 Acid and alkali**

A few women viewed their symptom of dysuria as an *“acid and burning sensation”* (12195p5), and thought that acidity of urine caused pathological changes:

*“I presume acidity affected the lining and that’s when you start bleeding.* (12195p2)

It is uncertain where this concept comes: acids cause burns and indigestion from excess stomach acid causes a burning sensation, so there are precedents! As a consequence of this, women consider alkalis a good choice of treatment, as they neutralise acids: *“alkalis, counter-attack acid urine”* (BGp3). If the acid can be neutralised, the theory goes, then the acid symptoms disappear. A few women think that equates to cure; others consider it symptomatic relief:

*“I think it is just to restore the pH in your bladder to like a more sort of normal level. It just helps sort of ease the symptoms and the burning sensation”* (FG87p5)

One woman, however, who had not had a UTI, questioned the idea of acidity:

*“I have just had a thought, whether it is to do with your pH of your urine as well. You know whether it is acidic or alkaline because cranberry juice whatever, would probably be more acidic”* (FGNp3)

### **3.5.10 CONSULTATIONS FOR UTI**

Pain is the most accurate predictor of whether women consult. They often feel that their symptoms are trivial, but the need for symptom relief overcomes their guilt. Female doctors are preferred as they are expected to understand better or to have had similar experiences, but life-experience, openness and illness severity alter women’s consulting behaviour. In trivialising, women appear to assume everyone, including clinicians, will not take their illness seriously as it has no outward signs.

#### **3.5.10.1 Why do women consult?**

Women do not consult for every urine infection:

*“I get it more than twice a year, but it is only maybe twice a year I take antibiotics and go to the doctors for it” (121274Ap29)*

Pain, severity of illness, and previous experience appear to be the three factors that are most likely to cause women to consult their doctors:

*“...probably if I was experiencing the pain to be honest. If it was a bit more frequent. I probably wouldn't think about going straight away I would give it a few days, but if there was pain then I would go then” (FGNp11)*

*“If you have never had it before and it starts, maybe you should dash to the doctors straight away, because you don't know what it is” (12195p5)*

Some women are keen to manage illnesses on their own if they can. Those expressing this sentiment would still alter their approach if they felt an episode was more serious:

*“I am not a Doctor's person to be honest with you - I would rather treat something myself” (121208p3)*

*“if I can drink and get in the bath and if I can look after myself I will, but if it really is acute and I cannot stand it, I have got to go to the doctors” (121145p5)*

and embarrassment may be a factor in the decision to consult:

*“I mean these sort of diseases - like any of them - like thrush and all the rest of it - people do not tend to talk about it and that's maybes why people don't dash to the doctors or they use over the counter remedies more” (12195p5)*

#### **3.5.10.1.1 Symptom scripts and consultation behaviour**

Specific patterns of symptoms may dictate consultation behaviour:

*“I would immediately go to the doctor if I had blood in my urine, but just having light cystitis I wouldn't go to the doctor, I would try for a week at least to cure myself” (FG239p10)*

Women have different predominant patterns of illness. Many, but by no means all, women develop severe symptoms sooner or later: some have severe symptoms straight away; others develop severe after initial mild symptoms. One woman, who described ‘infections’ as less severe than a bout of ‘cystitis’, would only attend if she had ‘cystitis’. Such variation leads to different consulting behaviour.

*“...but when you get where you are only passing a spoonful and it is so sore and there is pain, then that is when I would go, when it gets to the point where you are dying to pass water and as I say, you go and only pass a spoonful. You get desperate. That's when I would go to the doctor”* (12194p2)

#### **3.5.10.1.2 Avoidance of consultation**

Quite a few women try and avoid going to the doctors as long as they can

*“I only go to the Doctors if I have to - desperate measures you know”* (121274Bp2)

Visits to the doctors are passports to antibiotic prescriptions:

*“I have to be forced to - before I go. And that is only if I need an antibiotic which you cannot buy over the counter”* (121274Ap9)

but as previously noted, worries that antibiotics will trigger thrush cause some women to be reluctant consulters. A number of women expressed a wish for more effective treatments at the chemist, and one was more specific:

*“It would be loads better if you could just go to the Chemist and buy something and you have got something in at hand”* (12185p16/17)

#### **3.5.10.2 Triviality and being a nuisance**

Many women feel that they may be bothering doctors unnecessarily; some feel as if they're a nuisance, and others suggest that many fellow patients appear more in need of care when they attend their surgery:

*“I feel as if we are wasting the Doctors time and I am not with the symptoms I've got, but you feel the pressure they are under with other people in the surgery”* (12185p15)

On the other hand, many of the same women felt that their symptoms were serious, and antibiotic treatment was the only way they would get relief:

*“Talking about it now it sounds trivial, but it is serious at the time when it happens to you”* (121208p6)

*“I don't like going to the doctors... because I always think it's a sort of a waste of his time because you are not ill, but then you are...” you just cannot cope, it is incapacitating, it progressively gets worse if you don't treat it”*(121208p4)

Many women experience on occasions the combination of typical cystitis symptoms and a negative urine test (dipstick or culture). This is more likely to make them feel a nuisance, but at the same time they are left perplexed by this apparent contradiction:

*“I leave it and leave it and leave it and then when you do go, they cannot find anything. I feel like a fraud or a hypochondriac”* (FG87p1)

*“you ring up and they’ll say the results are okay, but what does that mean, you know, you don’t know what that means. Is there anything there, is there nothing there and you just feel that it was a complete waste of time and next time I think, well I won’t go”* (FG87p2)

Even women with severe and recurrent episodes express reluctance to attend their surgeries, despite holding positive views about their doctors. On the other hand, those who receive minimal contact and a mechanical approach to treatment appear to feel short-changed by this. Some have questions for their doctors, but whether they forget to ask, feel that time is short, or are too embarrassed by the consultation, they would like to go back but were inhibited from doing so:

*“You go to the doctors and you know you have only got seven minutes or whatever it is that your allocated, and you feel as though if you talk any longer than that, you are being a nuisance - you are going into it too deeply and there is this thing”* (121189p14)

#### **3.5.10.2.1 Seeking reassurance**

Women’s feelings of triviality lead women to avoid consultations where they are seeking reassurance:

*“What I really should have done is gone back to the Doctor and discuss it with him more, but you feel as though you are a nuisance and you are a neurotic woman and you know he has got far more important things to deal with. If you keep going back to the doctors you would get a reputation for being a hypochondriac”* (121189p13)

This sense is magnified by the belief that UTI is a ‘normal illness’:

*“I just thought it was something that all women got and you had to put up with”* (FG239p5)

#### **3.5.10.3 Access to health care**

Opinions are divided on ease of access to doctors

*“Well it is just not worth bothering them - they are always busy and it takes that long to get an appointment”* (121274Ap9)

*“...you feel as if you have to have something done that day - that's the impression - they'll say can you come now”* (12185p16)

Access is not a simple concept and ease of access is sometimes judged by the availability of convenient appointments or appointments with specific doctors:

*“It is not always possible to get an appointment - so that's what puts me off. With working as well”* (121208p4)

Most requests for specific doctors are preference for a known and trusted doctor and one or two participants had found wider problems with continuity of care, which they felt adversely affected their consultations:

*“There is problems with continuity and building up a relationship with a doctor. I have seen several doctors here, locums and temporary doctors. It is so frustrating when you cannot get to see who you want”* (121189p14)

Women, however, will take any immediate appointment on offer if they perceive their infection to be severe:

*“I mean sometimes if I want a certain doctor it could be two weeks - if my kidneys are bad I am not waiting two weeks. I will just see whoever is on”* (121274Ap23)

Some women perceive that access to health care is variable. Perhaps, there is a preference for walk-in clinics for acute problems, though systems in participating surgeries appear to have a direct influence on women's ideas:

*“you know you can go to the Doctors and you don't have to phone up and get an appointment, it is very good I think. In the town you have to wait two to three days for an appointment don't you?”* (12194p10)

NHS direct received only one mention - from a woman with no previous UTIs. It may have a particular role in providing initial advice for women with less knowledge and experience of the condition. In this case, it would provide a passport to consultation:

*“The first thing I would do is 'phone the NHS helpline... if I had to go to the doctors straight away I'd insist on an appointment for the next day and I would say I had spoke to the NHS helpline and they say I must see a doctor today, this is very important”* (FGNp9)

Sometimes, however, we forget how accessible health care is in the UK. Compare this with one women's experience on board a ship:

*“he (the Chief Steward) had a look in the book and he said it is not in the book, and I said it must be in the book ‘how are you spelling it’, ‘well S’, ‘no it begins with a C’ and he said ‘Oh that’s probably why I cannot find it’, which doesn’t instil you with a lot of confidence in these people. But again, once he spelled it right he found it and yes I got the tablets”* (12195p3)

### **3.5.10.3.1 Alternative ways of providing consultations**

A few women from different surgeries (which suggests that this was not an isolated arrangement) report that their doctors have a system for leaving urine tests and having their illness treated without a face-to-face consultation.

*“Dr \*\*\*\*’s a doctor we never had to see. We put a sample in a bottle and the medication was there for you”* (FGDp13)

Telephone consultations may afford more direct contact, but not everyone is comfortable with these:

*“I always get flustered on the ‘phone. I never know what to say - I get all flustered - I prefer one-to-one you know”* (121274Ap26)

*“It is very disjointed talking to someone over the phone. They cannot see you, they cannot see how you feel - I know you cannot see how a person feels - but you can see if they are distressed or if they are worried or upset”* (121274Bp16)

Prescribing without an appointment is seen as a ‘double-edged sword’- whilst it provides easy of access, women value a face-to-face consultation.

Women may use nurses as a quicker mechanism for accessing healthcare:

*“Yes seeing the nurse....she just put the sample up against the chart, but still sent it away, but it is quicker for you to get treated”* (12185p16)

Women found this approach useful if they preferred to explain their symptoms to a woman, or if these symptoms poorly reflected severity or the presence of infection.

### **3.5.10.3.2 Referrals**

Generally women don’t seek referrals for UTI, presumably because discussions with relatives, doctors, or other sufferers are reassuring, and there are other concerns:

*“if you go into hospital with one thing - you come out with another - so I wouldn’t go in”* (12127Ap15) – predating the majority of the media scares regarding ‘superbugs’

One woman had suffered complications and in retrospect considered that earlier referral may have helped (though acute admissions hadn't led to any follow-up):

*"I think from that point I should have been referred to the hospital because it obviously wasn't going to go away"* (FGDp9)

#### **3.5.10.4 When do women decide to consult?**

Women often delay treatment with antibiotics, seeking help when their symptoms are, or become, more severe, or if particular symptoms worry them more than normal (e.g. bleeding). One suggested waiting a week. Others would wait less:

*"Probably if I have had it a day...I just want some antibiotics to get rid of it because I know it is not going to go away"* (12195p5)

Medical staff also react differently. Women commonly mention that their illness is taken more seriously if blood, especially if visible, is present:

*"Normally they send it away and you get your antibiotics when it comes back, but when they saw blood in it...she said you are going to need antibiotics"* (27405Ap3)

Others think they aren't assertive enough about getting appointments:

*"My leg is hanging off, I can see the bone, when can I see the doctor"* (1212011p9)

##### **3.5.10.4.1 Reluctant diagnosis**

Women sometimes find their doctors sceptical about their symptoms and diagnosis, especially when they had no previous history, or had atypical symptoms:

*"I was sure that I had a urine infection because of burning sensations and he absolutely denied it and said it couldn't be, but then finally when I pressed him, he allowed me to have a test, you know, a urine test and he admitted and put me on antibiotics"*(FG239p2)

#### **3.5.10.5 Does the gender of the clinician matter?**

##### **3.5.10.5.1 Influence on women's health-seeking behaviour**

A number of women suggest that their health-seeking behaviour is altered by the gender of their GP. Sometimes this leads them to manage UTIs themselves:

*"I just used to think I will just get some Cystopurin from the chemist instead of going to the doctors. Yes maybes if it had been a lady I might have gone to the doctors"* (121910p5)

Most women think that female doctors are easier to talk to about UTIs. A few confide more readily with women doctors on any subject:



*“Yes just easier to talk to. For me in my experience, I can express myself easier to her than a male doctor” (121910p6)*

A lot of women are keen to point out that they are very happy with seeing male GPs, but just not for ‘women’s problems’:

*“I am not getting at them because they have always been brilliant, don't get me wrong and they have always treated it and they have always been very sympathetic and all the rest of it, but it is what I said to you, if you have never experienced something, as much as you can be sympathetic, you cannot get down to that level, you cannot truly appreciate” (12195p14)*

One woman suggested that the likelihood of being examined determined whom she would choose to consult. Perhaps, if examination were a standard part of consultations for UTI then more women would have been influenced in their choice of doctor:

*“I mean if I go for other things down below - I would go to a female doctor...as long as they don't examine me I am alright with a male. I would prefer a female, but you cannot always get one can you” (121274Ap22...23)*

A few others suggested that embarrassment regarding the condition, rather than any procedures, was the prime determinant on who and when to consult:

*“some people might go to the doctors and not give it a second thought explaining their symptoms and other people feel a little bit embarrassed” (12185p15)*

### **3.5.10.5.2 Influence on women’s consultation behaviour**

Women’s consultation behaviour may also differ according to the gender of the doctor, employing a more mechanical, symptom-based approach with male GPs:

*“I don't tell him about the dribbling. I just tell him about the pain and hopefully he will give me something to take the pain away” (121145p10)*

*“He is a person I could always talk to but when it was a problem down below I would say (quietly spoken) ‘well I am sore down below doctor’, but now I think I would just say ‘Doctor I think have cystitis, can you give me anything.’(12194p7) - following a life experience this participant felt she had become more open about health problems.*

A number of women think that shared experience, of a ‘woman’s body’ or a ‘woman’s mind’, if not the particular condition of cystitis helps female doctors to understand their predicament:

*“a female doctor knows more about a woman's body because they know what it is like to live in one”* (121274Bp5)

*“male doctors just don't think the same as - well they don't - they can't. Women think differently”* (121274Bp5)

Sometimes to facilitate discussion of their illness with a female health professional, women would preferentially consult nurses:

*“So get in to see the nurse before the doctor because she is a lady and she can understand”* (12185p15)

#### **3.5.10.5.3 Empathy not gender?**

Although most women prefer female GPs for this condition, others value a ‘sympathetic ear’ as much as or more than gender:

*“Being understanding, being sympathetic, have time to listen”* (FG87p7)

*“you get vibes about which one you can talk to and who would be sympathetic”* (121189p14)

#### **3.5.10.6 Do attitudes change according to circumstances?**

Holidays or travel away from home for prolonged periods (such as two or more weeks) appeared to alter women’s usual attitudes to their illness-seeking behaviour.

*“it was getting near my holidays and I wanted it sorting out before I went, so I had better go to the doctors, or else I probably wouldn't have gone and just sort of soldiered on”* (121910p6)

In these circumstances, women who might postpone visiting their doctors, would overcome their inhibitions and embarrassment to ask for antibiotics ‘just in case’. Antibiotics can be more easily available abroad, but fear of the unknown, a lack of knowledge or previous experience of how to obtain prescriptions created anxiety:

*“I think I would probably have to go to the rep to see who you had to get in touch with to get a prescription. You just don't know what they would give you abroad”* (12185p11)

Women had a lower threshold for consulting before weekends, when only emergency cover would be available:

*“I am thinking to myself I cannot go all weekend feeling the way I was, especially over the weekend and how much worse it could get”* (121208p8)

### **3.5.10.7 Faith (or lack of faith) in doctors**

In previous sections I demonstrated that women's faith in regular doctors and continuity of care is a valued commodity. Positive statements about doctors, whilst quite common, were usually brief, whereas there was a deeper exploration of women's experiences when they had encountered problems. A typical example of a brief positive statement is:

*"He mustn't be worried, so why should I?"* (121274A14)

A few were more expansive about the reassurance gained from a consultation:

*"Weeks and weeks and weeks of sitting and worrying about things or worrying about one particular thing in your mind, and a ten minute conversation can just get rid of that"* (121189p14)

One woman expressed some concern regarding the possibility of all her tablets interacting, but she had faith that her doctor would spot anything important:

*"the doctor knows which tablets I take all the time, so knows which is the best ones to give me when I have anything like that"* (12194p5)

Women hold a range of viewpoints, and whilst questioning health professionals is of our time, in general they are still accorded the benefit of the doubt:

*"Is it just the fact that you take antibiotics and the symptoms clear up, is that enough for the doctors to say yes that's what it was and to be happy with the diagnosis"* (121189p8)

Another woman had changed her perception of doctors from 'blind faith' to a more critical, but still positive, viewpoint in a more equal partnership:

*"I used to have the opinion that the doctor was God and they could never be wrong because they know everything about you and if the doctor says don't worry it's nothing to worry about. I believed them when I was younger, but as you get older you learn and now I question, you know, a lot more than I perhaps did in my teens"* (FGNp8-9)

#### **3.5.10.7.1 Adverse experience**

Adverse comment was most often about missed diagnoses and communication issues.

This participant had recurrent severe UTIs without further investigation and was found to have underlying disease:

*"They put me on long term antibiotics; I think from that point I should have been referred to the hospital because it obviously wasn't going to go away"* (FGDp9)

One comment related to a disagreement over the urgency of a (night) call:

*“Mum called the doctor and he was a bit annoyed at having to come out at night and he told me to act my age and he didn't do anything, but it got worse, so mum 'phoned up again and a different doctor came out... and gave me antibiotics” (FG239p4)*

#### **3.5.10.7.2 Communication issues**

One participant wondered if a recently diagnosed, but possibly longstanding, chronic illness had caused her to suffer UTIs for many years. Unfortunately, she felt her doctor had failed to address her concerns:

*“‘You're okay, those tablets will clear that up' and that was it, the only answer I ever got” (FGDp15)*

Some adverse comments may have arisen from misunderstandings; this is a comment from someone who appeared to suffer from a vaginal condition more often than UTI:

*“I go, but they never get to the bottom of it or tell me anything. So that puts you off!” (12125p9)*

Others felt too ill for deep conversations, but their doctor hadn't picked this up:

*“I had been waiting a long time in the waiting room and I felt very uncomfortable and I didn't really want to get into a big conversation about anything” (121189p15)*

#### **3.5.10.8 Costs of treatment:**

Many women paid for their prescriptions, but the cost of prescribed treatment can affect how readily they access health care:

*“I pay for my prescriptions, so I have to be really desperate before I go to the doctors”(12185p11)*

However, self-management can also be costly; this must push up the overall cost as women appear to attend their doctors sooner or later unless their symptoms are mild:

*“I paid nearly £4 for the sachets; you only get six and then in the end I still had to go to the doctors and it cost me another £6 to get tablets - so that's like £10.” (12185p4)*

One woman wondered if patients eligible for free prescriptions might be less careful in their use of delayed prescriptions and if this affected doctors' decisions:

*“they might think no we won't give them to people who don't pay for prescriptions - they might abuse that” (12185p11)*

Doctors prescribing long courses of treatment may suggest that short courses do not represent ‘value for money’; one woman seemed to echo this sentiment:

*“The price is so expensive, especially when you think how much it takes the manufacturers to make them: 50p. I am in pain and they are taking £6 profit, it does put you off!”* (12125p12)

It is uncertain whether she saw the drug manufacturers as the ‘villains’, though the Exchequer is, of course, the beneficiary of this price difference. Nevertheless, she felt a little guilty that the money could have been put to better use:

*“I think well I spent £20 on tablets - I could buy something for the kids”* (12125p11)

### **3.6 DISCUSSION**

#### **3.6.1 SYMPTOM DESCRIPTIONS, SEVERITY, AND ILLNESS CAREERS**

As protocols for the management of UTI are based on the recognition of the classical symptoms of UTI, especially dysuria and frequency, it is helpful to find that women consider these characteristic symptoms of UTI. In a recent questionnaire survey, 90% women had dysuria, 93% frequency and 80% urgency (357). Similarly to other studies (3, 4, 7), women also complained of abdominal pains and generalised symptoms, such as feeling generally unwell or irritable, and these can form part of a prodromal stage to their UTI. We confirmed that women can confuse UTI with thrush (7), but this most commonly occurs after antibiotic treatment when they may perceive it as non-resolution of symptoms.

##### **3.6.1.1 How severe is UTI?**

Women view the severity of UTI symptoms on two levels- as an illness similar to flu, and as a painful condition similar to severe toothache, migraine, or severe period pains - for many, of course this means the equivalent of flu and toothache when they have a UTI. Despite this, women feel that its effects are under-estimated. As it can be cured and because it often has no outward signs, they feel they shouldn’t make a fuss about UTIs.

##### **3.6.1.2 How do illness careers affect presentation?**

Many women who attend will have a previous, sometimes long, history of UTI. They may present with a ready-made diagnosis of cystitis, largely based on previous experience, but clinicians need to be aware that the use of this term may be imprecise. Many women find mechanisms to ameliorate regular symptoms, though these change as they age. Previous studies have also found that patients draw on past experience to determine their response to

infections including UTI (7, 363). Women in our study, especially those with recurrent UTIs, take this a stage further and become ‘expert patients’.

### **3.6.2 WOMEN’S CONCERNS ABOUT UTI**

Women are concerned if they cannot control their symptoms, and they therefore, worry more about the effects on work than their social lives. They don’t consider UTI as life threatening and rarely consider it a concern for their long-term health.

In common with another study (7) women often linked haematuria and severe pain to more severe illness. The prospect of cancer and renal failure are mostly feared by those with personal or familial experience, and is affected by anxiety levels and illness. Incontinence, frequency of micturition, and dragging sensations create anxiety about their underlying significance. Most women we interviewed believed that antibiotics had a superior effect in treating UTI, and only one worried that antibiotics weakened her immune system, in contrast to a recent study (7). Whilst dysuria sometimes responds to alkalinising agents and analgesics, women report that frequency is only reduced by taking antibiotics.

### **3.6.3 HEALTH BELIEFS OF WOMEN WITH UTI AND FOLKLORE**

On the surface, women’s health beliefs range from the predictable to the unusual. Linked to illness representations, they may be shaped by past experience and current medical conditions. Women are naturally curious about the cause of their UTIs, and most associate their illnesses with specific internal or external causes. Many of the more obscure beliefs rather than representing fanciful notions, have their origins in general belief systems.

#### **3.6.3.1 Folklore**

Women recognise many pieces of advice as ‘old wives’ tales’ but, at the same time, these formed the basis of many of their illness beliefs. As would be predicted (214), some folk beliefs about UTI not only survive the impact of scientific medicine but are also reinforced by the contact. This has significant implications for medical consultations.

Folk remedies classically treat with opposites (214) and this phenomenon is quite apparent in the self-care of UTI. Most commonly, heat is applied, through soothing warm baths (sometimes followed by a shower for hygienic reasons), hot water bottles or warm drinks. Occasionally, heat is viewed the other way and some women have cool baths or drinks in response, no doubt, to the concept of counteracting feverish symptoms or symptoms that mimic fever. Others view the burning pain as a sign that acid is attacking the lining of their bladder or urethra and, therefore, urinary alkalinisers are seen as a natural response, whilst

acid foods are seen as triggers This is a prime example of folklore being reinforced by western-style medicine (I hesitate to say scientific medicine as there is little evidence for a significant benefit of these treatments even though they are widely advocated).

‘Chills’ are a ‘below the waist phenomenon, in contrast to ‘colds’, which have associations with higher organs (214). As UTI is a ‘below the waist and above the knees’ illness then women suffer from chills. The idea that kidney chills can be caught from exposed flesh, not wearing socks, or having one’s feet in cold water for a significant time, all accord with the concept that peripheral areas of skin are seen as more vulnerable and act as a point of entry for disease (214). Mothers exhort their children to ‘wrap up’ to prevent this, considering their children to be lacking in responsibility for their health – colds and chills are often ascribed to ‘foolish behaviour’. In time, these children become mothers themselves and find they exhort their own children to continue this cycle of belief.

Higher levels of education and social class lead women to voice greater scepticism of folklore, but this doesn’t always translate into holding different beliefs. Patients sometimes report that health professionals also hold such beliefs.

### **3.6.3.2 Beliefs about triggers**

Women’s ideas about triggers are very similar, though unlike previous studies I found little emphasis on diet (4), and no-one expressed a desire to avoid caffeine (7). The association of vulnerable portals of entry, especially the feet, is previously unrecognised in UTI research but is a belief reported in other infections (214). Most women understand the concept of UTI as internally mediated, and thereby considered conditions that favoured internal spread as the most significant triggers. As in previous studies, cited triggers ranged from stress and reduced immunity, inherited or induced, to damp and clammy conditions (195). Whilst we know that immune defences are important in the aetiology of UTI, many other perceived triggers lack supporting evidence. In confusing the symptoms of UTI and thrush, women may also confuse the aetiology. Women reject some suggestions e.g. to avoid tight clothing, as experience shows no discernible risk. Nevertheless, they abide by the general principles of this belief and make various attempts to combat moisture. Some women had long-held beliefs that UTIs were contagious and that they could catch it from dirty toilet seats, supported by the notion of the dirty perineum, and as with some other folk beliefs they appeared to have had their beliefs substantiated by health professionals.

### 3.6.3.3 Why do 'absurd' myths persist?

The interviews produced some (bio-medically) absurd myths as well as a few that are potentially plausible. Perhaps, such myths persist when orthodox medicine can offer neither an alternative explanation nor an alternative stratagem. Myths may be closely related to belief systems and some become more rather than less entrenched when they come into contact with scientific medicine. Once established in the public (or medical) consciousness, do these myths survive by becoming 'bombproof'? Only overwhelming evidence or a series of alternative explanations could shake confidence in these myths. Many are quaint and comfortable in the face of uncertainty and are not prime targets for research. Some are 'noble myths', but not all are so virtuous.

A few myths appear to be widespread e.g. drinking plenty of fluids, both as a treatment of UTIs and as a method of prevention. There is no evidence of benefit (5), and perhaps, it endures because it sounds plausible and has no disaffirming evidence. Another common 'semi'-myth is that sex causes UTIs: research is contradictory (39, 55); women are unsure. There is undoubtedly an association, though health professionals seem convinced that it is the prime cause. To urinate after sex is common advice, but studies at best show a modest effect (59, 65, 160). Cotton underwear and loose fitting clothes are other (noble?) myths (160), though they may prevent thrush, which thrives in dampness.

Many myths seem to pass down the generations, especially from mother to daughter. One research participant described how she was sceptical about drinking lots of fluid and despite having experienced little benefit, would tell her daughter to drink more. Perhaps, this is how many cultural norms/ traditions are established. Another possible explanation comes from a parallel with soothsayers, who pick up verbal and possibly non-verbal clues from their clients; the recipients take on board relevant associations and mentally discard anything irrelevant. The resulting message is given special status. Medical folklore can run in parallel to lay folklore. The medical profession passes myths down generations in the same way as the lay model; as a result the origin of non-evidence-based 'truths' are obscure. They are communicated to patients on a one-to-one basis or through leaflets. Health professionals also hold lay beliefs themselves. Though these are commoner in less highly trained health professionals, participants reported some surprising doctors' beliefs e.g. that dirty toilet seats may cause UTI.



#### **3.6.3.4 Beliefs and complementary medicine**

Women generally use holistic medicine for prevention rather than cure, a view shared with doctors' accounts of the use of Ayurvedic in South Asia. We found little use of herbal medicines, despite being the commonest complementary therapy, and no use of acupuncture despite its research base. Use of reflexology, however, appeared quite common. Participants recounted that reflexologists diagnose correctly through the contours of the foot rather than from a history, a practice that is not endorsed by national certification boards. We cannot be sure whether women's' memories of their consultations served them well, but the act of diagnosis had a significant impact on their belief in the technique. Prevalent folklore suggests that the feet are a portal of entry of infection (214), but reflexologists don't appear to use this belief system. Certification boards emphasise the place of reflexology as an adjunct to conventional therapy through beneficial effects on stress and immunity; whilst the feet and hands are viewed as having important neural connections to organs and other parts of the body, there is no apparent association with folk beliefs about the susceptibility of feet in infective illnesses.

#### **3.6.3.5 Beliefs and home remedies**

Many illness management strategies noted in previous studies re-appear. 'Mist Pot. Cit' , cranberry, and drinking extra fluids are frequently used by sufferers. Advice related to clothing and hygiene is met with significant scepticism. Barley water as a home remedy was commonly cited by our population and is previously unreported. It seems to be falling out of use but many women remember their mothers and grandmothers producing the proper homemade variety rather than shop-bought equivalents. Perhaps, the skewing of our sample to a rural population contributed to the prevalence of its use.

#### **3.6.3.6 Beliefs and consultations**

Even in mild illness, women attend doctors or nurses for treatment after, at most, a week of symptoms. Whether this is facilitated by easy access cannot be assessed. Women attend promptly when they consider their symptoms more severe and requiring of immediate attention, or if they have suffered complications in the past. They attend less promptly if they suffer thrush after antibiotic treatment. Women think that they may be able to fight off minor doses of UTI, and self-treat in the hope that it won't become more severe.

In the absence of official sources of information, colleagues, friends, magazines or other informal sources contribute to patient knowledge and myths. No doubt glossy magazines tickle the imagination more than clinical information sheets, though it is reassuring that on

the few occasions that the Internet is mentioned, reputable, impartial sites are well used. Doctors appear to be poor at transferring knowledge, and consultations are often kept firmly in bio-medical territory or are relatively brief pragmatic affairs. In these circumstances there are few opportunities for meaningful patient-centred explanations. Information leaflets receive mixed reviews: they are thought most useful for women, who have occasional recurrences, but some of the advice is poorly evidence-based and this is soon uncovered. Women in this study don't comment much on using pharmacists for advice, even when buying over-the-counter treatments, probably due to the lack of privacy.

### **3.6.3.7 Misaligned models**

Some myths gain credence, as they seem superficially to explain mechanisms of disease or treatment. The analogy of flushing a plumbing system, sits well with the idea that we could reduce bacterial load by increasing kidney output. Of course, human systems don't work precisely the same as a plumbing system - their complexity is much greater, so that increased throughput of water doesn't translate to improved outcome. Women report increased volumes of urine but don't perceive any direct benefit to their overall well-being or to the comfort of passing larger volumes of water instead of little trickles.

### **3.6.4 THE SECRETIVE WORLD OF DISEASES (BELOW THE WAIST AND ABOVE THE KNEES)**

Women talk mostly to women about UTIs, and the closer the relationship the more likely they will talk. Female relatives, especially their mothers, friends and work colleagues are common confidantes. Women and their doctors find it hard to talk about UTIs in depth (4), even at times female to female. An element of taboo remains, though nowadays this is probably a hangover from the attitudes of previous generations and an anatomical association: the 'down below' factor. No one seemed to view UTI as a sexually transmissible disease, a myth that appears to have largely died out. A perceived association with (a lack) of personal hygiene maintains stigma – this association seems to arise as much from health professionals and information sheets as women themselves, who may view related advice as a criticism of their levels of hygiene (4). Women sometimes felt their illness to be trivial, and the fact that it lacks outward signs contributes to its secrecy.

Whilst pain is the symptom most complained about, frequency of micturition has the greater effect on social or occupational interactions. Women are embarrassed by going to the toilet frequently, the thought that they may smell, and the perception that some people think they are shirking at work. Women feared being away from a toilet - 'being caught

short': this was a particular problem for those in non-office based jobs. 'Hanging on' risks an 'accident' and is generally perceived as deleterious to health: this creates a dilemma.

One focus group described doctors as 'honorary females' and the participants would have been happy to discuss UTIs openly as long as they felt comfortable. This, was far from a universal finding and many women actively seek to consult a female doctor, or in their absence, a nurse. Previous research matches our perceptions that age influences preference (364); it is unclear if social factors are an influence. Many felt that only women could understand a predominantly female disease, and they would keep discussions superficial and/or technical with male doctors. For many women, though, their primary aim is to seek a rapid end to their symptoms and they may collude in short mechanistic consultations to achieve this goal and discussion appears more important when they seek causation. Telephone consultations were not favoured per se but for some women it was pragmatic, quick, and suitably impersonal. Drop-in urine testing was viewed similarly. The secret may lie in the skill of the medical communicator rather than the actual modality of treatment.

#### **3.6.4.1 Have attitudes/ perceptions changed?**

In many ways, little seems to have changed over the years. Mothers and daughters often appear to have the same perceptions. On the other hand, we cannot envisage what our interviews would have turned up twenty years ago! Women today can access multiple sources of information, including medical professionals, colleagues, friends, and written materials. The evidence-base of Western medicine has moved forward over recent years, and there is greater openness, helping knowledge acquisition. The quality of information determines how useful this is, and as more women enter the medical professions, perhaps female patients will be more willing to discuss their UTIs with their doctors.

#### **3.6.4.2 To attend or not to attend?**

UTI may be slightly more common than incidence calculations suggest, and pain appears to be the most accurate predictor of whether women will consult. Perceived severity of illness, worries that it may get worse, and prior experience are also important factors in health-seeking behaviour, as found in another study (7), and predicted by medical models (215, 216). Many find themselves in a dilemma over attending a doctor: if their symptoms were mild most preferred to manage their condition themselves as long as possible since they are concerned about wasting medical time and don't wish to be seen as presenting with trivial illnesses. In these circumstances they often try over-the-counter medicines first, but with variable results. This is subtly different to a recent study (7) that suggested that

women find themselves caught in ‘double-binds’ – wanting to use self-care methods whilst wishing to effectively ameliorate symptoms, and wanting to balance their individual need to consult with a wish not to bother the doctor. In our study, the key inhibitor to consultation was the fear of triviality.

Women also worry that they might ‘look silly’ if they have a negative test result despite their symptoms, but the need for symptom relief overcomes any guilt. An exception to this rule was apparent: women who are less certain about their diagnosis, through a lack of experience or atypical symptoms, appear more ready to consult. Conversely, women who muddle their symptoms with thrush are less likely to consult. A good few feel that these are self-imposed delaying tactics and would prefer to attend for most episodes of cystitis. This is worth remembering if health care provision changes e.g. pharmacist prescribing. We found that usual inhibitions about attending are altered by circumstances such as forthcoming holidays or weekends. The cost of a prescription is an issue for some women, though they would often pay significant sums out for over-the-counter medicines. Women do not have blind faith in their doctors, but despite this they find consultations reassuring.

## **CHAPTER 4 THE USE OF METAPHOR AND OTHER NON-METAPHORICAL FIGURES OF SPEECH BY WOMEN WITH A HISTORY OF UTI**

*Midway between the unintelligible and the commonplace, it is a metaphor, which most produces knowledge. (Aristotle)*

### **4.1 INTRODUCTION**

In this chapter, I will describe the theoretical background to the use of metaphor in language and highlight some examples of common metaphorical themes that appear in descriptions of illness. In the results section I compare previous findings with those from the fieldwork, both focus groups and one-to-one interviews for patients' beliefs about their Urinary Tract Infections (UTI). I examine patient beliefs about UTI, metaphors to describe participants' illnesses, symptoms, effects and treatments. The aim is that the assessment of metaphor in this study will enable insight into patients' perceptions at a deeper level than would be possible by a more superficial analysis of their beliefs.

This chapter emerged unexpectedly from the data on patient experiences. The frequent appearance of metaphor in patient descriptions had not been predicted, though in retrospect, and with greater knowledge of the literature, it may have been less of a surprise. We had also considered the possibility of using visual imagery in order to provide rich data on women's illness histories, so overlooking the likelihood of a plentiful supply of metaphor does seem careless!

Metaphors appear spontaneously in women's narratives of their illness, and the interviews from the previous chapter are perfectly framed to allow dual analysis of women's experiences and the use of metaphor. This is further considered in the methods section.

### **4.2 BACKGROUND**

#### **4.2.1 WHAT IS METAPHOR?**

*Metaphor n. application of name or descriptive term or phrase to an object or action to which it is imaginatively but not literally applicable (e.g. a glaring error, food for thought, leave no stone unturned); instance of this (354)*

Metaphor works by association, comparing two non-associated entities, and highlighting ways they resemble each other. Metaphors shape perception, identity, and experience going beyond the original association by evoking a host of multiple meanings (365). Metaphors do not add facts to a description, rather they add depth of meaning to the nature of a phenomenon, as expressed through its relationship to something else (366).

In metaphor, there exist stratifications of meaning, on the one level producing incongruity, but on another level producing an influx of significance (367). Metaphorical associations rely on pre-established knowledge and belief systems. They establish meaning and extend meaning systems in other directions (368).

Lakoff and Johnson challenged the traditional concepts of metaphor as a device of poetic imagination and rhetorical flourish, and a characteristic of language alone (rather than of thoughts and actions) (369). They considered that metaphor is pervasive throughout the processes of language, thought, and action. Our conceptual system, which relies on these processes, commonly functions at a sub-conscious level. They suggested that language acts as the conscious expression of this system, and thus concluded that our ordinary conceptual system is metaphorical in nature, and that human thought processes are metaphorical.

Individual concepts of importance are not always clearly defined in an isolated fashion, but rather in terms of their roles in natural kinds of experience. Definition, on the other hand, is not a matter of giving some fixed set of necessary and sufficient conditions for the application of a concept, so concepts arising from experience are open-ended. Concepts may thus obtain clarity through other concepts (e.g. time, space, objects). To manage this, we use metaphor. Thus, metaphors are systematic devices for further defining a concept and changing the range of applicability (369).

#### **4.2.2 EXPERIENTIALIST THEORY, SCIENCE AND METAPHOR**

Experientialism is the philosophical theory that experience is the source of knowledge (370), and metaphors are descriptions of our experiential concept of the world (369).

Experientialism is a middle road between the twin concepts of “Objectivism” (reality is independent of the mind), seen as central to the Western World and its obsession with facts and “scientific truth”, and “Subjectivism” (perception is reality), which is central to the ideal of Romanticism, and to the ideals of spiritually based societies. Lakoff and Johnson (369) see objectivism and subjectivism as myths. They contend that there are no absolute truths, and that objectivism misses important meanings and realities. On the other hand, subjectivism seeks to deny that our understanding of our surroundings is grounded in our concept of our physical and cultural environment.

Experientialism, and therefore, metaphor unite reason and imagination, bridging the gap between the opposite philosophies of the objectivists and the subjectivists. Much scientific description is ‘metaphorical’ as it gives abstracts a material form or makes a visible

representation of something invisible (371). Some consider that all knowledge, including science, is ultimately based on finding an appropriate enlightening comparison or metaphor (372), whereas others contradict this standpoint: “metaphoric language increases the more complex or unknowable the topic” (373).

The experientialist view influences, amongst other things:

- Interpersonal communication and understanding including negotiation of meaning
- Self-understanding
- Ritual (providing structures and coherence to our lives)

These three aspects are important in our understanding of patient experience and doctor-patient communication. Breadth of imaginative metaphor makes practice more rewarding for the practitioner and, from the viewpoint of the patient, it deepens the practitioner’s comprehension and makes practice more flexible and adaptable (371).

If metaphors are indeed the embodiment of experience rather than, or as well as, surface analogies for the sake of lucidity, an understanding of metaphor is as important for doctors as is an understanding of patient health beliefs (355).

#### **4.2.3 METAPHORS IN HEALTH AND SICKNESS**

Cultural theorists focusing attention on expressions of discourse identified recurring narrative structures and tropes (figurative use of words) in the portrayal of illness experience. Metaphor and visual imagery were found to be the two important and pervasive ways of conceptualising illness and disease (368). The use of metaphor in a medical context is predictable as it is used in all areas of verbal communication as an epistemological device to conceptualise the world, to define notions of reality and construct subjectivity (365, 369). Disease is rendered meaningful through the use of metaphor (374): “It is hardly possible to take up one’s residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped”. Study of the use of language, and in particular metaphor, is a valuable approach to an understanding of the experiential, lived world of the patient (366).

Medical metaphors are used to describe non-medical situations, and vice-versa. For example, disease metaphors often describe disorder, chaos, and corruption.

Metaphors may be used to describe general states of health or specific disease states.

Oriental metaphors are examples of those used to describe general states of health.

Healthiness is positive, and is represented as being “up” or “on top”: “I’m feeling up

today”; “peak of fitness”. Sickness, a negative condition, is described as being down: “down in the dumps” “depressed” “under the weather” (369). Such orientational metaphors probably reflect the posture of healthy and unhealthy people: erect or drooping postures, depending on one’s state of health. There are some exceptions where the association with orientation is of secondary importance e.g. illnesses settle down as they are cured.

A study of general practice consultations discovered that doctors and patients use different metaphors. Doctors use mechanical metaphors as a reassuring signal of expertise to explain disease. They spoke of themselves as ‘problem-solvers’ and ‘controllers of disease’(355). Patients employed a range of vivid metaphors, but fewer of a mechanical nature. Another study, however, suggests that patients strongly relied on physical and technical conceptions to narrate their understandings of body and health to doctors. The mechanical system provided ‘a useful metaphor to mediate between patient and doctor’ (212). Patients use metaphors to describe symptoms and are more likely to use metaphoric language at the interface of physical and psychological symptoms (355).

Just as in general speech, metaphor can modify the strength of an association pertaining to health or sickness. The use of position and form in a sentence will alter the strength of expression e.g. “my patient has cancer” is stronger than “my patient suffers from cancer”. Proximity in sentence construction reflects closeness of association (369).

#### **4.2.3.1 Metaphors of infections**

Military metaphors are common in two medical conditions: cancer and infections/infectious diseases. The association of infection and militarism dates back to the Middle Ages (375). In times past, illness, and infections in particular, were conceived of as an evocation of evil incurred by the wrath of God. In Edwardian times, the germ theory of disease based on anxieties about pollution, purity, and boundary maintenance (376) was central to medical and lay discourses on illness.

In modern society, the emphasis has changed to a microscopic invader intent on entering the body and “causing trouble”. The concept that germs can only be bad or abnormal is common-place (214). Germs are conceived as having motivation and evil intentions. They are seen as living, invisible entities, which have no free existence in nature, but exist only in people. They are sometimes thought of as occurring in a cloud of particles (368).



Immune systems “mount defences”, “have sieges against aliens”, “fight” against microbes, which are “attacked” or “killed” by white blood cells, drugs or surgery. These metaphors are prominent in public health campaigns as well as being standard descriptions in medical discourses. Such language appeals to the need to mobilise defences for an emergency, to make sacrifices, and to everything possible to counteract the threat to life. The first such public health campaigns using such metaphors arose in the time of the First World War when syphilis was a scourge of the troops. After the war, a similar campaign to educate the population about the risks of tuberculosis was undertaken (374). Interestingly, tuberculosis had previously bucked this trend of military metaphor as a result of its association with artists, in particular the Romantic poets of the 19<sup>th</sup> Century. Tuberculosis was described as leading to a noble and often lyrical death. Images of ardour, conceptualised as disintegration, transparency, and hyperactivity alternating with elegant languidness were features of its description (374). This contrasts most deeply with descriptions of AIDS, which has many similarities in metaphor to cancer. These are seen as punishments for living unhealthy lives (377). In the Middle Ages, plagues were seen as judgements on society and AIDS has been described as a modern plague. The choices of metaphor for AIDS emphasise stigma and discriminatory attitudes (e.g. pollution, invasion) (377).

#### **4.2.3.2 Metaphor in the wider medical literature**

Many studies of metaphor relate to psychology, mental health, and nursing care. Early studies of metaphor in the management of cancer and AIDS led to a belief that it had a negative impact on doctor-patient communication (378). More recently, there has been broader interest in the use of metaphor, and a balance of views has emerged.

Study of the use of language, and in particular metaphor, is a valuable approach to an understanding of the experiential, lived world of the patient (366), and serves an educative function (366, 379). Metaphor is a valuable gateway into the perceptual world of others, in particular those facing the crisis of illness (366). Experiences of patients with cancer can illustrate two functions of metaphor: the instrumental and the expressive. Illness metaphors may have negative consequences, imbuing myth, fear and stigma, but awareness of the expressive function of metaphor provides a valuable focus for listening to and understanding patients’ experiences (366). Metaphor also enables nurses in training, who have limited experience of illness, to gain greater understanding of their patients (366).

Metaphors are frequently observed in consultations of patients presenting with symptoms of physical disease, and tend to mirror the pathology, the organ(s) involved, and/or its body

location (379). The authors of this study use this finding to promote doctors' understanding of patients' narratives (through a visual modelling technique). They hoped that physicians will move away from simplistic, reductionist, observer patterns to a position where they may accommodate physical and "story" perspectives in the same clinical space.

A few studies have been conducted on the use of metaphor in the context of specific diseases. In a study on sufferers of Hepatitis C, researchers found that participants fell into two metaphorical camps: those who believed in a biomedical approach to the treatment of their disease invoked metaphors of conflict and warfare; those who favoured a more naturalistic approach conceptualised the virus and its effects as part of their 'self' (380). In a study in the field of anaesthetics, the author warned that patients are sometimes worried by metaphors they hear in the doctors' speech (381).

Another study considered that metaphor helps in the understanding and management of pain. As pain is often a diffuse concept (pain can be poorly localised, and difficult to relate to specific disorders) it is interesting that an abstract concept like metaphor is considered useful in creating understanding in situations where standard language content is deemed insufficient or inadequate. Metaphor is not limited to specific age groups and it is in frequent use in paediatric practice (382).

A review of qualitative research findings welcomes the creative perspective of metaphors and their ability to illuminate experience (383), but warns against their misuse, which could distort or obscure meanings. Some suggest that metaphors should not be used to describe illness since they are 'untruthful' (377).

### **4.3 METHODS**

During the process of analysis of the study of patient experience, it became clear that participants often used metaphor to describe their symptoms and dilemmas. We realised this at an advanced stage of analysis, but decided that specifically asking about language in the few remaining interviews could bias the natural use of metaphor by participants. We included questions about metaphorical language, however, in the focus groups for health professionals, though they had only a superficial recall of their patients' use of metaphor.

#### **4.3.1.1 Methodology**

This study is predominantly descriptive, rather than interpretative. As it was unplanned and developed from the study of patient experience, it was not desirable to impose grounded theory on its data collection and analysis. We took a pragmatic approach, and applied a

generic thematic analysis initially to the narratives of our patient interviews. When it was clear that there was material aplenty we used critical discourse analysis, which encourages analysts to go beyond the description and interpretation of language towards explanation. As such it appears to bear some resemblance to the principles of grounded theory.

#### **4.3.1.2 Researchers**

Data analysis: Iain Edgar (IE) and James Larcombe (JL)

One-to-one patient interviews: Audrey Dougall (AD)

Focus group interviews: Nicky Hall (NH)

#### **4.3.1.3 Data Collection**

Most of the patient interviews were in-depth, one-to-one semi-structured interviews, resulting in illness histories. Unlike typical narratives, our method of grounded theory interviewing produced a less co-ordinated illness story, but a narrative nevertheless.

#### **4.3.1.4 Data analysis**

Two of us (JL and IE) formally and independently analysed transcripts for metaphor, with additional analysis from field notes and post-interview summaries from the one-to-one interviews (NH). Formal summaries and field notes were not kept for the focus groups. Initial themes were identified and agreed by the analysts and discussed with our interviewer. At this point, I searched the literature, and borrowed themes from standard texts. A number of themes, however, appeared to be disease specific, fitting poorly or traversing traditional metaphorical boundaries, and are presented separately.

#### **4.3.1.5 Further description of methods**

The methods, are otherwise identical to those employed in the study of patient experience, and are, therefore, fully described in the background.

### **4.4 RESULTS**

Women use metaphorical descriptions where they are unsure as to how to convey meaning. In response, they produce parallel descriptions, sometimes quite florid, that encourage understanding and insight from a listener without the need for scientific accuracy.

Women's factual knowledge is variable, despite some long and complicated histories of repeated urinary infections. As a result, one might have expected great use of metaphor to help with description. The lack of use may reflect different personalities, since low users comprised both those women who were likely to have good knowledge, and women who had little or no experience of UTI.

#### **4.4.1 NON-METAPHORICAL FIGURES OF SPEECH IN WOMEN'S DESCRIPTIONS OF UTI**

##### **4.4.1.1 Simile**

Similes are often used to describe more absurd appearances: “(my stomach) blows up like a balloon”; “the pressing feeling is like someone standing on you” (I85), “it just stays there like a mountain for ages”(FGN) describing wrinkled skin caused by dehydration. Similes are also used to describe absurd concepts: “it feels like it's taking the lining off my stomach sometimes”(I211). A further appearance of simile was in an opening gambit for ‘the flu metaphor’: “a fluey-like illness” “I felt quite poorly- like fluey”(I189) was followed up by the simpler statement “I felt fluey”.

##### **4.4.1.2 Colloquialism**

Colloquialisms and local sayings are day-to-day language to many of us, and are often specific to certain areas of the country. It is recognised that many common idioms are in fact, metaphors (369). As a northerner myself, I found it difficult to separate out normal speech from metaphors. However, a number of obvious metaphors are present as colloquialisms in the transcripts e.g. “out of fettle”, “all to pot” (I85), “run of the mill thing” (I145). Some descriptions may have further meaning, but as colloquialisms, their significance is uncertain e.g. “dying to pass water/ go to the loo” (I85/94), implies great distress, but as a common figure of speech it may be wrong to read too much into this. “Honeymoon disease” was described by a few women; this phrase appears to have been coined generations ago, and refers to an increased risk of UTI related to a sudden and unaccustomed increase in sexual activity.

#### **4.4.2 TERMINOLOGY**

##### **4.4.2.1 Infections**

The metaphorical term “water infections” was almost ubiquitous (and doctors appear also to settle for this lay idiom). Similarly, women commented on their “waterworks”, though we did not enquire whether this was commoner in Monopoly players! Some suggest that such mechanical metaphors are the preserve of doctors (355), but we found that women were quite happy to use this term. They more commonly used the medical term ‘cystitis’ for their typical symptoms and would use ‘waterworks’ where they were making a more general point. Anatomically based terms, kidney and bladder infections were also used.

##### **4.4.2.2 Anatomy**

Descriptions were not always anatomically accurate. Anatomical labels could be vague e.g. pelvis, related to structures that were either well recognised (or, perhaps, more acceptable)

such as kidneys, or relied on common metaphors. *“One of those diseases between the waist and the knees”* (I95) leaves something to the imagination!

#### **4.4.3 SYMPTOM DESCRIPTIONS**

##### **4.4.3.1 Dysuria**

In a previous study from Sweden (3), the headline quote was *“peeing barbed wire”*. This may be a peculiarly Swedish concept as no women in this study used this metaphor. Instead they have described the sensation in terms of temperature (hot, burning- see below), pressure, glass or sharp implements: *“glass inside you”* (I94), *“broken glass”* (FG2), *“knives”* (FG2), *“razor blade”* (I95), or *“cutting it”* (FG2). Two women described their symptoms in ways that were specific to themselves: *“like peeing grapes”* (FLD); *“the feeling of oh - ouch and not much coming out”* (I189).

##### **4.4.3.2 Description of frequency and urgency**

Descriptions of frequency and urgency are often bound together. They are more practical and less florid than the descriptions of dysuria, possibly as the concept is easier to convey. Similes and colloquialisms were as common as metaphor: *“it’s more like something doesn’t close – you know it keeps being open and you cannot finish wanting a wee”* (FG2). *“I was desperate to go to the loo, but you are not really desperate to go the loo, but you are and that’s a nightmare”* (I95). Many women described themselves as having *“trickles”* and *“dribbles”*.

#### **4.4.4 USE OF SPECIFIC TYPES OF METAPHOR**

We most commonly encountered directional and conduit metaphors in patient descriptions.

##### **4.4.4.1 Directional metaphors**

###### **4.4.4.1.1 Anatomy**

Directional metaphors e.g. *“down below (type things)”* or *“down there”* confirm the sense of embarrassment that some women associate with their symptoms. One woman alluded directly to this when describing her use of terminology (I88). Another appeared to refer detachedly: *“can it actually spread anywhere else down there”* (I189). Another referred to her problems as coming from *“the pit of your stomach”* (I45), but elaborated no further. One woman said despairingly *“that sort of area”* (I211). These metaphorical concepts may explain why the kidneys are an anatomical site frequently referred to (more than would be expected from a clinical point of view): a more acceptable source of infection, situated relatively high up in one’s back rather than low down in the messy area of the pelvis!

#### 4.4.4.1.2 Infection

Women consider that infection is introduced into the body. They give a number of factual descriptions, particularly about bacteria coming from the bowels, or being introduced during bottom wiping or sex. More florid metaphorical concepts include:

*“getting sort of foreign bodies in your tubes”* (meaning the urinary tract), *“injecting something foreign into our bodies, so there is no reason why it shouldn’t or can’t cause an infection”* (FGU), *“sending cold into your body”* (I85).

Women use circular metaphors to describe combinations of infections: *“vicious circle/cycle”* (I145). The directional metaphor encapsulates the relationship between thrush arising from the treatment of UTI, with which it may be confused. The circular metaphor illustrates how women end up with the same symptoms (as a side effect) after treatment.

*“Off”* occurs in women’s metaphorical descriptions of the causes of infection, though the use of a directional word is more commonly part of normal speech e.g. *“trigger off”*, *“set off”*, *“sparks it off”* (I145).

#### 4.4.4.1.3 Spread

I have suggested that women generally describe their urinary system as *“down below/there”*. As a result, infections, or the effects of infections, are viewed as spreading upwards: *“the potential to spread further up... further into you”* (I189). After childbirth: *“something’s bound to track up”* (FGU). More generally pain *“built up”*. The downward directional metaphors are generally considered as indicating baser matters, things or thoughts that should be suppressed.

#### 4.4.4.1.4 Treatment

Women used directional metaphors when they describe their management of UTIs, especially *“off”* and *“out”*: *“flushing things out of the system”* was practically a universal metaphor. Remedies were described, as might be expected, *“take it away”*, but quite commonly *“take it off”*, or *“takes the soreness off”* (I94). In contrast women use *“up”* when describing symptomatic treatment: *“wrap up warmly”* or *“cuddle up”*.

#### 4.4.4.2 Conduit metaphors in the treatment of UTI

Metaphorical references to war or fighting might be expected, as these occur in the treatment of other infections. Surprisingly, this is an uncommon feature of patients’ descriptions of UTIs and their treatment. Commonly, metaphors that pertained to eliminating infection could be categorised as conduit or container metaphors; in other

words, patients perceived a need to remove the offending cause from their bladder, kidneys, pelvis or other description (either anatomical or lay-descriptive) and that cure was dependent on removing it from the body (conduit metaphors). One common conduit metaphor: *“flushing it out of the system”* also conjures up thoughts of dirtiness, given that flushing is commonly associated with toilets. Some other infections e.g. AIDS attract such metaphors. The idea of ejecting bugs has many parallels in other diseases e.g. diarrhoea as a way of removing bugs from the gastrointestinal tract: or surgical incision and drainage for abscesses- *‘better out than in’*; or even the watery eyes and nose of hay fever where the body’s natural defences flush out the pollen from sensitive areas of the body.

#### **4.4.4.3 The body as a machine (and mechanical metaphors)**

Only a few women describe their symptoms in terms of electrical or mechanical metaphors. This is in contrast to doctors, who were, in one study, found to prefer mechanical metaphors as a means of imparting expertise (355). The use of the term *“waterworks”*, perhaps, is common ground.

Infections *“set off”* and treatments *“kick in”*, mechanical metaphors: *“it kicks in (antibiotics) and sorts it straight away”* (I95) (or sometimes not!): *“you know for a fact that it’s not going to kick in straight away (chemists’ treatment)”* (I208). Some women complained of *“feeling drained”*, no doubt using the electronic terminology from a drained battery; *“sparking off”* also suggests an electrical charge.

#### **4.4.4.4 Defence against invaders and susceptibility to disease**

Perhaps, in this category the metaphors come closest to those suggested by the literature. Increased susceptibility leaves the body open to attack by disease. Infections were associated with weaknesses, usually with stress and tiredness, but also through more factual problems such as underlying disease, and more abstract concepts such as immunity.

*“Weak spot inside you”* (I85); *“tiredness... seemed to come as a water infection, rather than a cold or anything”* (I211); *“coeliac disease left me open to water infections”* (I211); *“run down”* (I211); *“immune system getting run down”* (FG2)

Bacteria or germs are seen as foreign objects present in the body. One participant described differences between *“good”* and *“bad”* bacteria, and the need to promote the former at the expense of the latter. This caused her to try folk treatments that promoted an alteration in this balance e.g. yoghurt. More commonly a treatment for vaginal thrush, some women considered yoghurt as a treatment of UTI, perhaps because of the similarity of symptoms.

#### **4.4.5 NON-STANDARD METAPHORICAL CLASSIFICATIONS**

##### **4.4.5.1 Hot and cold as metaphors**

Associations with temperature were common in the study of patient experience, both in simple descriptions of perceived triggers e.g. ‘putting your feet in cold water’, and also in a metaphorical sense. The sensation of dysuria is often referred to as “*hot*” or “*burning*” and one woman went so far as to suggest that the infected urine could cause “*burning of the lining*”(I95); another woman used a similar description, but perhaps, in order to show that it was merely a descriptive term, used simile rather than metaphor. Metaphorical descriptions relate more commonly to heat rather than cold, though “*a cold feeling in the stomach*” (I211) was an exception. The words ‘cold’ and ‘chill’ used respectively for an upper respiratory infection and a feverish illness may be medical misnomers (logically they represent heat) or perhaps their origins are themselves metaphorical? Women talked about: “*a cold in the kidneys*” and “*a chill on the kidney*” (both I94), and drew comparisons with respiratory illness: “*catching a cold-type of thing*” (I208).

When talking about temperature sensations, women often mentioned that they used ‘treatments’ that had an opposite effect e.g. they would treat chilly stomachs by “*wrapping up warmly*” or using hot water bottles and hot drinks. They would combat sensations of heat with cool drinks or anti-pyretics.

##### **4.4.5.2 Metaphors that invoke death and desperation**

Metaphors of death were sometimes encountered. This is presumably a way of describing symptoms as being worse than might be imagined, or out of proportion with their medical significance. Colloquial phrases encountered included: “*if I were away... I’d probably die*” (I85) referring to the greater difficulty in accessing health care when abroad. Another woman suggested “*it would be purgatory knowing you have cystitis*” (if you were manning a check-out at a busy supermarket) (I208).

Less dramatic references include: “*it gets so desperate you have to go*” (FG2). Desperation in general was associated with frequency of micturition, rather than with chronic disease.

#### **4.4.6 METAPHORS IN THE EXPRESSION OF WORRIES**

##### **4.4.6.1 Anxiety about the diagnosis**

“*I must have at least several different sorts of cancer*” (FG2). “*My mum said to me that you can know too much you know!*” (I189). “*I don’t bury my head in the sand I want to know*” but the same lady: “*I end up worrying myself sick*” (looking on the Internet) (I189)



and as a result finds trips to the doctors useful *“for dispelling fears”*(I189). However, surprisingly few women mentioned this, with no obvious differences between experienced and inexperienced sufferers.

#### **4.4.6.2 Embarrassment**

Directly mentioned on occasions e.g. *“it’s a taboo”* (FG2). *“I just feel rather exposed”* (going to the doctors and being examined – after shaving of pubic hair). Directional metaphors emphasise the embarrassment: the *“down below”* issue. An association with dirt was common *“you do feel dirty”*; *“I did feel as if people would think I was unclean even though I knew I wasn’t”* (both FG2). A lack of embarrassment was suggested by the use of phrases including the word open: *“we are pretty open with them (friends)”*.

#### **4.4.6.3 Superstition**

Many patients use metaphors that reflect superstition. These are associated with the randomness of episodes of urinary tract infection, uncertainty regarding aetiology, and uncertainty regarding trigger factors. The phrases *“touch wood”* in response to descriptions of frequency of episodes (or wishing to maintain their symptom-free status), and *“old wives’ tales”* with regards to aetiology are common examples. Women mention the phrases *“hearsay”* and *“Chinese whispers”* (I208) alongside *“old wives’ tales”*, suggesting that women take note of folklore but don’t give too much credence to it.

### **4.4.7 METAPHORS AND GENERATIONAL DIFFERENCES**

The use of the word *“open”* characterised women’s descriptions of younger people’s approach to describing their symptoms and problems. The younger generation’s openness was seen in a positive light: *“don’t beat about the bush”* (I85); *“straight up front”* (I85). Women often felt this was an improvement on the arrangement they had with their mothers and their generation. This didn’t spill over to openness with males as a whole, though male doctors or nurses might escape these constraints: *“it is not swept so much under the carpet”* (I189) nowadays.

### **4.4.8 INDIVIDUAL METAPHORICAL ASSOCIATIONS**

Some metaphors were only associated with single participants.

#### **4.4.8.1 Accessibility**

*“I’m not a doctors’ person”* (I208). The same woman worried: *“Am I being trivial”*. Other than these comments, metaphor was absent from comments about accessibility, though there were factual references.

#### **4.4.8.2 Explosions**

One woman repeatedly used metaphors of explosions (I85): “*it (my tummy) blows up*”; “*it’s like something going off inside of you*”; “*it set something off down below*”; “*it just hit me*” (the acute onset of an infection); “*the pain shoots up*”. This may relate to a speedy onset of symptoms and change from health to ill health. This woman was a frequent user of superstitious phrases, perhaps, reflecting her lack of control over the symptoms.

#### **4.4.8.3 The body as a tree**

Another woman described her pelvis as the “*trunk*” (of the body). She later expanded on this metaphor “*it goes out in a tree*”, and “*its branches... send infection to other places*”. The concept of seeding of infection (as of fruit or pollen) was suggested.

### **4.5 DISCUSSION**

Treatises on metaphor in medical disease are not common, and often relate to the most serious diseases and psychological or psychiatric problems.

In previous studies, descriptions of infections are generally characterised by metaphors of battles (375), but were in this study almost completely replaced by conduit and directional metaphors. Descriptions of lowered immunity tallied with defensive weaknesses, but were then couched in non-combative ways; it would be interesting to see if this is gender-specific. Instead, we found metaphors relating to the experience of contracting UTI such as: symptom effect, especially pain; embarrassment; and cause. These occupied women’s imaginations more than metaphorical descriptions of destroying external invaders. Perhaps, women become accepting of what is commonly a recurrent infection: they realise that there is no war to be fought, just a series of skirmishes. Their metaphors reflect a need to be rid of their symptoms, whilst understanding that it is merely another episode in their illness history. Alternatively, this may mirror a set of responses in a previous study (380), and signifies an underlying naturalistic, or holistic, approach of women to their illness.

Doctors tend to reject the more vivid sharp/dull metaphors in favour of the concept of ‘severity’. In this respect, they may refer specifically and quasi-technically to UTI, and restrict the concept of ‘burning’ pain (355). We did not study communication with doctors, but women often described the symptom of dysuria as a burning pain to the interviewer. We can only speculate on this contradiction. It could be that women’s descriptions were inhibited in audio-taped consultations, but perhaps, some doctors might proactively use metaphorical language, thereby reducing the scope for women to respond in kind.

In one study (355), patients apologised for their inability to describe symptoms and then proceeded to use vivid metaphors to convey meaning. In this study, severe pain and dysuria produced more vivid metaphors ranging from explosions to razor blades, glass and knives but this was not universal. None quite compared with the oft-quoted ‘peeing barbed wire’(3), which embodies the best of metaphor, in that we can almost feel the discomfort ourselves. In this study we found “*the feeling of oh/ ouch and not much coming out*” particularly evocative, even for those of us who had never experienced such sensations.

In one study of metaphors in primary care consultations (355), similes and metaphors were treated as one and the same by the authors. We found that women used figures of speech differently rather than interchangeably, preferring simile for vivid descriptions. Simile has a softening effect on metaphor (381). Perhaps, realising subconsciously that their language was more emotive, women chose to reduce the emphasis by the less strident tones of simile. At times it was hard to decide whether phrases were used metaphorically, as standard speech or as colloquialisms. Perhaps, historically, less vivid metaphors have become accepted figures of daily speech and straddle these linguistic boundaries.

#### **4.6 CONCLUSIONS**

Women use metaphor quite freely to describe their symptoms. Commonly, these take the form of well-recognised symptom descriptions such as ‘burning pain’, but they only occasionally use mechanical metaphors, in contrast to doctors. A few women gave more vivid descriptions: these seemed to reflect the severity of symptoms. There is scope for further research into the use of metaphor in different cultures or ethnic groups, especially those regarded as less inhibited than the English!

This study listened to the women’s descriptions without contamination from interaction with health professionals. It is interesting that the differences in type of metaphor in this study were less marked than in one previous study based on language used in consultations. This suggests that women may add to their descriptions during consultations, alluding to features that have not already been covered by their health professionals. As metaphor is delivered subconsciously, however, an ethnographic study could produce more definite conclusions.

Viewing this study of metaphor in isolation, I could conclude that the treatment of infection is viewed as a secondary priority for women behind symptom relief, and understanding their illness in a holistic, or naturalistic manner.

## CHAPTER 5 THE MANAGEMENT OF UTI: VIEWS FROM HEALTH PROFESSIONALS

*Being efficient pragmatists we favour the hypothetico-deductive clinical approach. We guess what's up with you and how to treat it. So when you're peeing barbed wire every ten minutes, we don't send you off for resource-consuming tests. Instead we say: "I reckon you've got cystitis". Then we prescribe antibiotics, the choice of which is based on experience, guidelines, a knowledge of local urinary pathogens, and, in some cases, whatever pharmaceutical company-sponsored pen we are writing with.*

*'Dr Copperfield' (The Times)*

### 5.1 INTRODUCTION

In this chapter, I have undertaken a qualitative study of medical professionals' views on the diagnosis and management of UTI. This complements the previous chapters, which outline patient experience, and the use of language in consultations. It also provides a link to the subsequent chapter, which considers information available via the Internet.

On balance, evidence has suggested that the traditional methods to diagnose and manage UTIs are outdated, causing unnecessary prolongation of illness. Thankfully, more serious morbidity is rare. Since the inception of this PhD there has been open debate on the management of UTI in medical circles. Whilst no participants suggested that they had been influenced by this debate, it is likely that their management has been subliminally affected by the gradual changes in professionals' clinical decision-making. The opinions I heard during the interviews with doctors differed subtly but significantly from the discussions I heard in 1998/9, five to six years before this project started, when I led a 'Beacon Practice' initiative on an evidence-based approach to antibiotic prescribing.

During the study, the responsibilities of different professionals to patients with cystitis changed. Nurse practitioners and practice nurses both inherited the ability to prescribe according to a limited formulary, and pharmacists were encouraged to increase their involvement in the management of 'minor illness'. In order to reflect these changes, we widened the remit of the study to include these professionals' views.

This study uses modified grounded theory methodology as discussed in the background chapters and focus groups provided the predominant means of data collection.

## **5.2 AIMS**

A qualitative study to elicit the ideas and beliefs of medical professionals regarding the diagnosis and clinical management of UTI in adult women aged 18-64, and to draw some comparisons with the study of women's experience.

## **5.3 BACKGROUND**

The conceptual foundation for doctors practising Western medicine is the biomedical model, whereas the basis for lay beliefs is more diffuse and often socially constructed (4).

Effective communication between patients and doctors is an essential criterion for effective care (4, 249). GPs and patients may have differing agendas and expectations in the consultation as well as having separate worlds of experience (4).

A survey considered doctors' beliefs on risk factors for UTI. 22 GPs were asked in face-to-face interviews about how they managed women with urinary symptoms and what advice they usually gave whilst 99 women had a telephone interview and 14 completed a questionnaire (4). This study shows that what doctors know and believe about urinary tract symptoms is not always transmitted to women and, furthermore, what women know and believe is not in transmitted to doctors during the course of a consultation. It also showed that doctors have beliefs unsupported by scientific evidence (4).

Most doctors think that female anatomy is a risk factor for UTI and slightly fewer blame sexual intercourse. Age and hormonal change were blamed by 23% of participants and other factors, including fluid intake, clothing and hygiene, less frequently (4). Women infrequently recalled their doctors' explanations. Doctors described UTI as a bladder infection, and reflecting their predominant beliefs, cited sexual intercourse or female anatomy as causes. A few suggested tiredness, perineal hygiene, it 'just happens' and in one case bruising from cycling.

The paper also reports figures for GPs' questions. Reportedly, 78% GPs ask about dysuria, and 78% frequency. 50% (especially younger doctors) ask about haematuria; 50% previous history; 27% fever; 14% duration; 9% urgency. Women doctors all asked about dysuria and frequency but only around half of male doctors. Risk factors they asked about were: new sexual partner 32% (especially younger and female doctors); contraception 18%; recent intercourse 18%; tight clothing 9%; perineal hygiene 5%; vaginal symptoms 5%.

Half of the GPs said they prescribed an antibiotic on the basis of symptoms, half said they used dipsticks to help decide on empirical treatment. They commonly advised voiding after sex; and a few would mention perineal hygiene and high fluid intake. Generally if advice was given it was during a consultation for recurrent UTIs, but unfortunately doctors could use confusing language which occasionally gave offence e.g. advice on perineal hygiene was sometimes perceived as personal criticism (4).

Some illustrative comments suggest that communication in the consultation had been deficient: 35% doctors felt women were embarrassed talking to them, and 23% reported that they were uncomfortable; women's reports are in general agreement (4). Doctors most frequently cited female anatomy as a cause of UTIs, and sometimes used metaphors such as 'honeymoon cystitis', which puzzled some women. GPs view these consultations as straightforward as they have an immediate solution, but this may mask unresolved issues.

Several other studies demonstrate a marked variation among physicians in the diagnosis and management of women with acute dysuria (102): several different diagnostic strategies and 82 different management strategies emerged from 137 questionnaire replies (163), and in an observational study 50 strategies were used for the management of 201 consecutive patients attending a health maintenance organization in the USA (164).

Most patients are not treated according to current guidelines(89), but nurses have been shown to follow guidelines more readily than family physicians in the USA (164). GPs' diagnostic and therapeutic accuracy is low (89), but can be enhanced through previous knowledge of patients, a situation which leads to lower antibiotic prescribing (6). Doctors find it easier to predict a correct diagnosis in patients of higher social class (6).

Doctors rarely change their management of UTI based on the results of tests (384). One study placed GPs in three categories of laboratory user: 'frequent users with low positivity' (i.e. samples sent for urine culture were often normal) who didn't use urine dipsticks and sought to confirm clinical diagnoses with laboratory tests; 'frequent users with high positivity' advise patients with negative dipsticks and send all other specimens to the laboratories for antibiotic susceptibility testing; 'infrequent users' who did not value the laboratory for diagnosis, made great use of dipsticks and had a low threshold for empirical antibiotic treatment (173). This was reported in the media as 'chaotic treatment of suspected UTI' (385), though evidence supports the effectiveness of empirical treatment of UTI even when tests are negative (54).

## **5.4 METHODS**

### **5.4.1 RESEARCHERS**

Focus group moderator:	Dr James Larcombe (JL);
Individual interviews:	JL
Data analysis:	JL; Dr Iain Edgar (IE); Prof. Pali Hungin (PH).

### **5.4.2 PARTICIPANTS**

Most participants were doctors active in general practice. Doctors near to the completion of their training accounted for approximately a third of our sample. Some were part of mentoring schemes, having qualified as GPs in the European Union. We held one focus group for nurses and in a further focus group there was a mixture of nurses and GPs. We convened a focus group for pharmacists and a smaller group for their managers and pharmaceutical advisers. We interviewed two GPs with particular perspectives of interest.

### **5.4.3 METHODOLOGY**

Although ‘handicapped’ by a bio-medical background, available evidence on patients’ consulting behaviour, and assumptions on doctors’ beliefs, my aim was to keep any pre-conceptions to a minimum. This suits a modified grounded theory approach (12).

#### **5.4.3.1 The difficulties of applying grounded theory**

As in the earlier patient study, the descriptions and experiences of participants was an important early phase of interviewing. On the one hand, this improved objectivity and allowed us to challenge our pre-conceptions; on the other hand, it risked slipping into a phenomenological approach and consequent methodological slurring. This was, exacerbated by a tendency for doctors to be unquestioning of their own and others’ experience, unless specifically prompted. This might reflect modern medical training, which relies heavily on group work. Training groups often employ ‘Pendleton’s Rules’ (353), which involves listening before reflecting or criticising, and beginning with positive rather than negative comments. The effect on group discussion appears to be a ready and unquestioning acceptance of differences – excellent for group cohesion, but less suited to grounded theory! This effect was more apparent in the groups involving doctors still in training- it is unclear as to whether this difference reflected the proximity of being taught by these rules or whether it was due to age or experience. Triangulating through asking questions in different ways, repeating the questions with different groups, reflecting on

previous responses, and challenging our participants to consider their underlying beliefs and motivations were all techniques to uncover hidden themes e.g.:

*“Now that's possibly what used to happen 20 to 30 years ago when people came with symptoms - but you are all being very flexible and I am interested to know if you've got any ideas about why you are flexible and how you develop that flexibility”...“have you changed the way you manage something like this and given some thought as to why that might be.”...“but you say you are not happy about it - what is it about three days?”*

We noted that some doctors changed their stance on issues between the beginning and end of the interviews. Perhaps, the interviews stimulated them to think more deeply about their actions, particularly if they were less experienced: this phenomenon appeared commoner in groups of younger doctors.

#### **5.4.4 DATA COLLECTION METHODS**

I used focus groups for the majority of the data collection. These were supplemented by a duo of medicines managers (which became a trio) and individual interviews with a PCT prescribing lead and a dispensing doctor. The initial groups were intended to represent a cross-section of doctors in general practice. A number of focus groups were then included to address particular areas of divergent ideas, to sample different professional groups, and to pursue particular theories. Registrar groups were used to address two concepts: the influence of age and experience on ideas and beliefs, and the influence of countries of undergraduate and post-graduate training. We also included two groups of EU trained doctors to develop the interpretation of international differences. During these groups we were able to judge the effects of training on young doctors' ideas, and to ascertain how their ideas were formed and modified. We used all groups as commentators on their peers and teachers, thus enabling a wider insight into medical practice.

#### **5.4.5 INTERVIEW SCHEDULES**

The initial interview schedule was drawn up in response to ideas coming from the project on women's experiences, which preceded this study, and initial ideas on doctors' opinions formed during the 'Beacon Practice' initiative.

The doctors' schedule was more direct than that for the patient interviews. After a round of introductions, more for my benefit (as most participants knew each other), the interviews commenced with questions on terminology and symptoms. Questions of greater depth, asking participants to analyse their reasons and motivations for their actions, including



diagnosis, and treatment, were introduced later on in the interviews. During the introductions, participants' backgrounds were discussed, especially their countries of origin, where they trained, and their prescribing/ dispensing status. I did not include warm-up questions since the groups had already formed a relationship.

IE and JL met formally on three occasions and communicated by e-mail to discuss theoretical changes to the interviews. Progress of the interviews was a regular topic for supervisory discussions, resulting in changes of emphasis, additional theories, and version 2 of the schedule. Except at the beginning (sampling a cross-section of views), and at the end (diverse and unconnected groups), there were significant time-gaps between focus groups. I based the pharmacist and nurse interviews on the same schedule, but as their perspectives were less predictable, I allowed much of the interviews to be unstructured. These interviews were an opportunity to triangulate information that we had obtained from patients and doctors. The one-to-one interviews also used this format.

#### **5.4.6 INTERVIEWER/ GROUP FACILITATOR:**

As an experienced medical trainer, educator and facilitator of small groups of medical professionals I undertook all interviews. My background risked introducing bias to the research, but we felt that experience of running medical groups was a distinct advantage. I attempted to minimise bias by 'bracketing' my experience and knowledge and avoiding any temptation to get involved in discussions of fact with participants.

#### **5.4.7 RECRUITMENT AND SETTING**

No-shows can be a problem for focus groups, but I was unable to find statistics for groups of doctors. It was widely felt that attendance rates would be much lower if we attempted to convene groups from scratch, and our first attempt confirmed these fears. On the other hand, we felt that nurses and pharmacists would be more willing participants as they were discussing extensions to their role. Professionals invited to individual interviews and a 'duo' had specific remits that we predicted would produce a good response.

##### **5.4.7.1 Identification of potential participants**

Where possible, we used pre-existent groups to avoid cancellations or small numbers. We convened the early focus groups with the help of a Pharmaceutical Advisor and GP tutor in a PCT a moderate distance away. The first two groups were pre-existent (one had a fluid membership) and presented diverse views. They included GPs from small rural and single-handed dispensing practices and a large urban group surgery. A third group of doctors

from local medium-sized practices failed to materialise despite much greater effort. This lack of success and extra effort tainted our recruitment policy thereafter. Registrar groups, all convened for the research, signalled the onset of theoretical sampling. There were groups both homogenous and heterogeneous for early medical training and experience. Nurses, pharmacists, and overseas doctors' mentoring groups were all pre-existent and fitted the sampling strategy. Suitable participants for individual interviews were theoretically sampled to refine and check theories and to obtain diverse views. The practice nurse group included prescribers, non-prescribers, and a nurse practitioner, working in surgeries that varied from single-handed to large groups. The pharmacists worked for independent pharmacies or medium-sized chains; most, however, had experience of working for national or multi-national providers earlier in their careers or as locums.

#### **5.4.7.1.1 Facilitation of recruitment**

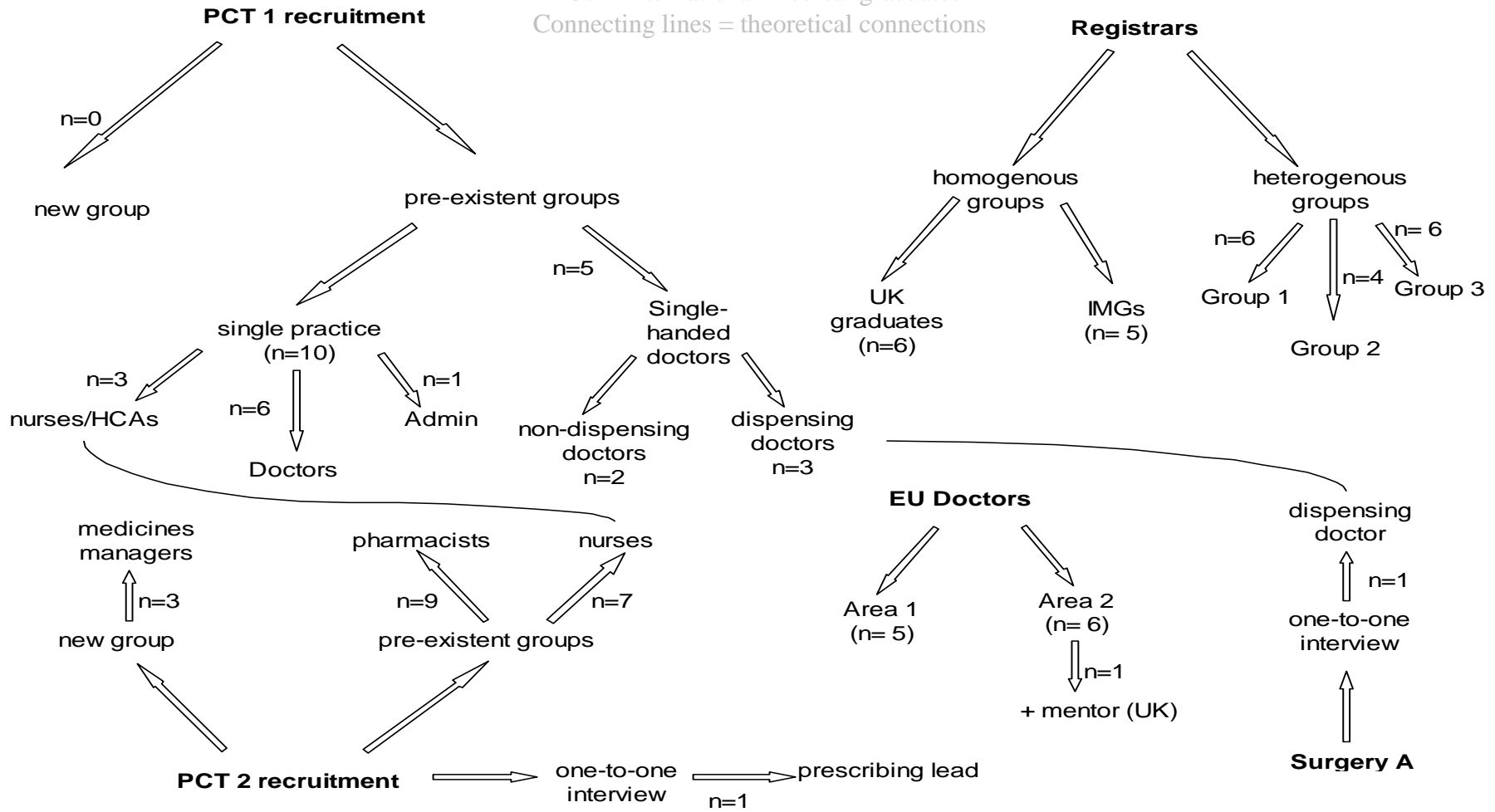
We expected difficulty in involving participants from busy General Practices. To facilitate uptake of the focus group interviews, we considered various strategies. The research team decided to use the concept of a 'passport' into groups; commonly this is achieved through payment, but for both financial and ethical reasons we decided to add an educational session into the package rather than a payment. The 'passport' we used was my time. In some registrar groups, interviews were sandwiched between a small amount of specific education and longer sessions on exam preparation. Pre-interview educational sessions had the added advantage of creating a group dynamic (these groups were not pre-existent).

#### **5.4.7.1.2 Potential sources of bias**

During planning, we identified a number of sources of potential bias, and actively sought, where possible, to reduce its effects. To maintain my distance from participants' responses, all factual enquires were postponed until the educational session, which followed the interviews. Participants informally remarked that the interview itself was educational and my role frequently became one of clarifying discussions or disagreements, and correcting misunderstandings more than providing an insight into the evidence-base for the management of UTI. The choice of a PCT, a moderate distance from our home patch was designed to reduce contamination from ideas arising from our previous 'Beacon Practice' status. Complete eradication of this potential bias could not be guaranteed in any part of the northern and eastern areas, but to travel beyond this sphere would have risked poor recruitment and significant difficulties in organisation. Many of the later focus groups included clinicians who weren't in practice at the time of the 'Beacon Practice' initiative.

# RECRUITMENT AND SAMPLING: HEALTH PROFESSIONALS

PCT = Primary Care Trust  
 IMGs = International Medical graduates  
 Connecting lines = theoretical connections



#### **5.4.7.2 Focus Group details**

We convened two focus groups from PCT1 (26/3/03 and 23/10/03) with five and ten participants respectively. In between I held a registrar group (six UK graduates) on 11/6/03 (FG1). An EU focus group of five doctors was held on 31/3/04 and thereafter, groups were convened to follow theoretical ideas: registrar groups were recruited between 2/6/04 and 25/11/08 (4-6 doctors), an EU group on 1/6/05 (six doctors and their UK mentor) and nurse (6/11/06) and pharmacist (10/1/07) groups with seven (five of them prescribers), and nine participants respectively. To complete the sampling we interviewed a duo of medical managers and were joined by another member of the team. I convened two individual interviews with GPs with special perspectives. We reached saturation differentially for themes between the fifth and tenth focus groups. A few issues didn't reach saturation.

#### **5.4.7.3 Setting**

Participants chose where and when they would prefer to be interviewed. The setting varied according to the group. Many already met regularly, and chose their usual meeting place and time. Where groups were assembled for the research, participants travelled to my surgery, where a large specialised meeting room is available.

Individual interviews and small group interviews took place at the professionals' usual place of work, scheduled around work commitments. Some of these interviews were shorter, and were, therefore, more flexibly arranged.

##### **5.4.7.3.1 Refreshments and sponsorship**

Refreshments depended on the time of day, location, and usual arrangements. The refreshments at my surgery were the least enticing, consisting of only coffee and biscuits in the evening! A number of groups had pre-existent arrangements for their educational meetings, including sponsorship, and varied from sandwich meals through buffet lunches to take-away pizzas. Pharmaceutical companies sponsored some lunches/ evening snacks but I was not involved in any promotions, and no products promoted were relevant to UTI.

### **5.4.8 DATA AND ANALYSIS**

#### **5.4.8.1 Data collection and transcription**

##### **5.4.8.1.1 Focus groups**

I facilitated and audio-taped each focus group. The interviews were scheduled to take from 30 minutes (smallest groups) to an hour (largest groups), though there was considerable variation depending on circumstances.

#### **5.4.8.1.2 Individual interviews**

I undertook these interviews, keeping field notes, which were subsequently transcribed into an electronic document. The interviews were scheduled for one hour and lasted 45-75 minutes. I sent the final documents to participants for validation.

#### **5.4.8.2 Data Analysis**

In keeping with grounded theory our analysis followed the “constant comparative” method. Technically, we began with open coding, proceeding to axial coding then to selective coding. In reality the stages overlapped: the methodology caused us to assemble and reassemble theories, and themes reached saturation at different points in the iterative process. Coding proved easier than in the study of women’s experiences as professionals had less diversity of opinion and more limited narratives.

Computerised transcripts were placed into a ‘home-grown’ framework to simplify open coding. JL undertook the initial and final analyses, and IE provided a non-medical perspective. The axial coding stage owed a significant amount to the themes identified in the study of women’s experiences, which helped the comparison of medical and lay views. PH and CC provided analysis primarily at the stage of selective coding. All three supervisors were responsible for adding novel ideas and highlighting discordant themes. We triangulated findings from the study of women’s’ views, especially where they had offered opinions about medical treatment, and included evidence from informal medical media sources as well as formal references. Quotes were chosen because they expressed common experiences, attitudes or topics or because they showed the breadth of experiences of participants.

### **5.4.9 ETHICAL CONSIDERATIONS**

#### **5.4.9.1 Ethical approval**

County Durham and Darlington local research ethics committee granted ethical approval. The committee agreed an amendment to allow interviews with pharmacists and nurses.

#### **5.4.9.2 Consent**

We produced information sheets and consent forms to standard formats, and agreed by the ethics committees. Consent forms have been retained in locked cupboards.

#### **5.4.9.3 Confidentiality**

We addressed this issue in the information sheets and re-iterated it before an interview or group session. We placed particular emphasis on participants’ responsibility to maintain

each other's confidentiality during and after focus groups. Many groups shared a degree of commonality as they were either pre-existent or had formed themselves (rather than being formed by the research team). These groups had a pre-existent code of conduct, including confidentiality.

Individuals and groups may have well defined characteristics, recognisable by peers. As well as maintaining anonymity in transcriptions and analysis, we also took care with the selection of quotes, removing identifiable features.

#### **5.4.9.4 Safety netting**

We outlined pathways for dealing with concerns about a professional's practice or patient welfare. I, as lead investigator, was responsible for both of these. In the former case, we would follow standard PCT clinical governance or vocational training scheme arrangements. In the latter case we would give advice, approach a trainer (if in training) or the PCT depending on the severity of the problem. No such concerns came to light during the project.

#### **5.4.9.5 Data collection**

I audio-taped each interview and focus group after obtaining written, and just prior to the session, confirmatory verbal consent. Tapes were marked and passed to transcribers, with no known connections to participants, at Sedgefield surgery or the University of Durham who produced electronic and hard copies of the interviews as soon as practicable. For interviews, the procedure for consent was the same, but I relied on field notes alone.

#### **5.4.9.6 Data storage**

Tapes, hard copies, and field notes are kept in locked cupboards at the University of Durham and Sedgefield surgery and electronic material is stored on password-protected computers. Data will be kept for one year after publication.

#### **5.4.10 CONCLUSIONS: METHODS**

This qualitative study embodies rigorous methods, and follows the concept of modified grounded theory, which is appropriate to research in familiar territory. Professional responsibilities for the management of UTI are gradually changing and as a result, nurses and pharmacists were included in the study. Doctors were less questioning of the basis for their management strategies than we imagined. Perhaps, as a result, the outcomes are less certain than we might have hoped for, but it is unlikely that any alternative approach would improve on this situation.

## 5.5 RESULTS

### 5.5.1 UTI: ITS SYMPTOMS AND EFFECTS

#### 5.5.1.1 Terminology

Some nurses suggested that cystitis was a bladder irritation rather than an infection. Other than this, most professionals use the terms cystitis and pyelonephritis to describe lower UTI and upper UTI, though they are comfortable with all these terminologies. They feel that ‘water infection’ is a common term used by patients. ‘Urinary tract infection’ may not be universally understood and many doctors avoid it. These terminologies are used in the same way across different languages and cultures.

#### 5.5.1.2 Incidence

Few participants commented on the incidence of UTI, though they made general comments that it is a common problem. For upper UTI, one doctor suggested:

*“I probably see pyelonephritis once a year if that, I would say.” (Ld4p2)*

#### 5.5.1.3 What are the symptoms of UTI?

Professionals feel that cystitis is an easy diagnosis:

*“as a community pharmacist it is not seen as a difficult diagnosis to make” (FGMM)*

They almost universally adjudge the combination of frequency and dysuria to be the characteristic of cystitis. Some think urgency is important, some mention abdominal pain, and some use vaginal discharge as a negative marker for UTIs. One focus group suggested that dysuria was the most important symptom for them, but another group expressed caution if it was an isolated symptom:

*“I wouldn't just go on dysuria because often if they have had a urethritis or just an inflammatory thing, they will have those symptoms anyway, so it would always be a combination of their history and urinalysis.” (Bp3)*

Doctors associated certain extra symptoms with upper UTI:

*“With pyelonephritis, most people would probably be more ill possibly with a temperature or loin pain or renal pain. Also have other symptoms like vomiting”*

(Ld5p1)

##### 5.5.1.3.1 Do professionals think haematuria is important?

Some professionals are impressed (or worried) about the presence of blood, and a number think that blood is an indication for looking for other diagnoses:

*“I think it is complicated cystitis or something else” (CSdep11)*

Others are less impressed, so long as blood is associated with active infection:

*“Haematuria with another symptoms for me is not that important...(but) if haematuria appears after the cure or treatment or with no symptoms at all” (CSdip11)*

On the other hand, one doctor had picked up a renal tumour from a finding of microscopic haematuria and was, uniquely influenced.

#### **5.5.1.3.2 What else do professionals take into account?**

Professionals think that symptoms differ depending on women’s age, but this perception generally translates only to different management of the elderly or young children rather than the adult population. Nurses and female doctors are more likely to ask about sexual history and as a result, consider the different triggers of UTI:

*“I would be looking at menopausal symptoms in a 50 year old and more towards kind of sexual health kind of things (in a 20year-old)” (N4p6)*

Pharmacists were attuned to picking up ‘alarm’ symptoms and changes from women’s usual presentations. Haematuria and ‘feeling unwell’ were the commonest symptoms that caused them to refer women to a doctor. They were more worried about diabetes than other health professionals and usually avoided giving advice to the over-60s, in case they had other medical problems, and the under-16s and men because they are managed differently.

#### **5.5.1.4 How do women describe their symptoms?**

##### **5.5.1.4.1 The importance of symptoms**

All health professionals feel that women’s descriptions of their symptoms are a very important part of the diagnostic process. Experienced doctors, in particular, appear to place more emphasis on the patient’s symptoms:

*“I think the patient’s symptoms carry weight, I really listen to them for their symptoms...I think the patient’s symptoms carry a lot of weight. You have to take the patients symptoms seriously” (Ld2/3p16)*



Conversely, they use tests in a less structured way than their younger colleagues when making a diagnosis. Younger doctors, however, may not have had a chance to develop a feel for the symptoms of cystitis:

*“I don’t think they come with symptoms as such – I have never seen anybody who comes and says it hurts when I pass water – I have never seen that”* (26d1p13)

Women commonly present with symptoms of dark, and strong smelling urine but doctors don’t find these symptoms predictive of disease. Some feel that women associate back pain with urinary infection, to the detriment of other associations:

*“Any pain in the back for some patients is coming from the kidney”*(Ld1p2)

Doctors appreciate that a number of symptoms cause women distress:

*“When I am working I have to get up 10 times to go to the toilet...the pain...leaking, dribbling”* (2511db/dr/dall/p7)

#### **5.5.1.4.2 Women’s metaphorical descriptions**

Doctors and pharmacists in most of our focus groups were unable to recall specific patient metaphorical descriptions but nurses have clearer recollections:

*“It’s like weeing razor blades – that’s the cleaned up version!”* (N4p3); *“weeing glass”* (N2p3) is another florid description.

One Spanish GP recalled women remarking: *“I have a beehive down below”* (CSdep15) and *“fish-hooks”*

#### **5.5.1.4.3 Professionals response to women’s descriptions**

Professionals vary in how they perceive patient descriptions. On the one hand, some felt that patients were stoical and uncomplaining, whilst others felt that patients tended to talk up their symptoms, though whether this was through misunderstanding, a need to have a ‘passport’ for the doctors’ time, or because they genuinely wanted to exaggerate their symptoms is not clear. Two examples from a single focus group illustrate the differences of opinion:

*“Very rarely would people say I have got a kidney infection. A lot of them only answer that when they are actually asked the question – do you have a pain higher up or anything like that?”* (Ld1p5)

*“Patients tend to talk up their symptoms, so it has got a lot more clout if you have got a kidney infection than just good old cystitis and I would say that the majority of patients who say they have got trouble with their kidneys are talking about a lower urinary infection”* (Ld4p2)

#### **5.5.1.4.4 Women who present with a diagnosis**

Women often present with a diagnosis rather than symptoms. They attend all health professionals in this way:

*“Most patients would describe cystitis as a symptom, rather than dysuria or frequency”* (Ld5p1) - a doctor

*“I think most of them describe a previous condition that they have had, that has been previously diagnosed. They sort of tend to know what they’re coming in with”* (P9p1) – a pharmacist

Younger women present in this way more commonly than older women, and are more confident and less diffident about their diagnosis. Most doctors consider that women who express their problem in this way are usually accurate, but they wonder if they come to these decisions in a logical manner:

*“When they come to you most of the time they come with a preformed idea and have the symptoms...but they are often correct”* (2511dgy+bp11)

*“they always come and say they have got cystitis or a water infection and then you go into what cystitis is and then they don’t have a clue about what cystitis means at all.”* (26d1p13)

Nurses, however, are less convinced that women’s diagnoses are accurate; this may reflect the different ‘populations’ that nurses and doctors see. Women’s belief that they have a UTI may also be implied by their preparation for their consultation:

*“I also find that people who think they have a urine infection bring a sample with them”* (26d1p14)

Doctors report that women don’t spontaneously suggest that they have an upper UTI:

*“Very rarely would people say I have got a kidney infection. A lot of them only answer that when they are actually asked the question – do you have a pain higher up or anything like that?”* (Ld5p1)

The same doctor noted that women present with ‘cystitis’ rather than with individual symptoms unless they had haematuria. This suggests that women will make a simple diagnosis but leave the diagnosis to professionals when they think they have something more complicated.

#### **5.5.1.4.5 International differences in presentation**

Women present earlier with UTI in Spain, but later in India. The difference is due to the ability to access health care and the likely management rather than differences in disease patterns. Spanish doctors feel that women in the UK are more likely to present with a diagnosis, and consider that they know more about their symptoms. Smelly urine is an important symptom in the UK, unlike other countries:

*“One of the things that surprised me here is that they give a lot of importance about the smell, the smell is strong and is a sign of infection”* (CSdmp13)

This is not an international phenomenon and may be due to inadequate hydration:

*“It could be because in this country the water is more concentrated. People don’t drink water here”* (CSdpp13)

#### **5.5.1.4.6 The effects of age and experience**

Throughout the studies we have noted that women’s responses are multi-dimensional. Decreasing age and increasing experience (of UTIs) have consistently come across as determinants of behaviour.

*“You tend to find that younger women tend to come in and say I have got cystitis or I have got a urine infection. The older ladies often I find say – ‘my wee is smelling strong’”* (166dcp7).

*“I mean, take the case of a woman with no history of UTIs - they usually explain very well their symptoms”*(DSdbp5).

This apparent contradiction occurs as a result of the interaction of the two dimensions of age and symptom experience.

#### **5.5.1.5 Making a diagnosis**

Doctors showed signs of individual and contextual decision-making by weighing up the significance of combinations of symptoms, and taking background information into account. Pharmacists and nurses, who often follow protocols, acted similarly but often

deferred complex decisions to doctors. Some doctors appear to have an ‘internal calculator’ working out the chance of disease for each patient:

*“When you see this particular patient with this particular or these particular symptoms, how likely is the possibility of a UTI...you are trying to consider all the symptoms, signs and everything and then you produce a decision with all this information”* (DSdb/ap11/12)

*“I wouldn't just go on dysuria because often if they have had a urethritis or just an inflammatory thing, they will have those symptoms anyway, so it would always be a combination of their history and urinalysis”* (Bp3)

One group discussed how they would subtly change their management strategy for a pregnant woman with UTI, and others take the patient’s background into consideration:

*“You wouldn't think a 50 year old woman would be getting cystitis through bonking her head off”* (N4p6)

## **5.5.2 WOMEN’S CONCERNS**

### **5.5.2.1.1 What symptoms do professionals think women are worried about?**

Both doctors and nurses have a reasonable appreciation of women’s concerns about the effects of their symptoms. They feel that frequency of micturition causes the most disruption. This accords well with our study of women’s experiences:

*“...for me the most important to them is the frequency...because maybe they have to wake up in the night, it interferes with their job, or they have to run to the toilet which is not always available”* (CSdep12)

*“(they say) when I am working I have to get up 10 times to go to the toilet.”* (251108dbp12)

Professionals worry about haematuria and think that their patients have similar views:

*“The patient takes it very seriously as soon as they see blood. They really want us to do something initially”* (Ld2p19)

### **5.5.2.1.2 What complications do professionals think women are worried about?**

Health professionals think that women worry about the cause of their infection, and about infrequent kidney infection, or the potential for progression to kidney infections, but this exchange of views shows that it is not universal:

*“you get a few who have had problems with kidney problems and they’ve said ‘look if I don’t get something’ then quite often they really deteriorate, and they have temperatures and they are really unwell...they are worried about spreading...I don’t think patients perceive UTIs as being particularly serious” (N1/N2/N6p14)*

Professionals agree that UTIs are a problem for many, but that they are dangerous for only a few, and that they are not unduly worried if they know it’ll remain localised

#### **5.5.2.1.3 Is patient expectation changing?**

Many professionals think that patient expectations and in particular, the need for explanations, were rising. Increased expectation concerns professionals when they can’t meet these needs. This quote followed a discussion of medical school teaching:

*“(Are there any differences from when you were at medical school?) ‘nods again’.*

*“I have noticed that they used to come just with the complaints - nowadays they want to know why it is happening to them again and again...and sometimes I find it difficult to explain why it is happening so frequently.” (166dbp4)*

Coming from a younger doctor, this suggests that the wish for greater explanation is a recent phenomenon. The manner of delivery suggests a reticence to express such an opinion: criticism, or even wariness, of patient-centred care is ‘politically incorrect’.

#### **5.5.2.1.4 Confusion of symptoms**

Professionals think that patients quite commonly confuse the symptoms of vaginal thrush and sexually transmitted infections (STIs) with UTIs:

*“Some of the older ladies seem to associate it with sexually transmitted diseases, so they take a little bit of reassurance” (166dap4)*

From other studies, we know, of course that some professionals appear to make the same mistakes, though we didn’t elicit this during these interviews!

*“A lot of patients say that they have been to the chemist and got something and they sometimes think that they might have got antibiotics from the chemist” (26d1p13)*

- talking about an over-the-counter prescription for an antifungal.

Mechanical back pain is a very common condition, but loin pain is characteristic of upper UTI. Professionals feel that patients can confuse the two similar symptoms, creating problems for diagnosis, unless there were clear systemic symptoms:

*“Then if you have leading questions, they always complain of a pain in the back. Any pain in the back for some patients is coming from the kidney” (Ld1p2)*

#### **5.5.2.1.5 Professionals’ perceptions of women’s ideas about the causes**

Doctors couldn’t remember many instances of women recounting ‘old wives tales’. They remembered that women had mentioned Jacuzzis and sex as causes.

*“There are just people that mentioned how frequently they have it after intercourse and soon afterwards they started to develop the symptoms” (166dcp5)*

and sometimes their patients mistakenly think that UTIs are contagious:

*“Sometimes they think it is a sexual, does my husband have it?.. they don’t understand and because it is the same area they associate with sexually disease” (Csdi/ep12/13)*

Other causes cited by their patients include inadequate fluid intake and dirty toilets.

#### **5.5.2.2 Health Beliefs, concerns and knowledge of doctors**

The majority of doctors’ beliefs elicited during these interviews were of a predictable biomedical nature. They view pyrexia and/ or vomiting as warnings of more serious, systemic infection. Systemic illness itself is seen as a marker for kidney infections. Some doctors are wary of vague or atypical symptoms; in these circumstances they are more likely to consider alternative diagnoses and to actively rule them out.

For visible (i.e. frank) haematuria doctors would consider referral looking for causes other than infection. They have a higher threshold in women (compared to men) as they are more likely to suffer from infection. Doctors often ask women to provide follow-up samples of urine if they had found blood (usually they don’t ask for these):

*“Probably I would confirm the blood has disappeared two or three days after she has finished the course of antibiotics, to make sure I am not missing anything underlying there” (DCddp6)*

##### **5.5.2.2.1 The effect of previous experience**

A few of our interviewees had worked in medical and surgical specialities before turning to general practice. Although they behaved similarly to others when managing UTI, their previous experiences still influenced their decisions:

*“...because I come from a more medical background and you like to have all the information, you do all the investigations” (2511djp3)*

Although the spectrum of disease in hospital and community practice was noted to be different, generally doctors would manage women with particular presentations in a similar manner whatever the setting.

#### **5.5.2.2.2 Doctors' belief in folklore and old wives (or doctors)' tales**

Despite some of the tales in the study of women's experiences only one participant expressed a non-biomedical health belief - the effect of wiping after weeing:

*"I don't know whether the usage of toilet paper in this country - as compared to water back in India - I don't know whether that would have a difference"* (166ddp11)

Undoubtedly, some doctors do believe in folklore and medical journalists either appear to believe in more than most or are more forthcoming. Many articles expound the virtues of actions such as passing urine after sex or drinking more fluids, and warn of the dangers of such things as tight clothing and bath additives. This even extends to national guidance (5). The following examples are of more unusual beliefs:

*"Symptoms are exacerbated by acidic foods of any kind...the corollary of the symptoms being exacerbated by acid is that they are relieved by making the urine more alkaline with sodium bicarbonate"* (386)

*"A new partner subjects both people to commensal bacteria to which they have no resistance...before this (acquisition of resistance) has happened, the bacteria of the new lover may cause some inflammation"* (360)

### **5.5.3 PROFESSIONALS' PERCEPTIONS OF WOMEN'S CONSULTING BEHAVIOUR**

#### **5.5.3.1 Does embarrassment affect consulting behaviour?**

There was widespread agreement that women were embarrassed by UTIs, and that they altered their consultation behaviour in order to circumvent their feelings:

*"I have a feeling it is more because of embarrassment again. They would rather just get the treatment and not see a doctor"* (26d4p14)

One strategy is to present the UTI as a secondary consideration ('a hidden agenda'):

*"They talk about other things and then they may just say something like 'oh by the way I also have a water infection' which is probably the main reason why they came...but sometimes they are quite up front if they have had it before"* (26d4p12)

The widespread use of over-the-counter treatments may also reflect embarrassment. Often, women with recurrent UTI talk more openly about their UTIs. Generally, but not universally, medical professionals thought that younger women were less inhibited, and older women and those with first time UTIs were more embarrassed:

*“I think the young women want quick relief as it is sometimes embarrassing to come to see a male doctor”* (CSdpp12)

*“Older ladies are possibly or probably more embarrassed”* (Bp6)

Clinicians mentioned telephone consultations, and self-treatment as strategies for avoiding face-to-face consultations:

*“They like it if they can ring up and tell you the symptoms and actually just get the prescription over the 'phone- I mean easy access without having to do anything”* (Bp6)

*“I think they are embarrassed in the first instance to come, because it is an embarrassing thing to discuss and I think that that might be one reason why they want to sort it out themselves first”* (26d4p12)

Doctors collude with patients on keeping consultations short. Most doctors attributed this to the benefits, in time management, of a quick and easy consultation, rather than a conscious decision to avoid embarrassing topics:

*“They are quite a nice consultation; you know you are going to get finished in time for a change”* (166dap4)

Some doctors, however, question whether it is women who are embarrassed:

*“Giving instructions about you know - first thing in the morning - mid stream and stuff like that. Is it because English doctors are more embarrassed?”* (DCdbp20)

*“I think very few express that after sexual intercourse they have developed a UTI but that is very few...perhaps we are embarrassed to ask such questions...(is that common that they think that is the cause?)..no, that is very rare. (Is that because we don't ask and they don't want to ask).. maybe...perhaps we are embarrassed to ask such questions”* (2511da/bp7-8)

Spanish doctors think that women in the UK are less embarrassed to talk about UTI, and other potentially more embarrassing conditions, than their counterparts in Spain.



*“I see many patients with thrush and you know, maybe more embarrassing problems, rather than a UTI, so I don't think it is really embarrassing for women most times”* (DCdbp20)

Worries about perceived associations with sexually transmitted disease, and concerns about incontinence (in older women) are also potential sources of embarrassment.

#### **5.5.3.1.1 Cultural variations in consulting behaviour**

A number of doctors had worked in other health care systems. Consultations in all countries followed a western style bio-medical model.

In Spain, women present earlier with UTIs; this makes diagnosis more difficult:

*“maybe it just started yesterday and it could be nothing or maybe it could be a UTI you know...the patient is coming after three or four days with the same symptoms, quite clear and you know, a quite clear picture - I think it is easier just to get a decision”* (DSdbp19)

Trinidad has a very mixed population and gives us a window into the nuances of consultation behaviour in different cultures:

*“In the West Indies the population is so multi-cultural...you would notice that people from Asia would prefer to see a woman - which I think is basically the case here as well...the African population is quite different - they will tell you what is going on...(and Chinese?) the doctor's always right for them I think. That's what I've noticed. Whatever you tell them goes. Especially the women will not look at you when you are speaking - which is a cultural thing I think”* (166dfp10)

#### **5.5.3.2 Does the sex of the doctor matter? - a professionals' perspective**

Female doctors are more likely to express an opinion on this issue, though they differ in their thoughts. On the one hand they think that the sex of the doctor matters less than familiarity, but on the other hand they suggest that women are more comfortable talking to women doctors, and this especially applies to women of Asian origin:

*“I think if they had any sexual, urinary, or vaginal problem I think they would probably come and see a female doctor if they weren't comfortable with male doctors, but I think if it is a doctor they have known for a long time they are probably quite at ease”* (Bp6) - female doctor

*“I would say whether they like coming to the Doctors or not, I would say depends on the doctor, not the gender of the doctor.”* (Bp5) - male doctor

Male doctors are, however, more likely to suggest that women prefer women doctors. This matches findings from the study of women's expectations. They value familiarity as well as female gender - but, as women consult female doctors more frequently, perhaps, they don't become so familiar with male doctors?

As an aside, some doctors feel that males tend to stick to male doctors, especially in traditional working class areas. Female doctors have a different perspective:

*"I would say the men are more choosy than the women...well I wish they would stop coming and seeing me with sexual and erectile problems."*(Bp5) - male/female doctors

#### **5.5.3.2.1 Do women describe their symptoms differently to women doctors?**

When we asked our participants about the ways in which women presented to male and female doctors, there appeared to be no differences in the way women described their symptoms. Intuitively women would discuss more personal and psychosocial issues, but in reality female-female consultations provide more biomedical history but include more partnership statements (387).

#### **5.5.3.2.2 Generational differences**

Nurses and pharmacists offered no particular opinions but doctors think that older women consult in different ways than younger women and hold different beliefs:

*"I think older ladies probably perhaps prefer to see a lady doctor if there's something personal, but I think the younger girls tend to be less bothered now"* (Bp5)

*"some of the older ladies seem to associate it with sexually transmitted diseases, so they take a little bit of reassurance"* (166dap4)

#### **5.5.3.3 Professionals' ideas about women's sources of information**

Women most commonly cite their mothers as the source of their ideas:

*"When I ask a patient why do you think its cystitis - they say well my mum's told me that"* (166ddp8)

Younger women are more confident about their diagnosis but recount that they are more likely to have asked their mothers for advice, an apparent contradiction. Other relatives were the next commonest sources and then written forms of media:

*"mothers telling children. I have had some people say magazines, do it yourself medical books people have read...less common than friends or family"* (2511db/djmp11)

Professionals, however, are dubious about the quality of information in the media:

*“they don’t have a clue about what cystitis means at all. They have read something in the health magazine”* (26d1p13)

The lack of publicity means that women haven’t reduced their expectation of antibiotics in the same way that has happened for coughs and colds:

*“there’s so much about viral infection which will get better with time but there is never in the media anything like urine infection getting better without antibiotics and so I don’t think patients are thinking of that option much”* (2511jyp11)

#### **5.5.4 WHAT ARE THE INFLUENCES ON PROFESSIONALS’ MANAGEMENT STRATEGIES**

There are many influences on professionals’ clinical reasoning. A few start with childhood experience or the influence of folklore. Medical school teaching, and postgraduate training are profound influences. Subsequently, evidence-based practice and experience are important. On another plane, professionals operate in different geographical cultures and contexts, or in different organisational contexts.

##### **5.5.4.1 How influential is early teaching?**

Early teaching seems more powerful than messages delivered later in professionals’ careers. When their opinions change, they aren’t always sure why they have gravitated to certain viewpoints – perhaps, this change is brought about by a combination of messages and experience or even subliminal messages.

All doctors feel that there are differences between taught and current practice but the differences are greater for those trained outside of the UK. The amount of difference varied from country to country; some e.g. the West Indies had similar teaching to the UK so the ‘culture-shock’ was less; others bore less similarity e.g. India.

##### **5.5.4.1.1 The influence of medical school**

Early teaching appears to be the strongest influence on young doctors’ management, and it acts as a default management strategy:

*“It often stays in your mind, you might not follow it but it stays in your mind”* (2511dap5)

*“Well initially that was what we were taught and I have stuck with it and it just seems to work most times”* (166dfp3)

Registrars are more able than more experienced doctors to recount the effects of their early training on their management, though even then with limited precision!

*“I vaguely remember some research and being taught about that at medical school”*  
(166dap3)

Where experience has borne out early teaching its effects are enhanced:

*“something that I think I have carried with me from Medical School days, is that sometimes even though the microbiology says the organism is resistant to say trimethoprim, you may actually find that it has actually worked”* (LPd4p8)

In situations where experience and ‘the absolute truth’ of early teaching are at odds, doctors find themselves in a dilemma:

*“We all were taught in medical college that these are the symptoms that should be investigated...I think that most of us still try to follow that plan but often you look back and question”* (2511dap5)

*“I think the first thing we learned still sticks in the mind can be very difficult ..(you almost feel guilty of getting rid of what they taught you at medical school? Am I putting words in your mouth or is that how you feel?)...All: ...laughter.....agreement”* (2511dbp5)

Overseas doctors are more likely to find themselves in this situation when first working in primary care in the UK. The biggest change for most are empirical treatment strategies. Whether guidance and standard management drives medical teaching or vice-versa is unclear: perhaps, the differences reflect variable speed of adoption of evidence-based practice; a more likely explanation, however, is that teaching is pragmatic, based on local resources and expectations.

#### **5.5.4.1.2 The influence of clinicians/ trainers**

Many registrars have close educational relationships with their (primary or secondary care) trainers and cite them as significant influences:

*“I think it was one of the surgeons who once said most of the antibiotics were given for five days”* (2511dap8) - re-pyelonephritis

Observation of practice and case based discussion are standard teaching methods:

*“so my trainer while having a look at the video said that if I was giving the antibiotics why did I do a dipstick”* (26d3p3)

Sometimes learning about UTI management was less personal. Protocols are more often mentioned as sources of guidance than trainers themselves. Nevertheless, teaching practices are a rich source of handy guidance for registrars:

*“when I started as a GP Registrar I just checked what we are supposed to do for these kinds of things, because you would follow a protocol”* (166dep3)

*(you don't happen to know where they got that protocol from do you?)...No. When I joined as a registrar it was something that was handed over”* (26d4p5)

Another young doctor had been taught by a nurse practitioner whose extended training had included a detailed assessment of the management of UTI. Nurse practitioners are themselves influenced by prescribing courses, which cover the management of common conditions such as UTI. Most registrars adopt their training practice's ideas, whether evidence-based or otherwise, but this isn't universal. Registrars aren't surreptitious about their different approaches, suggesting that trainers and their practices tolerate differences of opinion. One registrar, who had worked in practices with different approaches, had adopted the more evidence-based strategy and tried to influence her current training practice - to no avail! Thus registrars learn from their trainers but perhaps, trainers despite suggestions to the contrary are less willing to learn from their registrars.

#### **5.5.4.2 The place of guidelines and protocols**

The effect of protocols may only be short-lived however, and specific to the Practice. In one focus group three respondents had received training in one specific practice. Two had similar ways of managing; the other had moved to a different practice and had reverted to their original teaching. Registrars compared protocols with 'what sounded right' and would ignore or disagree with further education depending on their judgements. It might also take time to adjust to new guidance:

*“It could be that we were used to something and then you have new guidelines and you need time to get used to them. I don't know”* (DSddp16)

##### **5.5.4.2.1 Flexible use of guidelines**

Guidelines can be useful to begin with, but with experience professionals use them as a framework rather than a straitjacket:

*“I think a protocol can help you to make your decision, but at the end of the day you have got a patient there - so you have to balance your own decision”* (DSdap13)

Nurses are said to work well to protocols, but are less likely to show flexibility when the situation demands. However, we found a flexible approach, similar to doctors:

*“I used to work to a protocol but now I work to my own clinical judgement”* (N6p11)

There isn't universal acceptance of guidelines and one group expressed concern about a PCT suggested protocol. Other groups suggested GPs were more likely to use their own clinical freedom. Some doctors had practice policies, but for some the greater emphasis was on individual decision-making:

*“Individual policies - as we do for most things. There is a formulary and a policy, which identifies first line antibiotics”* (BHp1)

GPs who had trained abroad are more likely to use guidelines.

#### **5.5.4.2.2 Responses to multiple guidelines**

Doctors are aware of different sets of guidelines, some with contradictory messages. They use their judgement and experience to take a smorgåsbord of advice:

*“National guidelines come out with general what is best antibiotic for that condition, but if the local area shows that you have got a resistant population, then that is the population that is going to be affected severely as well and you are going to meet them”* (26d1p7)

Younger doctors are more likely to use hospital-based protocols at first, but, driven by experience, gradually switch to primary care methods:

*“I mean I think it also depends upon hospital policy to some extent – so I mean they cannot apply it in the general population”* (26d4p8)

#### **5.5.4.2.3 Do guidelines change clinical behaviour?**

Guidelines appear capable of changing behaviour. They may be more effective in younger and less experienced doctors, or in those changing culture:

*“It could be - that we were used to something and then you have new guidelines and you need time to get used to them. I don't know.”* (DSddp16-change culture)

*“2 years back it was not like that. I mean when I started we were sending everyone MSU, C&S and then waiting for the results to come back, but as there is evidence to say we can treat with trimethoprim in an uncomplicated UTI, we are doing that”* (2511dap3) – a younger doctor

Protocols were present in a number of practices, and appear commoner in training practices. This may reflect a proactive approach, and/or a wish for consistency in disease management. Formularies, and adoption of regional and national antibiotic guidance are other methods that practices use to standardise UTI care. Less experienced doctors valued protocols and guidelines:

*“My experience is not wide in for example, UTIs, I tend to follow what the guidelines or what the protocols say” (DSdcp17)*

Registrars and overseas doctors almost always accept these protocols and adopt their management decisions, even though they often differ from their previous practice:

*“For me it is clear on the use of antibiotics and I know which kind I use since I started here” (CSdpp18)*

Some clinicians, usually older, suffered from protocol overload and responded by filing new guidance:

*“When the PCT first set up they produced guidelines on all antibiotic use, but guidelines often go into a book or a file on prescribing, referring or whatever and it is a question of how actively they are used” (Bp2)*

#### **5.5.4.2.4 Reasons for not changing practice**

Reticence to change practice relates to real or, sometimes, unfounded fears:

*“The idea that you could treat infections blindly was a threat in the late nineties- doctors would think: ‘I’m going to condemn my patients to a renal transplant waiting list’ ” (12I2)*

Experienced doctors are less likely to change practice unless the evidence is very strong, or their current practice appears deficient. In time, however, positive experiences when following a guideline may help to alter opinion. As an example, acceptance of empirical treatment is easier but reducing investigation is thought to be riskier, but letting a registrar pilot the change allows a way around this dilemma:

*“I think they are strict with their experience rather than looking into the new evidence. They are thinking that they have done well so far this way and it works well” (2511djyp4)*

*“When they told about the evidence they agree that I can do but they are not changing their practice” (2511p7)*

Weighing up the pros and cons is important, but doctors may also hide behind a patient-centred approach:

*“They say – ‘it’s alright all of these guidelines, but we put our patients first’... ‘putting the patient first’ – this is an excuse for all sorts of bad practices”* (1212)

Even if they change, they need further reassurance to maintain their new position:

*“Change doesn’t work- doctors revert to their original ways”* (1212)

*“I think GPs are initially against everything ..unless it comes with money!”* (1212)

Changing practice, however, is made more difficult if opinion leaders do not promote evidence-based practice. Medicines’ managers had received conflicting advice from a nationally led course, and felt disempowered in their efforts to persuade GPs to change:

*“If I’m going to argue with GPs I’ve got to be certain of my evidence-base”* (FGMM)

#### **5.5.4.3 Other influences**

A therapeutics course had changed one doctor’s perceptions on the use of antibiotics (to a lower use strategy), but otherwise doctors also found it difficult to recall where they’d picked up all but the more recent management strategies from. For many nurses and pharmacists, their current roles are different than those expected when they underwent their basic training, and they show more deference.

##### **5.5.4.3.1 Experience**

Although pharmacists undertake post-graduate training in communication skills, they feel that the most important element is experiential learning. The views of experienced clinicians are an important factor in deciding upon best practice. This influences younger doctors and recently arrived overseas doctors more than others, and may also shed light on why early teaching has an enduring effect. For them, experience doesn’t replace evidence or guidelines, but cements messages:

*“I think experience as well, and not just working in England...with your experience you can be OK with just taking a history to decide”* (CSdep18)

*“Also I try to look at what other doctors with more experience than me do”* (DSdcp17)

Sometimes, this experience may wrongly cement a previous message. In this example, misinterpretation of evidence (taking results at face value rather than in the light of clinical response) by others undermined a nurses’ new strategy:



*“I always gave cefalexin, but then I did my nurse prescribing course and I went onto trimethoprim and I found that so many of those patients came back and got cefalexin anyway, that now I just give cefalexin first.” (N6p12)*

Experienced doctors may also use experience as an excuse to ignore evidence:

*“GPs think their own individual experience carries far greater weight than evidence” (1212)*

#### **5.5.4.3.2 Audit and feedback**

Audit isn't a common influence on clinical practice in UTI but probably reflects the underuse of this tool rather than a lack of effect when it is undertaken. Whilst personal audit is assumed to be most powerful, one young doctor was influenced by a peer's audit of treatment length of UTI:

*“I used to give five days when I started, but following an audit by one of the registrars on UTI and treatment for three days – now I just give three days” (26d2p6)*

Audit is a way of dispelling myths and providing insight into daily practice:

*“The important thing about audit is...as individuals we're not able to reflect accurately on what we do...I like to think we know what we do, but in reality it's not necessarily the same” (1212)*

Protocols that have feedback loops may increase reflection on best practice:

*“When I am working in one of the practices \*\*\*- and we sent a sample of urine asking for a culture on the back of the sample you have to write why” (Dsdep12)*

#### **5.5.4.3.3 Research**

Doctors in training sometimes related influences to specific pieces of research or guidance, but this isn't a trait observed in more experienced doctors:

*“I read the BMJ article which said that now in women of reproductive age we can treat them just on the symptoms” (2511dap4)*

*“The current treatment recommendation is three days treatment – the majority of them get better and there is no point in sending a urine sample” (26d1p2)*

As we found with other influences younger doctors are more malleable:

*“For example if I read an article or something and it said there is evidence to manage something correctly then probably I would try”(CSdpp19)*

### **5.5.5 WHAT INVESTIGATIONS DO PROFESSIONALS UNDERTAKE?**

Health professionals check dipsticks in the vast majority of women with UTI, and even when they admit that it won't change their diagnosis. Many also check MSUs despite guidance that supports treatment based on symptoms. Very few suggested that smell or cloudiness affect their assessment, but this may be implicit.

#### **5.5.5.1 Dipsticks**

Dipstick testing is commonly used to help management decisions for UTI. Women may bring urine samples expectantly, and doctors respond by checking dipstick tests:

*"I also find that people who think they have a urine infection bring a sample with them"*  
(26d1p14)

A few doctors use dipsticks selectively according to the evidence-base but most, and all nurses expressing an opinion, are less selective:

*"...normally do the dipstick because I have one with me and it is easier to do that"*  
(CSdip17)

##### **5.5.5.1.1 How do clinicians use dipsticks?**

Few clinicians have a comprehensive knowledge of the utility of dipstick tests. One focus group under-estimated their power when asked to estimate the predictive values of these tests. Despite this, it was obvious that a few members placed value on any positive indicator on the dipstick even in the absence of given symptoms.

*"(If somebody hasn't got many symptoms or just the odd symptom here and there, but the dipstick is positive, what would you make of that?)...Send an MSU...I would believe what the dipstick told me...(do you mean someone who has just got a slight twinge of dysuria?)...You can have symptomless urine infections...It's not always going to be decided by a dipstick, it is a combination of everything as regards what you do"* (Bx/y/z p5)

Some used dipsticks optimally, when it would affect the management decision:

*"If it's not clear then I would use the dipstick"* (26d1p15)

##### **5.5.5.1.2 How do clinicians use each element of the dipstick test?**

Most have embraced the use of leucocyte and nitrite tests, and most are aware that nitrite is a test with high specificity. Many primary care clinicians initiate treatment when dipsticks are positive for leucocytes and/or nitrites, but some are sceptical of infection if both aren't positive, or are weakly positive, and in these situations they relied more on symptoms,

whilst checking an MSU. One doctor suggested ‘two out of three’ positive elements were predictive of infection. Leucocyte tests cause the most debate: one doctor felt they were the least predictive of all tests, another worried re-Tuberculosis as that had been part of her past experience. A few doctors were working in practices that hadn’t embraced modern stick testing, and one commented on the confusion that this caused:

*“The dip sticks that we have they have no leucocytes and I am not sure whether they have nitrites It’s a lack of information and I am a bit disoriented at the present with the dip sticks”* (DSdcp4)

Some doctors, however, don’t utilise the full range of dipstick test:

*“...blood...but if it is with glucose and you have got proteins, I would think that should be related to infection”* (DSddp6)

One might have expected that the doctors who didn’t embrace new developments to be older, perhaps, ‘set in their ways’, yet they were just as likely to be young.

#### **5.5.5.1.3 Overuse of dipsticks**

Many professionals find negative tests unhelpful – but they were often using them in women with symptoms suggesting a diagnosis of cystitis:

*“what we say is that we are more worried about the negative because if it’s negative and they’ve got symptoms then, what is it?”* (N3p7)

#### **5.5.5.1.4 Pharmacists’ ideas on dipsticks**

Pharmacists didn’t use dipstick testing, but were interested in their ability to rule out other conditions or alarm symptoms e.g. haematuria, sugar, though they did feel that the presence of nitrites would be reassurance for their diagnosis.

#### **5.5.5.2 Microscopy**

One participant had been introduced to microscopy at their training practice, and another in hospital training, but no-one actively used in-house microscopy. A few took note of the result of the microscopy that accompanies a culture report.

#### **5.5.5.3 MSUs.**

Nurses and doctors varied from a blanket approach to selective use of MSUs. Their reasons for performing the test are the need to confirm infection, to check that the bacteria are sensitive, and to concerns about over-treatment with antibiotics:

*“I think a lot of women get unnecessary antibiotics and so I always even if I am treating I always as them to get an MSU off” (2511djp3)*

Some suggest that women who bring a sample expect more than a dipstick test:

*“They bring along a sample and patients have an expectation that you are going to do something more with it, rather than throw it in the bin” (116d3p10)*

Doctors are more likely to request MSUs in recurrent UTI as they want proof of infection for any future referral, as well as confirming the diagnosis:

*“If somebody comes with a repeat, just to make sure it is not an irritable bladder I would send an MSU” (251108p7)*

A few investigate less in recurrent UTI for the logical reason that women are well versed in their symptoms and diagnostic confirmation isn't usually necessary. These health professionals would still check MSUs in non-responders. For related reasons, some clinicians check MSUs routinely in first-time UTI, and some if the symptoms and initial investigations don't match. One group, however, reported that their local microbiologists supported a blanket approach:

*“I would only send an MSU off if they weren't getting better within two days - then I discussed this with one of our local Microbiologists and she couldn't believe that GPs weren't sending MSUs for every urinary tract infection” (Bp1)*

and the background of the professional may influence their approach:

*“Because I come from a more medical background and you like to have all the information, you do all the investigations” (2511djmp5)*

Professionals are aware of over-investigation and are attempting to address this:

*“The district nurses have done some work at a residential home, they would send, what 10 MSUs, every Monday because they thought these people had smelly urine, but now they have gone in and educated the carers and they now test and the amount of MSUs sent in now has really reduced” (N3p16)*

#### **5.5.5.3.1 The implications of over- investigation**

“Don't test if you don't know what to with the result” is a common teaching adage:

*“Once you have done the investigation you are bound to the results...that, if you show to the patient that you are better, but your results show that you have still got this infection,*

*however you are resistant to trimethoprim, then you have no choice but to treat that”*  
(Ld3/5p10)

This can lead to heightened expectations in the future, increased antibiotic prescribing, and difficult explanations. One participant thought that reliance on tests is a substitute for clinical assessment. Perhaps this arises through difficulties in managing uncertainty, or for reasons of time-efficiency:

*“I don’t know whether it is because as the years go by you become less clinically astute or you have just become more reliant on having what’s viewed as hard evidence in terms of say positive MSU”* (Ld4p5)

Culture results are considered an objective finding and, therefore, more valuable for reassurance and for negotiating management.

#### **5.5.5.3.2 Fear of resistance**

Some GPs are afraid that resistant organisms will cause treatment failure, and attach greater significance to this than may be warranted by the evidence:

*“I always do like to get a urine sample just to test it, just in case there is something unusual that crops up”* (CSdbp19)

*“it is amazing how often you will get a resistant organism back”* (2511jmp5)

#### **5.5.5.3.3 Collecting urine samples**

It is not uncommon for urine samples to be contaminated. Collection and storage are both important but our participants only commented on the former.

*“I think it is better that they do the specimen when they come to see us, at least they get a proper sterile bottle. You don’t know what kind of container or bottle they used to collect the specimen. You may get some contaminants”* (Ld1p5)

*“...in a medicine bottle, in a bubble bath bottle etc”* (116d5p10)

Spanish doctors noted that practice in the UK was more lackadaisical:

*“We used to be given very strict instructions about how to take the sample - and we have found that here they just give them a bottle and they go to the toilet”* (DSddp20)

but other doctors feel that less strict procedures don’t matter as contamination rates are low in adult women. One doctor had instructions on their wall; another thought that doctors

didn't give instructions as they'd got too used to relying on nurses during their time in hospital; others thought GPs might be embarrassed.

#### 5.5.5.3.4 Follow-up samples

Clinicians may ask for follow-up urine samples if women are at particular risk from UTI, if they have had pyelonephritis, or if they get recurrent UTI:

*"I would personally, only do that with an at risk patient, like the kidney disease just to make sure it's gone"* (N1p9)

Haematuria is also likely to trigger a request for a follow-up sample of urine:

*"Probably I would confirm the blood has disappeared two or three days after she has finished the course of antibiotics, to make sure I am not missing anything underlying there."* (DSddp6)

#### 5.5.5.4 Self-help, non-antibiotic treatments, and subsequent consultation

Doctors think that women try to manage their illness themselves, and that they attend if their illness is more severe. This fits the findings of our study of patient experience:

*"I think sometimes they think it is a minor problem that they can sort out themselves and unless the symptoms are very distressing they don't come"* (26d5p13)

With the exception of pharmacists, professionals rarely actively promote self-help treatments. Cranberry juice and urine alkalinisers are easily available. Advice on clothing, hygiene and bath additives are mentioned in leaflets but aren't otherwise actively promoted by health professionals.

##### 5.5.5.4.1 Fluids

Few mention this as a mechanism of improving UTI symptoms. Some advise women to reduce caffeine. When doctors or nurses mentioned fluids it was as a stop-gap:

*"Right at the beginning I would say yes keep on fluids and see what the MSU says"* (DSdap2) – a Spanish trained GP

Perhaps this reflects the tendency for women in Spain to attend early in their illness, perhaps after a day whereas women in the UK postpone attendance:

*"My experience here is a culture of waiting for maybe three or four days with the symptoms - they usually try with drinking more fluids and stuff like that"* (DSdbp18)

Pharmacists, another group that see women early in their illness, encourage fluids:

*“One of the things that we are continually advising patients is to drink more fluids anyway, so because of the folklore around cranberry juice you can suggest that and it sort of fits in”*(P7p11)

#### **5.5.5.4.2 Over-the-counter medication and home remedies**

In the UK, urinary alkalinisers such as potassium citrate and cranberry are available over-the-counter, and professionals feel that women will try these remedies first:

*“I think women coming with symptoms of UTI would have already made a diagnosis and most of them would have tried over the counter medication as well”* (2511p10)

*“It’s more likely they come and they have tried already over the counter, they’ve tried it and tried drinking plenty. We educate ours as well”* (N2p4)

A few doctors advocate initial treatment of mild infections with these remedies. Local pharmacists were cautious: they promoted these measures, as they are they have no alternatives but they recalled (hazily) a local critical incident when a woman with renal disease developed hyperkalaemia after exceeding the recommended dose of potassium citrate. Barley water was mentioned by one experienced GP who felt that the old home remedy was far superior to the ready-made alternatives:

*“We used to treat kidneys with barley water. People these days often confuse what you see on the supermarket shelves from the old fashioned remedies and barley water is nothing to do with Robinson’s Barley Water drink but they get confused about it”* (CSdbp14)

#### **5.5.5.4.3 Complementary medicine**

Professionals could recall little use of complementary medicine by their patients, but this could, of course, be hidden!

*“...couple of patients going to a nutritionalist for treatment for UTIs and chronic thrush as well. Whether it made any difference or not, I cannot remember”* (166dap7)

Ayurvedic is a traditional form of medicine used on the Indian sub-continent, which we had expected to be an alternative for the management of UTI:

*“I don’t think for acute symptoms - it is more medical - chronic rheumatism and indigestion and things like that, but not for acute”* (166ddp6)

*“I don’t think the patients are ready for it and go for conservative medicine”* (2511dbp14)

This, therefore, suggests that western medicine is now accepted as the norm, and an older traditional form of health care is seen as new and threatening!

### **5.5.6 WHAT INFLUENCES PROFESSIONALS PRESCRIBING HABITS?**

This is determined by a number of factors, which probably boil down to personality, knowledge, teaching, experience and external influence.

#### **5.5.6.1 Internal influences**

##### **5.5.6.1.1 (In)Tolerance of uncertainty**

Doctors' (in)tolerance of uncertainty significantly affects prescribing behaviour:

*"You want to cure the condition for the patient so you use the antibiotic which you know covers broad spectrum"* (26d1p7)

*"Perhaps because I have had a couple of UTIs that have come back where treatment with trimethoprim has been ineffective...I don't remember anyone that got major problems, but they may have had continuing symptoms"* (166dcp3)

*"I mean two days - by the time you get a culture report - the patient by then knows if the treatment is going to fail - you have the report in front of you and you can change"* (166dfp4)

This variation in professionals' tolerance seems to be the greatest reason for different management decisions:

*"you work within your own confidences at all times. I mean, some of the GPs do dip urine, some of them don't; some of them send MSUs off, some don't; some just give a prescription. They all work differently, you know"* (N2p11)

##### **5.5.6.1.2 Misunderstanding**

As well as variable interpretation of evidence and guidelines, professionals may not understand some conditions. Some treat asymptomatic bacteriuria, and some prescribe alternative antibiotic courses even if a resistant organism has responded to initial treatment.

##### **5.5.6.1.3 Stress**

One doctor owned up to internal factors affecting their management, though this phenomenon is likely to be more widespread:

*"It also depends how busy you are, what day it is, is it a bad day?"* (Ld5p17)



## **5.5.6.2 External influences**

### **5.5.6.2.1 Resistance rates**

Knowledge of, or feedback about, resistance patterns is a significant influence on the prescribing habits of some doctors, and the opinions of specialists may carry great weight. Others base their opinions on what works in practice or what is contained in guidelines. In particular Spanish doctors changed their prescribing habits to suit the UK's lower level of antibiotic resistance:

*“the reason behind it is there was a report that 20% of the \*\*\* population is resistant to trimethoprim and it is probably not the best first line. That was a statement that was given in one of the lectures by a microbiologist and then people changed...I don't want them to come back saying that they have the same problem again for me to find out that one in five of them is having problems” (26d1p9/10)*

### **5.5.6.2.2 Pharmaceutical companies**

Common urinary antibiotics are mostly off-patent, and aren't actively promoted by pharmaceutical companies. An exception at the time of the study was ciprofloxacin:

*“I mean the company did try to bring the 100 mg into six tablets to persuade all of us to use it as a first line, but I don't think it actually worked” (Ld5p7)*

and a geographical association with high prescribing suggests external influences:

*“It's (ciprofloxacin) used a lot in certain pockets. Why? Reps? Other reasons?”(1212)*

Dispensing doctors may also be wary of company price inducements:

*“Firms often offer new drugs as loss leaders but the price goes up later” (1211)*

### **5.5.6.2.3 Directives**

GPs often view guidelines as directives, though their authors would argue otherwise. Ciprofloxacin, probably more than any other antibiotic, and with some justification according to the evidence, has been subject to disincentives to prescribe:

*“we cannot really prescribe ciprofloxacin – I think we would get punishment from the microbiologist.”(Ld2p6)*

## **5.5.6.3 Different perspectives**

### **5.5.6.3.1 Young doctors**

Much of registrars' training is undertaken in hospitals (though this is changing), where they are influenced by hospital policies. Mostly they adapt to primary care policies without any qualms, particularly as they understand that antibiotic resistance is less of a problem in the community. Concerns about the levels of antibiotic resistance to the first-line antibiotic, trimethoprim, shapes some hospital and overseas policies. Registrars had often experienced successful outcomes in primary care and were generally persuaded of its acceptability as a result. Registrars who spend a long time in hospital practice are less likely, or perhaps take longer, to adapt. The following round-table discussion about antibiotic choice illustrates the influences on doctors' prescribing habits and maintenance of their beliefs through experience, successful management, and feedback from laboratories:

*“ it seems to work quite well - and sensitivities do come back as positive...I am slightly more likely at the moment to prescribe cephalexin, rather than trimethoprim, which is probably what I have been encouraged to do...it used to be amoxicillin, but they said it wasn't sensitive to it - strains have been resistant, so I think we just went onto trimethoprim and then that's how it took off...clinically it seems to work well - the vast majority in my experience would resolve with trimethoprim. That was what we were taught and I have stuck with it and it just seems to work most times...when I started as a GP registrar I just checked what we are supposed to do for these kinds of things, because you would follow a protocol of what you are used to ” (166d/b/c/a/d/f/ep1)*

Registrars noted that different hospitals and different departments had different policies. Secondary care policies are more likely to influence their opinion for second-line treatments and the management of more complicated illness. When justifying different opinions, doctors were likely to cite experience, even early in their career:

*“I think it is more experience rather than hard evidence base ” (26d4p8)*

#### **5.5.6.3.2 Dispensing doctors**

Dispensing doctors are just as likely to be as evidence-based as other GPs:

*“Dispensing doesn't affect our prescribing – it's the other way round- dispensing follows how we prescribe ” (1211)*

*“I use plain Nitrofurantoin -this is a dispensing doctor talking here!” (Ld4p8)*

It is recognised that some dispensing doctors may act differently, but there are logical reasons for working to an evidence-based protocol:

*“My impression is some of the other dispensing practices might be orientated to something that might make a greater profit. Changing prescribing depending on the good deals, it’s disruption really - working to a standard stock of drugs. We don’t want the new latest thing because it’s offered at a good price” (1211)*

#### **5.5.6.3.3 Pharmacists**

Pharmacists expressed faith in their formulary and most consider this more appropriate than abiding by their local GP opinion.

*“I don’t care what the GP would give, if that’s what fitted then you would give trimethoprim. I think it’s by formulary, you can’t break the formulary” (P1p7)*

Another suggested that local microbiological opinion could overrule a protocol. Medicines managers agreed that pharmacists are more protocol driven.

#### **5.5.6.3.4 Nurses**

Interviewees from all backgrounds agree that nurses are strongly influenced by protocols and are most likely to follow guidelines. Independent management is initially limited to women with typical UTI, but experience changes this approach:

*“quite a few of us are prescribers, so we tend to work of our own.... I use to work to a protocol but now I work to my own clinical judgement” (N6p11)*

### **5.5.7 WHAT DO PROFESSIONALS PRESCRIBE?**

Could we obtain a true picture of prescribing for UTIs through qualitative interviews?

*“What doctors do and what they tell you they do – it’s the complete reverse...GPs won’t admit to over prescribing. Even nice GPs will get shirty when challenged” (1212)*

We used focus groups, triangulation of data, including comments on colleagues’ prescribing, and a range of participants to address this issue in particular. As a result, I think we have obtained a version of the truth, although it may sometimes be sanitised! Closer monitoring has led to improved prescribing and whilst there is still *“some willy-nilly prescribing of antibiotics”* (FGMM), use of reserve antibiotics such as ciprofloxacin is now unusual for simple UTIs. Thus, there is less to hide than in the past!

#### **5.5.7.1 Antibiotic prescribing**

##### **5.5.7.1.1 Choice of antibiotic**

Most doctors prescribe trimethoprim as first-line; one nurse participant suggested that younger doctors used cefalexin preferentially, and medicines’ managers thought that

cephalosporins were quite often prescribed as the first choice antibiotic. This study predated the *Clostridium difficile* scare, which may have altered their approach. One doctor cited the convenience of twice daily dosing. Overseas trained doctors, brought up with different policies, were very accepting of a new approach:

*“Here is understand you always use a first line even with a new patient with trimethoprim”* (CSdmp17)

Some doctors are concerned about published rates of resistance and make increasing use of broader-spectrum antibiotics. Many are aware of the effectiveness of antibiotics in different contexts and prescribe appropriately to the situation:

*“It is a bit like domestos in my view. It is a nice thing to hold back for someone with a severe infection, you know for someone who was admitted to hospital”* (116d1p8)

Pharmacists agree with these conclusions but would prescribe trimethoprim if given the opportunity, as it is still more effective than non-antibiotic measures.

Some doctors prescribed nitrofurantoin as it isn't used for other diseases, reducing concerns about increasing resistance. Those who have spent a greater time in hospital practice are more likely to prescribe broad-spectrum antibiotics for cystitis, though there was a consensus that these are preferable when managing upper UTI.

*“Nitrofurantoin. I tend to use that because I think UTI is about the only thing it is really very effective against and I have got this notion that maybe it is a good thing not to be splashing amoxicillin about all the time”* (Ld4p8)

*“If they have got systemic symptoms or if I know that they have had recurrent UTIs and if I know in the past she has had organisms which have been resistant to trimethoprim, then I would give her another antibiotic”* (26d4p8)

#### **5.5.7.1.2 Treatment length**

Most treat uncomplicated cystitis with three-day courses of treatment. One doctor mentioned single dose treatments but didn't prescribe these. Medicines' managers commented that nurse prescribers are most likely to prescribe for three days; quite a few doctors follow the traditional five or seven days' course, and despite robust evidence of equal efficacy for the shorter course I still met significant scepticism during interviews:

*“I read that it should be three, but I am still not very happy about it”* (DSdap15)

*“but I don’t know why five but I think it was one of the surgeons who once said most of the antibiotics were given for five days” (2511dap5)*

Some clinicians connect shorter courses and reduced antibiotic resistance:

*“The argument about using shorter courses is because the longer you expose the bacteria to antibiotic, more likely is resistance to emerge. It does make sense to be pulled down to five days or less” (Ld4p21)*

It is quite common for doctors and nurses prescribe longer courses if women have more frequent or more severe symptoms. Some rationalise their clinical decision-making; others seemingly arrive at the same point through experience.

*(what makes you give five days instead of three days?) “only if I think it’s significant, like ‘I was up and down the whole night’ so just out of my sixth sense that it is not symptomatic or mild cystitis I am dealing with and maybe it’s something more” (2511dap8)*

*“...but if I felt there was a reasonable clinical suspicion that it might be renal rather than just acute cystitis, I would probably go for a lot more than three days on trimethoprim and treat more vigorously”(Ld4p5)*

In (community) hospital settings, the length of course may be accidentally elongated and some doctors in general practice give an extra three days’ treatment if women are still symptomatic, but another said that in these circumstances:

*“I reassure them sometimes and I say well it is because the inflammation of the urinary tract is still a bit inflamed and the symptoms may be happening because of that” (DSdcp16)*

In one practice, clinicians prescribed antibiotics according to a formulary, but the lack of advice on treatment length meant that they diverged on this point:

*“I think we probably have different ideas in what we do regarding the length of prescriptions, but I guess first line most doctors probably use trimethoprim or cefalexin for adult UTIs.” (Bp1)*

Pack sizes and default treatment lengths on computer systems inhibit good practice until recently, trimethoprim defaulted to seven days’ treatment – this remains the default for some other urinary antibiotics:

*“Nitrofurantoin is 28 tablets ‘as directed’ (hint of dismay in voice)” (1212)*

If pack sizes are for a week's treatment, dispensing doctors can override this problem, but pharmacists don't have the same clinical freedoms.

#### **5.5.7.1.3 Old habits die hard**

This affects all professionals, but experienced doctors are more likely to (or to own up to) prescribe longer courses. They can be reluctant to change from a method that has worked well for years, especially if they perceive that the evidence is conflicting:

*"I am stuck in my old ways, I prescribe 7 days of trimethoprim despite the evidence that 3 days is perfectly good enough. I am just not convinced. I think another thing of course is remembering that resistance to trimethoprim does exist, 10% or thereabouts"* (CSdbp19)

*"I would tend to prescribe five day courses out of habit, as opposed to three day courses"* (Bp2)

Worries about resistance and severity of symptoms are used as justification. Nurses and younger doctors are also not immune to this phenomenon:

*"Maybe I have some patient in which it didn't work - probably it is not because of that - I feel more reassured if I give five - I don't know. Probably there is no proper reason for that"* (DSddp16)

*"I think the 3 day thing if they have quite severe symptoms, I know you say it is and the books say yes it is, but I don't think it is. You tend to still be symptomatic."* (N2p11)

#### **5.5.7.2 Empirical treatment**

Empirical treatment isn't a universal strategy. Some doctors new to UK general practice were initially surprised by this method:

*"I was surprised by a patient who came to the surgery and the doctor when it was suspected just from the symptoms it was enough"* (Csdep16)

*"...and by the time they have said 'cystitis' out comes a prescription"* (166ddp9)

but it does appear to meet women's expectations of treatment:

*"I think patients are happy with it, because when they come in they come in expecting some sort of treatment"* (166dbp1)

Empirical treatment is commoner now than in the past as observed by pharmacists:

*"Going back 10-15 years, where you had to prove the infections before you could get anything. Whereas now, it is 'take the trimethoprim'"* (P3p4)

#### 5.5.7.2.1 Who prescribes empirically?

Most GPs spontaneously entertain the possibility of blind treatment whatever their overall views on treatment and investigation, and pharmacists confirmed this. Nurse prescribers and less experienced doctors treat women with clear diagnoses empirically but in other situations appear uncertain as to the best course of action:

*“I just think that sometimes they come in and you see how desperate they are, how can you say send a sample and leave them 24 hours like that because they are really uncomfortable...but patients will tell you themselves, that they are not prepared to wait for that and I want to see somebody”* (N6/7p13)

*“...vague symptoms and abdominal pain, feeling unwell, sometimes burning, but it is not clear - in this case I won't treat until I get the result from the lab”* (DSddp5)

Some doctors consider that empirical treatment is worthwhile as it is low risk:

*“If there's not potentially any damage of leaving something and you can treat them empirically and then see whether their symptoms resolve, as long as there is a safety net as far as returning”* (116d1p5)

Non-prescribing nurses make decisions on empirical treatment by proxy:

*“We're not prescribers so the GPs do tend to go on what we say, we've dipped it and it's got this and this. We've sent an MSU, will you do us a script?”* (N3p13)

Medicines' managers considered that if pharmacists' prescribed antibiotics then there would be less promotion of self-care. Women may 'shop around', though many well-informed patients can already choose doctors who prescribe empirically, and pharmacists considered that they were just as capable of offering this treatment:

*“That would actually promote the argument of allowing us to sell trimethoprim, because of you're not testing then there is no reason why we can't do the same as you are doing”* (P2p5)

There might, however, have to be some arrangement to ensure that failure of empirical treatment is appropriately communicated to clinicians.

#### 5.5.7.2.2 Who receives empirical treatment?

Women are more likely to be offered empirical treatment if they voice their suspicions of UTI and have typical symptoms or the same symptoms as in the past:

*“I have done the prescription in situations where they are very sure about their symptoms, because they have had it in the past” (DSdep4)*

The lack of the normal combination of symptoms, in particular, would encourage clinicians to perform investigations such as an MSU before treatment:

*“If I had somebody who had just a bit of dysuria and there was a trace of protein on the dipstick, I wouldn't give them antibiotics there and then” (Bp5)*

Women with severe symptoms or significant past history more readily receive empirical treatment even if initial tests are negative:

*“If somebody had a full house of symptoms I wouldn't let them go away without having some treatment, even if the urinalysis was negative” (Bp4)*

In making their decisions clinicians respond to women's level of distress:

*“The best way is to ask them to provide a urine sample the next day and then give them antibiotics...if you have symptoms they are very uncomfortable and I think to say to a young woman to come back tomorrow is not nice” (CSdph/Ip17)*

#### **5.5.7.2.3 Economic reasons**

In the UK, studies had suggested that a strategy based on empirical treatment is the most cost-effective, though that has recently been challenged (7). Pharmacists are paid a small fee for a consultation, so managers suggest that there is a perverse incentive to prescribe more antibiotics, resulting in increased budget costs and decreased self-care.

#### **5.5.7.2.4 Delayed prescriptions**

Delayed prescriptions, with one exception, didn't feature as a strategy for UTI in our study. It was used to circumvent the need for diagnosis when investigations weren't available. Following a recent project (7), this strategy may become commoner.

### **5.5.8 EFFECTIVE USE OF RESOURCES**

#### **5.5.8.1 Cost of antibiotics**

Cost is occasionally an issue, but perhaps, as doctors tend to stick to guidelines on antibiotic choice, it appears less of an issue than in other infections or conditions.

*“Patients quite often say you have given me a prescription for £6.20- I am paying for it and all I am getting is six measly tablets and when you look on the computer it says 14p or something doesn't it?” (116d1p8)*



#### 5.5.8.1.1 Sources of influence

Guidelines, peer pressure, trainers, and the recent introduction of pharmaceutical advisers to practices influence doctors' and nurses' cost-effective prescribing:

*"I don't know why I went back to trimethoprim again, but I went back because the cost was less... cost – yes. There were raised eyebrows in my surgery because I prescribed co-amoxiclav."* (26d1/3p9)

*"So I was told that sometimes giving antibiotics was wasting resources to get the dipstick done, because I had already decided that I was giving the script, so why use the dipstick".* (26d3p3)

*"We have a community pharmacist now- they help with the pattern of our prescribing"* (1211)

#### 5.5.8.1.2 Cost or effectiveness?

*"I have never thought of money, I must say that. I just say I am least happy that I would have treated it better in the sense that I would hope less people would come back telling me about UTI which didn't get resolved in the first instance"* (2511dap8)

One group of registrars were set a scenario, asked to discuss their response and then their ideas checked by altering the scenario:

If an antibiotic was only 5-10% more effective (e.g. due to improved clinical response) for cystitis, they chose the cheaper drug. At 15% difference in response their choice would depend on the exact costs. When applied to a more serious condition, opinion differed, but around a 5%-10% difference would not be tolerated. However, other issues such as side-effects might have an effect on the decision.

*"It all depends how expensive co-amoxiclav would be compared to trimethoprim and if it was a vast difference in the cost I might still stick with the trimethoprim first, hoping it would get better"* (26d4p10)

#### 5.5.8.1.3 Guilt on price of treatment

*"Should we keep trimethoprim in our top drawers and give to the patient rather than give prescriptions?"* (Ld5p22)

By the time of this study, this wasn't such an active concern as when we discussed prescribing regimes ten years ago - perhaps the effectiveness of short courses and a lack of side-effects have calmed fears. At first, doctors were reluctant to prescribe short courses:

they felt that their patients were short-changed even though a 7-day course of trimethoprim also costs the NHS a lot less than a prescription charge:

*“When I used to do some on call I would actually give ladies six trimethoprim tablets out of my bag, rather than give them a prescription knowing that they would have to pay a prescription charge” (Bp22/23)*

One doctor advocated charging the actual cost rather than a flat fee. Another gave a full course of antibiotics to women visiting an out-of-hours centre instead of a day’s supply, precluding the need for a GP script. Others try to compromise by giving a larger prescription but encouraging women to take tablets only until they felt better. Only one doctor mentioned any comments about cost from women themselves.

#### **5.5.8.2 The association between ease of access and increased antibiotic prescribing**

I found opposing views from different groups of professionals, reflecting their individual standpoints. Pharmacists and nurses don’t feel this is a concern, and in the context of expanding roles in the management of UTI they view this in a positive light. Medicine managers and most doctors hold opposite views.

##### **5.5.8.2.1 Access to doctors:**

Doctors think that ease of access to health care increases the pressure to hand out antibiotics at a time when they are being encouraged to reduce their prescribing:

*“I mean easy access without having to do anything...has changed the face of some of our treatments and antibiotic prescribing and I also think providing access within 24 hours has a significant effect on it as well...(interviewer: “do you think it has made you prescribe less or more antibiotics?”)... “More” (Bp6)*

The extension in routine opening hours increases access and prescriptions:

*“If you have urine symptoms you can go even after work to see a doctor to ask for a prescription. I think it is changing because basically you can go easily to see an out-of-hours doctor” (CSdpp7)*

The medicines managers felt that urgent care centre prescribing had risen greater than the equivalent reduction from practices, applying an upward pressure on antibiotic prescribing. In Spain, extended hours have had the opposite effect as it has caused women to shift from self-medication (of antibiotics) through pharmacies to general practice.

##### **5.5.8.2.2 Access to pharmacists**

Pharmacists feel that one of their great advantages is accessibility and are keen to extend prescribing in the community schemes to prescribing for UTI.

*“People want it sorting out there and then or at least they want the symptoms relieved pretty quickly which is where we can help” (P7p5)*

They felt positive about the change to over-the-counter prescribing of chloramphenicol eye drops. At present, they recognise the limitations of their interventions and are frustrated by them. Pharmacies aren't private places and it isn't surprising that patients only have straightforward conversations about their symptoms. Pharmacists are addressing this by making side-rooms available and by undertaking courses in communication skills. Doctors in Spain still manage many cases of UTI because of privacy, as well as the 'carrot' of a 40% discount in prescription charge when they endorse a script:

*“Even people who pay for prescriptions they come because they have 40% discount even if you are working” (CSdmp6)*

Women with recurrent UTI who know their symptoms are more likely to manage their illness via the pharmacist. In the patient interviews, we noted that women might be wary about accessing health care abroad, but there are two sides to the story!

*“So this is something because of the easy access in Spain and people on holiday will sometimes buy antibiotics for urine infection” (CSdpp5)*

#### **5.5.8.2.3 Over-the counter antibiotics for UTI**

The prospect of over-the-counter prescribing of trimethoprim and nitrofurantoin polarises debate. Pharmacists maintain this would cut GP workload; some, but not all GPs and medicines managers share a fear that antibiotic prescribing will increase:

*“We are hoping this will be the end of it but we are already worried it won't be. They need to say this process of making more drugs available OTC should not be applied to antibacterials” (Pulse7410p3)*

*“If I had my community pharmacist hat on from 10 years ago, I'd want to do this, but with my PCT hat on, I'm worried about increasing antibiotic use in the community” (FGMM)*

*“You can only base your decision upon what you can ascertain in that consultation and so we're offering the same kind of thing, just a smaller range of products” (FGP1p9)*

*“I don’t have a problem with chemists prescribing. Doctors are incredibly conservative aren’t they? Trimethoprim from the chemists should reduce their workload”* (1212)

Pharmacists, however, may find that their own workload is in itself a problem:

*“Pharmacists don’t have time to get off their stool”* (FGMM)

*“with up to 1000 scripts to check per day, medicine reviews, and increasingly complex clinical responsibilities, simple consultations could be left to counter assistants”* (FGMM)

As patients often present with a diagnosis, and are reluctant to describe symptoms fully, this may lead to missed signs and symptoms, or abuse of the procedure by patients. Consultation rooms in pharmacies are a relatively new phenomenon, but the lack of access to notes is a concern for pharmacists.

Older pharmacists may be reticent to take on a new consulting role, even though their experience gives them a natural advantage. With fees for ‘care in the chemist’ pharmacy chains may exert more pressure to meet targets, creating tension between numbers and quality of consultations. Consultation skills are now integrated into undergraduate training, and there are opportunities for postgraduate training, including NVQs, via the multi-nationals, or through distance learning. Quality control, however, is at present, variable and dependent on PCO contracting visits. Recently some pharmacists have received special training locally for specific roles e.g. managing COPD, but with the prospect of reduced funding and the imminent demise of PCOs such developments may be more complicated to replicate in the foreseeable future.

#### **5.5.8.2.4 Educating patients**

Messages on self-treatment and the responsible use of antibiotics are disseminated to both the public and the professions. Clinicians generally viewed it as a difficult task:

*“In Spain are doing a great effort to try to educate the patients by this because it has been like that for many years. I think it is something practitioners have achieved in England.”* (CSdip7)

*“Educating about antibiotics is a bit of an uphill struggle”* (Ld4p13)

It helps if clinicians educate women about changes in management strategies:

*“I remember one patient calling back to confirm what I had done was right – she probably used to get seven days of treatment and I gave three days course of treatment and she thought I had missed out four days or so” (26d1p7)*

Medicine managers who had seen this system used with positive results locally favoured the use of leaflets instead of an antibiotic prescription.

#### **5.5.8.2.5 Knowing your patients**

There is a constant tension between increased access to health professionals and the ability to provide appropriate medical cover. Political parties are keen to offer increased services to improve their standings but are curiously reluctant to ensure that the health professionals have the resources to meet their targets. In the study of patient experience, we found that continuity of care whilst not essential for UTI is valued.

Health professionals also value continuity - *“frequent flyers”* (P7p1) in pharmacies- from a medical as well as personal perspective. Some pharmacists have a casual rather than a regular clientele - a lack of knowledge of past history is a source of anxiety and has implications for the wider developments on access to health care

#### **5.5.8.2.6 Telephone consultations**

As the diagnosis of UTI is very often based on symptoms alone, it lends itself to time-efficient telephone consultations. On the other hand, this contradicts advice not to prescribe antibiotics over the phone, which some professionals stuck rigidly to, despite expectations to the contrary:

*“We get a lot of telephone calls saying I just have a water infection, can I collect a prescription? They do sometimes get irate when you say that we need to see you to prescribe antibiotics and they say well I already know what the problem is I have – so why should I need to see a doctor to give me antibiotics” (26d4p14)*

A compromise solution adopted by some practices was to combine limited investigation with ‘remote’ prescribing:

*“I have often women calling up to the receptionist - to say that they have got a water infection and can they have antibiotics - so it tends to be - quite a few tend to come straight through the telephone - which makes it much easier - they don't come down to the surgery any more - they can drop off a water sample - they can get their prescription and in three*

*days time we know whether they are right or wrong and they will come back if their problems continue” (166dfp8)*

Doctors perceive that women prefer telephone consultations, though the study on patient experience doesn't bear this out.

#### **5.5.8.2.7 The Friday afternoon and similar consultations**

A study in the Seventies showed that doctors' prescribing for sore throats was affected by the social and psychological information presented by patients (388). Health professionals frequently refer in conversation to 'the Friday afternoon syndrome', a number of inter-linked events: the last-minute presentation of symptoms that have been present for a period of time; the lack of resources for investigation available at such times; and, the pressure to provide quick relief to alleviate symptoms and to obviate the need for weekend medical care:

*“They don't want to be left with that festering over the weekend or be told if it doesn't respond...then they will need to go to the surgery” (P4p5)- a pharmacist*

Time of day affects doctors' management of UTI, mostly because it is difficult to obtain a urine sample later in the day, especially if women, who may only be managing to pass small amounts, haven't arrive with a 'pre-prepared' sample. Doctors are more likely to give empirical treatment in the afternoon:

*“If they come at the end of the day and I know the sample isn't going to go off, then I might just give the antibiotic” (26d4p1)*

The 'Friday afternoon' may be a reason for investigating at more convenient times:

*“It may help in future UTIs as well. Say if somebody had a positive MSU and then Friday night she comes and you see what her last MSU was”(Ld5p3)*

*“If its 4:45 or 5:00, or Friday afternoon or whatever you would be much likely to give a delayed prescription out or something like that or go off a dipstick” (N4p9)*

Consulting soon before holidays creates similar dilemmas.

#### **5.5.8.3 Referral**

A few GPs had a flexible approach to referral, which depended on the nature of symptoms and frequency of recurrence, but most referred according to set criteria:

*“If three or four times this patient is getting recurrent UTIs, I would really like to investigate further” (Ld2p4)*

One GP mentioned acute admission for pyelonephritis, but didn't specify any particular indicators. Nurses have no direct access to hospital referral, but would refer via a GP. They follow the same 'rule-of-thumb' on recurrent UTI.

### **5.5.9 MANAGING EXPECTATION**

Managing expectation appears to be a balance between the personal advocacy of primary health care workers and their public health role. Some professionals use metaphors of battles to describe the discomfort that arise from this dilemma:

*“There is this sort of battle going on all the time...some days we win and some days we lose...some days you are lost before you start” (Ld4/1/4p15)*

#### **5.5.9.1 Women's expectations of treatment**

As women have often self-medicated as an initial step, they have higher expectations of a prescription for antibiotics when they attend. They perceive (no doubt correctly) that doctors' treatment will be more effective:

*“They want you to give them something stronger” (26d1p12)*

##### **5.5.9.1.1 Patient-centred or patient-led?**

Women's expectations are a strong influence on doctors' management:

*“Some of them say ‘oh yes doctor I'll wait until the result comes back’, some of them say ‘no – I want antibiotics now’...they do say that don't they?.You are absolutely right, the patients will tell you what treatment they should have” (Ld3/2/4)*

This may suggest that some consultations and management strategies are patient-led, but the ideal of the 'patient-centred, doctor-led' consultation is implied in this quote:

*“Maybe it is coming back to this issue of wanting to find objective evidence, I mean it is not that I don't believe my patients. I just wonder whether it is something about retaining control of the situation” (Ld4p18)*

##### **5.5.9.1.2 Changing attitudes to antibiotics**

Discussions moved from the specific situation of UTI to the general philosophy of antibiotic prescribing. Patients aren't as keen to accept antibiotics as in the past, and this

seems to extend to the management of UTI. However, this probably manifests itself as increased self-treatment rather than reduced expectation of antibiotics:

*“I think sometimes patients will almost say they are happy to be swayed against not having antibiotics in the good of mankind, but what they really want is antibiotics and we are now justifying not giving them all the time which is really quite hard work, you know” (Ld4p13)*

Acceding to antibiotic requests may be the path of least resistance (an ironic turn of phrase) though doctors do try to manage their prescribing responsibly:

*“Why is he resisting? He could have written the prescription in two seconds and got me out of here instead of keeping me here and giving me a lecture on antibiotics” (Ld5p14)*

Despite changes in patients’ expectations of antibiotics, doctors still view this as an area of disagreement and tension, finding that they are stuck between their individual responsibility to a patient and the collective responsibility to prescribing carefully:

*“The actual battle which is the way I perceive it, of denying patients antibiotics, which is the way they perceive it and I think if you have got something really objective like an MSU and you can say to a patient: ‘there is nothing to make us suspect anything more than cystitis’” (Ld4p13)*

And then went on to remark that this might also be (subconsciously) about retaining control in the doctor-patient relationship (see section 5.5.9.1.1)

#### **5.5.9.1.3 The influence of affluence**

Few mention socio-economic and educational factors in patient expectation. Greater lay knowledge can, however, be a ‘double-edged sword’ when it comes to streamlining attendance and managing explanations:

*“all these posh houses and I feel they are better. What we are trying to do now is change that slightly by saying that if the MSU is normal they can now put a stamp on and say the result was normal and if you are feeling OK you don’t need to see the doctor...so clever lot will say right I am better, I will come back to you and have your cefalexin if I feel the symptoms are coming back. The others will say, if you think I need, give it to me” (Ld5p11)*

#### **5.5.9.1.4 Symbolism**

Professionals use this tool to help lend weight to their explanations. They use patient perception that stronger antibiotics are kept in reserve:



*“It’s a broad spectrum antibiotic, not a stronger one I would have thought...we use the word stronger I think because it sounds nice for the patient” (Ld1/5p7)*

Dipstick testing may be a substitute for ‘a laying on of hands’. The symbolism of examination can be quite powerful, and in dipsticks doctors were able to recreate this in a situation where examination was likely to be unhelpful and unwarranted.

*“I think doing something is quite important and in this instance it becomes doing a urine test rather than an examination...the patient perceives that you are doing something, because they can see that you are taking them seriously, you have tested their urine” (Ld4/5p18)*

More mundanely, dipsticks, and other investigations, are a way to reassure patients that antibiotics are unnecessary:

*“I think the main reason for dip sticking in my opinion, is that you can convince the patient...if you don’t do anything at all and then say I don’t think you need anything, then they are less likely to be convinced” (Ld5p17)*

#### **5.5.9.1.5 Doctors need to be liked**

Patient expectation may be fuelled by doctors’ needs to be wanted:

*“I think it is a feature of GPs in particular and doctors as a broad group, actually like to be liked, which requires that you don’t necessarily do what patients want, but you go quite a long way towards meeting their expectations” (Ld4p13)*

We didn’t explore this to see if pharmacists and nurses have similar needs.

#### **5.5.9.1.6 International and cultural differences**

A number of our participants had worked in other health care systems, especially south Asia. Women were thought to be more tolerant of their symptoms in India, but it’s difficult to know whether this related to cultural differences or reduced access to health care. This may have an adverse impact on women’s health:

*“We see patients more with complications of untreated UTIs rather than the basic UTI” (2511dbp2) – India*

*“I do remember seeing quite a few cases of pyelonephritis and whether that’s because you don’t complain about the symptoms” (166dfp6) - Trinidad*

In Trinidad, the problem appears to be different from India: there are few GPs with an emphasis on private health care and the hospital acute units are over-burdened.

Whilst we think of cultural differences as relating to international boundaries, primary and secondary care represent different medical cultures. One doctor had moved from urology to general practice, but felt that their approaches were similar.

#### **5.5.9.2 Medico-legal concerns**

There has been a gradual rise in complaints and claims against doctors, with a consequent increase in ‘defensive’ practice (see background). We encountered direct reference to such concerns in only one focus group and one individual interview, all of who are experienced GPs. It is likely that the dynamics of the interviews caused the problem to be openly aired; some other groups discussed ‘defensive’ medicine but made no direct reference to medico-legal concerns.

Some groups (e.g. whole practice) are less conducive to disclosure; younger doctors are unlikely to have experienced complaints to the same extent as their senior colleagues; and, practice nurses and pharmacists are less exposed to clinical complaints.

##### **5.5.9.2.1 Reduced trust – patient and clinician**

Some doctors feel that patients trust their judgements less than in the past:

*“I think 10 to 15 years ago they trusted their local GP, they could have just said that and they would accept it. More and more people are much more educated, they have read all sorts of things and they are beginning to question”* (Ld5p12)

There is a greater onus on professionals to explain and justify their actions:

*“You are trying to sort of psychologically feel better yourself and that you have done the appropriate investigation to justify your decision, because it is less likely patients believe you now.”* (Ld5p17) and later the same participant was more forthright about this association: *“Legally you are covering yourself by doing something”* (Ld5p18)

*“I would suggest that that is put in the notes that you explained to the patient and the patient accepts it, because the same patient will change their story very quickly when they have a problem and they will immediately say ‘Oh well he didn’t say that’”* (Ld5p12)-based on personal experience

##### **5.5.9.2.2 Defensive medicine**

Over-prescribing, over- investigation and increased follow-up are ways that clinicians reduce their anxiety about errors and complaints. A doctor, experienced in leading group discussions on antibiotic use came independently to this conclusion:

*“(over prescribing) It’s the fear of litigation; the fear of having the patient complain”*  
(1212)

Over-prescribing may take the form of longer courses or unnecessary treatment. In earlier sections, I outlined how participants express their fears about uncertainty in clinical judgements, which cause some to do unnecessary tests for reassurance. These examples of practice nurse triage, and a doctor who treats empirically but investigates fully, illustrate that tests are performed and antibiotics prescribed to allay anxiety:

*“I suppose for my own security I always ask for a sample, whether we get those samples is another thing, but I always ask for one. I must admit I maybe's don't always follow up whether they definitely sent a sample (Bp4)*

*“Sometimes the symptoms are so much better you might as well not bother. You could repeat an MSU to see if there is anything left there, but litigation-wise you might think twice” (Ld5p9)*

Doing something is often seen as safer than doing nothing, even if inaction is best:

*“Litigation does actually make that even more difficult, because we can end up having to justify not doing something.” (Ld4p13)- not giving antibiotics*

*“GPs are more often criticised for not sending a test than for sending a test” (385)*

### **5.5.9.2.3 Fatalism**

A few clinicians accept that despite their best efforts they will make ‘errors’, and that these will be unpredictable. These fatalists seemed less concerned about complaints that arose from these incidents, accepting that they had little control over events:

*“I accept that in a way I am wide open if they had what appeared to be an innocent cystitis and actually end up with scarred kidneys because of an horrendous pyelonephritis that flared up after I had seen them...you are only going to find a nice professor who walked in and says the doctor was negligent there.” (Ld4/5p9/10)*

## **5.6 DISCUSSION**

Health professionals have a range of ideas about the diagnosis and management of UTI and are not immune to folklore. The variability is intriguing: medical and non-medical analysts perceive this differently. Perhaps, health professionals accept a range of normality (of clinical presentation and management) without questioning, whereas external observers are expect a more outwardly logical approach.

### **5.6.1 METHODS**

Focus group research is well suited to studies on the beliefs of health professionals, who operate naturally in groups. Mild homogeneity was the most successful format, promoting ease with expressing ideas, whilst providing sufficient shared experience to create debate. Health professionals appear ready to debate issues and confirming previous evidence, homogeneity promoted discussion through shared experience whereas heterogeneity produced wider perspectives (294). Some researchers consider that a focus group is equivalent to an interview; others have used focus groups to accumulate a larger sample size. At the same time it is generally accepted that focus groups produce different data than interviews. My experience suggests that for health professionals the breadth and depth of data is less than in patient interviews: patients had much more diverse thoughts.

Groups provide instant validation through peer comment and there were examples of health professionals modifying statements during sessions. On the surface this looked like muddled thought - and sometimes this might have been the case - but on other occasions this represented evolution or clarification of thought. Anthropological analysis accepts that there are three levels of cultural behaviour: what people say they do (for example, during an interview), what they are actually observed to do, and the underlying belief system which drives that behaviour (Hall's "primary level culture"). (389). Changing perceptions probably reflect a shift in this paradigm.

### **5.6.2 DO PATIENTS AND MEDICAL PROFESSIONALS UNDERSTAND EACH OTHER?**

Doctors, nurses, pharmacist and patients all use similar terms when describing UTI. They also appear to agree on both the important symptoms for diagnosis and the symptoms that worry sufferers, and describe these in similar ways, aiding shared understanding. Furthermore, women gain experience in UTI, its symptoms, effects and management, sometimes presenting with pre-formed ideas on diagnosis. Often these are accurate and clinicians generally respond positively to women who present in this way. Those women

with less experience, and those who present with fewer or less severe symptoms may be less accurate - they more often present to nurses, who view pre-formed diagnoses with greater scepticism. Younger women and women with multiple recurrences are more confident about their diagnosis.

Health professionals understand the difficulties that women have in distinguishing thrush and UTI. As this is a common and understandable error, it helps that clinicians are aware. Less common is the confusion with sexually transmitted infections, but clinicians are less likely to consider this diagnosis. Women quite often present with UTI and back pain but this is the one symptom that GPs are more sceptical about and clinical diagnoses of pyelonephritis are relatively rare; cystitis, on the other hand, is a very common illness.

Health professionals have a good appreciation of the disruption caused by symptoms. This is exemplified by the agreement between professional and patient accounts of the problems caused by frequency of micturition, and worries about haematuria and disease progression.

### **5.6.3 CLINICAL JUDGEMENT IN UTI**

Doctors' decision-making appeared individual, complex and sophisticated, and often driven by the patient, their condition and emotional state, personal influence, and objective evidence. Doctors may fail to follow evidence-based guidance as they have different beliefs and practices to academic physicians whose research and expert opinions appear in medical journals and clinical practice guidelines (229), but I found a gradual acceptance as long as clinical experience supports the evidence. Nurses, in keeping with previous evidence (164), and pharmacists are more accepting of algorithms and protocols, and readily refer to doctors when they feel that the situation is more complex. Many health professionals justify their approaches with a mixture of anecdote and evidence. Their preferences reflect their tolerance of uncertainty, place in the medical hierarchy, experience, and personal perception of risk. Personality is likely to play a significant part in clinical judgement in the diagnosis and management of UTI.

#### **5.6.3.1 Use of investigations and defensive medicine**

The significance of dipsticks is not always fully understood, and they may be used for purposes other than their clinical utility. Sometimes they are used just because of their easy availability, sometimes as a substitute for 'laying on of hands' since examination is not a normal part of the UTI consultation, and sometimes as a way of involving and reassuring women about their problems. Despite common use some doctors still weren't using sticks

that tested for nitrite and leucocytes, the most predictive indicators. There was as little enthusiasm for microscopy as evidence for its superiority. Health professionals over-use culture to investigate UTI but this is what most are taught to do, and it is also a common defensive strategy. They receive mixed messages from opinion leaders and specialist colleagues on the use of culture, even though the evidence makes a case for selective use.

Tests are not foolproof, but they may be believed in preference to the ancient art of clinical judgement. Some doctors who over-investigate feel bound to act on results whatever the reasons for requesting tests, whatever the clinical context, and despite a response to initial treatment. This leads to unnecessary or further investigation. An over-cautious approach may reflect a fear of complaints and predominantly affects more experienced doctors. Urine culture is often referred to as a 'gold-standard' test, giving it an unwarranted credence. The newer term 'reference standard' is preferable, as it doesn't imply perfection.

#### **5.6.3.2 Prescribing**

Health professionals mostly prescribe according to guidance. This is different from a few years ago. Prevailing attitudes appeared to change during this project, suggesting that many professionals eventually adopt guidelines, though the transition may be slow. Doctors also change their management depending on the social and psychological background to the consultation, and the availability of resources at particular times of day or week.

Health professionals are more likely to follow guidance on antibiotic type than on the length of course. The default prescription lengths on computers are unhelpfully long, and resistance to change may be a factor, but the difference in approach to guidance may reflect the way that targets are set for prescribing reward schemes: it is easier to audit the type than the length of a course, so the emphasis is on the former. Some, especially less experienced, health professionals view guidelines as directives, but most have a more liberal point of view. Fears of resistance are overstated - this appears to be a manifestation of defensive practice as well as a misunderstanding of its clinical significance.

The individual reasons for over-prescribing are difficult to tease out. On the surface it appears to be a lack of belief in evidence, but a few voices suggest that defensive medicine is in part to blame. What doctors do and what they say they do may differ. Prescribing is likely to suffer from a disparity in words and actions, as it is an oft-quoted performance target. Dispensing doctors are accused of having different priorities – they are said to be more likely to favour profit over good prescribing policies. I found an acknowledgement of

this issue but received a logical explanation of why this was untrue for the majority of dispensing doctors. Pharmaceutical companies no longer have a significant influence on antibiotic prescribing: the palate of available drugs has changed little over the past twenty years, so there is no motive or commercial advantage in promoting specific products.

#### **5.6.3.2.1 Empirical therapy**

GPs have long embraced the idea of empirical treatment (6), though a more recent study suggested that for half of doctors there needed to be more than just predictive symptoms to justify this approach (4). Doctors are divided on whether to treat on the basis of symptoms or on the basis of symptoms and the results of dipstick tests. Many, who were more cautious, still treat women whilst they wait for the results of urine culture.

#### **5.6.3.3 Cost and effectiveness**

GPs' choice of antibiotic depends on the severity of infection. Their tolerance of potential treatment failure is lower where they suspect a diagnosis of upper UTI. Part of their decision is based on cost, and just as decisions on diagnosis involve a quick mental appraisal of the likelihood of disease, the same applies to their judgement of appropriate treatment. Some GPs feel guilty that patients will pay over the odds for their prescription., as much due to the small number of tablets as the cost. Guilt appears to be on the wane as the evidence for the effectiveness of short course treatments becomes generally accepted.

#### **5.6.3.4 Accounts of international differences and lessons for the UK**

Our focus groups included doctors from many different countries, though most non-UK graduates were from Spain and South Asia. The basic models of health care are similar in all countries, but access to health care differs. Doctors also recount that women present with symptoms rather than pre-formed diagnoses in other countries, but otherwise explain their illness similarly. In Spain, women present earlier than in the UK; pharmacists advise and prescribe for UTI, but charges can be greater and many women still consult their GP. Antibiotic resistance is a much greater problem, and as a result guidelines and normal practice encourage the use of broad-spectrum antibiotics at much greater cost. This concerns both professionals and managers in the UK, as we have contemplated a move to a similar system. Spanish doctors, however, quickly understood the differences in the UK and adopted their new country's guidelines. In India the health care system encourages empirical treatment; late presentation is more likely due to concerns about costs.

#### **5.6.4 EMBARRASSMENT**

Health professionals perceive that women find UTIs embarrassing and as a result alter their consultation behaviour. They agree that younger women are more open. They are not sure why women are embarrassed to talk about UTI, though it is likely to be due to residual stigma or its status as a 'down below disease'. They correctly perceive that frequent trips to the toilet and leaking and dribbling are embarrassing features.

Telephone consultations are convenient, but also help to avoid an embarrassing consultation. Consultations are considered easy as UTI is relatively straightforward to diagnose and treat, but collusion between health professionals and their patients exists to avoid embarrassment. Some doctors suggest the embarrassment is mutual, and a previous study suggests that almost as many doctors are embarrassed to talk in depth about UTI as their patients (4).

Most male doctors think that women prefer to see female doctors but women doctors aren't so sure and think that a trusted doctor is more important, though this will more often be a female. Women of different ethnic backgrounds vary in their openness and doctors think younger women are less bothered about the sex of the doctor. In the future, care may shift to pharmacies, but at present women are uncomfortable talking about UTI to pharmacists.

#### **5.6.5 TEACHING AND TRAINING**

The most profound influence on doctors' management of UTI is their early learning experience in medical school. It is therefore, very important that teaching at this early stage is evidence-based and factually correct (at least at the time!). We couldn't draw any conclusions on the influences of early teaching for pharmacists and nurses but only recently have they had extended responsibility for diagnosis and management of clinical conditions. Experiential learning and specific post-graduate training are at present more important for these groups.

There are other influences later in professionals' careers. Contrary to previous research (390) guidelines and protocols do seem to alter clinical management, and appear to have their most significant effect at times of change in young professionals' medical careers e.g. during specialist training for general practice, and when changing clinical environment - either secondary to primary care, or from one country to another. Past experience is important - so hospital physicians do not stop acting like hospital physicians as soon as they venture into primary care. Also contrary to previous research audit was uncommon



but stated to be a powerful determinant of ‘best practice’. The key to why these factors had defied previous wisdom might be due to their mode of delivery: organisational factors, education, and contact with other professionals are strong determinants of change (390). These were found in participants’ accounts. There was little evidence that primary research has a direct effect on practice, but registrars about to take exams occasionally mentioned it. Younger doctors value experience and look to older colleagues for guidance. On the other hand, experience is sometimes held up as a barrier to change by older doctors; another is unfounded fear. Sometimes doctors hide behind concerns for patient welfare when this isn’t an issue. Personal experience establishes evidence and guidelines in the minds of health professionals. Bad experiences, even by chance, may mean that well-based evidence is rejected for some substantial time, perhaps forever.

#### **5.6.6 WOMEN’S MANAGEMENT AND SELF-TREATMENT**

We confirmed that many women self-treat before visiting a doctor with a UTI, unless their illness is severe (7). They use extra fluids, a method that has no evidence-base, and over-the-counter or dietary treatments such as potassium citrate, or cranberry, which has an evidence-base but limited benefit. Health professionals may promote non-evidence-based treatments, though many of our patients had a good appreciation of what really works. Health professionals aren’t aware of much use of complementary medicine by their patients, but it is quite possible that women wouldn’t readily offer this information.

##### **5.6.6.1 Over-the-counter antibiotics**

A proposal that would make antibiotics, including trimethoprim, available over-the-counter at pharmacies has created debate (391). Pharmacists are keen; the medical profession and pharmaceutical advisors more guarded. Elsewhere, widespread over-the-counter use of antibiotics leads to resistance and the need for more expensive drugs. Both the WHO and the EU recommend that antibiotics remain ‘prescription-only’ (391).

Having tried self-treatment (and failed), women expect antibiotics when they attend doctors’ surgeries for UTI. Clinicians usually meet their expectations as most prescribe empirically – younger doctors, pharmacists and nurses are less likely to follow this strategy. As women have also waited before attending, a delayed prescription strategy for what is commonly a bacterial infection may not be well received, though a study supporting this does qualify this recommendation by advising that the concerns of patients

need to be taken into account (7). The strategy should be further tested in a normal population attending primary care.

### **5.6.6.2 Expectation**

Health professionals feel that women's expectations of health care are rising, and some feel uncomfortable with the change in the locus of control of the consultation. Doctors cite the need for more explanation as the most obvious change. The situation on antibiotic therapy is much more complex: health professionals feel that when women attend they seek antibiotic therapy, having exhausted other methods, a view supported by the findings of our patient interviews. On the other hand, they feel that women nowadays are more sceptical of antibiotics. This may be expected to reduce the dilemma created by the GP's role of personal advocate versus a public health role to limit unnecessary antibiotics, but this doesn't happen. Clinical presentations, the response to antibiotics, and side-effects vary, so there is still substantial room for tension when antibiotics are not prescribed. Doctors are happier doing something than nothing – this meets expectations and is seen as a better defence mechanism. Doctors are satisfied with current antibiotics, though some women wish for a 'magic cure' and feel that UTI is a forgotten area for research.

#### **5.6.6.2.1 How have doctors coped with not being 'God'**

Doctors also use some tools to help them meet patient expectation. 'Laying on hands' carries a reassuring symbolism: in UTI examination is usually unnecessary and can be awkward; it is replaced by dipstick testing.

Doctors feel they aren't trusted in the same way as in the past, and that they are required to justify their actions more. This creates anxiety for some, though others have a 'fatalistic' attitude that incidents will happen and their ability to control this is limited.

## **CHAPTER 6 THE INTERNET- A NEW SOURCE OF ADVICE FOR WOMEN WITH URINARY TRACT INFECTION**

*Give a person a fish and you feed them for a day; teach that person to use the Internet and they won't bother you for weeks (Anon)*

### **6.1 INTRODUCTION**

In previous chapters I found that the symptoms of UTI and how they are perceived are central to the diagnosis and management of UTI, and that women's understanding of their illness is an integral part of this.

Searches for health information are among the most common reasons that consumers use the Internet, the use of which is rising inexorably (392). The purpose of this study was to find out what data patients could access on the Internet. The study of patient experience did not suggest any use of this resource, but many of our respondents had had long histories of UTI, had already acquired a significant amount of knowledge about their condition, and the rise in the use of the Internet has been a recent phenomenon. The Internet is likely to be relevant in two situations: before women attend with UTI and as a source of information suggested (or given) by medical professionals at the time of their consultation.

Women who have less experience of a condition are increasingly likely to seek information about their diagnosis and management before they decide to visit their doctors. A number of women also commented that they had received medical advice leaflets from medical professionals in primary or secondary care, and anecdotally, this tendency is increasing rapidly as a mechanism of supplementing explanations and shared decision-making. Whether these leaflets achieve their aim is beyond the scope of this enquiry, but it is pertinent to check that an increasingly important source provides reliable information.

An initial pilot survey concentrated on the content of Internet sites, and I drew comparisons with data from the study of patient experiences. However, both consumers and experts have raised concerns about the quality of information on the Web and the ability of consumers to find accurate information that meets their needs (392). After accessing sites through two search engines, it became clear that the information presented was targeted differently and was of variable quality and provenance, validating the criticisms. I, therefore, assessed the quality of information on cystitis on a wider range of sites, analysing the range, type, and origins of the available information available to patients; this included an analysis of the reliability, relevance, and independence (from

commercial interests). I used a validated checklist of quality in the assessment of Internet sites. The results of this are presented in the next chapter.

I also reviewed the original full study to discover whether the nature and quality of data is improving as the Internet matures. The aims, background, methods, results, discussion and conclusions of this, the final project in the PhD, a survey of internet information on UTI, and its development, is presented here.

## **6.2 AIMS**

To identify popular websites for patient information on cystitis, and to qualitatively and quantitatively assess their content.

To compare the content of the websites to identified information needs from the study of patient experiences.

To assess the provenance of websites and the effectiveness of different search strategies on three popular Internet search engines

## **6.3 BACKGROUND**

There are no studies relating to Internet information on cystitis or urinary tract infection, the closest in subject matter being on circumcision and on urinary incontinence. A wider search (conducted in 2007) of medical conditions and Internet information revealed 17 relevant papers with abstracts in English; backpain was the commonest subject. Since then, there has been an increase in papers on website quality, particularly on cancers.

Quality is a problem on the web (393) and even apparently credible websites may not provide higher levels of accurate health information (394). There is no control over who posts information, and no standards exist regarding the publication of medical literature on the Internet (395, 396). Relevant web sites vary dramatically in terms of content, quality, and accessibility (392, 395). Many site features affect the capability of search engines to find and index them (392), and misleading or inaccurate information poses a theoretical risk to patients seeking treatment for medical conditions (395). More particularly, there is a risk that the interests of the web producer may bias the quality of information (396).

The for-profit healthcare industry provides a range of information aids for patients, some of which are not balanced in their presentation of treatment options (397). Internet information is often medico-centred as opposed to patient-centred (398) and may include promotional materials for commercial interests (399). Despite this, 60% of patients in one

survey felt that the information they found on the Internet was as good as or better than that they received from their doctors (400). One further study, with a high response rate, found that only 8% of patients had accessed Internet information about their condition, despite 77% having access at home or from other sources. 57% of patients, however, said that would access a recommended internet access (401).

The vast majority of websites are of poor informational value and more than one-third seek secondary commercial gain (395); in this study, less than 10% of relevant websites were deemed to be of high quality. Similar values were found in other studies, and sites discussing more severe conditions are no better than others: only 5% of sites for Barrett's oesophagitis and 6% for colonic polyps, both potentially pre-malignant conditions, were of high quality (401). Among websites providing information on COPD, commercial sites are much more likely to be of poorer quality compared to sites of non-commercial organizations. In particular, commercial sites do not provide information about simple preventative treatments (396).

Most studies were undertaken in the USA, with the UK and France being the next commonest. Language and country of origin appears to have no affect on all of these findings. A study of Internet information about female urinary incontinence, written in French highlights the poor quality of information available for typical users. They concluded that doctors should play a greater role in evaluating these sites and/or developing their quality (402).

### **6.3.1 ACCESSING MEDICAL INFORMATION ON THE INTERNET**

The Internet has greatly improved access to health information for consumers (392). In 2009, 70% of UK households had Internet access (403), a figure that rises each year. Almost all 16-24 year-olds regularly access the Internet, but the biggest growth area is use by older age groups. Educational achievement predicts Internet access: only 52% of those with no formal qualifications have a connection. 72% of women access the Internet (less than men), but are more likely to use it to access health information (403). A recent study found that predictors of low use of the Internet – age over-65, low income, low educational achievement, or belonging to an ethnic minority - are associated with lower health-related technology use, but use increases after consulting health professionals, more so generalists and if the user is female (404). Accessing health information is second only to blogs and

chat sites as an Internet growth area in the UK, but still lags well behind the USA where 61% of all adults access the Internet for medical purposes (405).

Access to information can be seen as a means to better decision-making for the individual patient (406); indeed, the information that people find often directly affects the decisions they make about their health care (407). In some countries access to information is enshrined in legislation (406). The five most frequent reasons visitors searched the website were to seek: information about a condition, information about treatment, information about symptoms, advice about symptoms, advice about treatment (407).

Consumers vary greatly in how they seek information via the Internet, and in how successfully they search for health information (392, 408), using search terms that vary in sophistication; the process can be time consuming (401, 409), though it may have improved since these studies were conducted. Consumers rarely look beyond the first page of search results, and 71% follow a link listed in the top five (410); they look for keywords, descriptions, and the source of the information (408). When assessing website credibility they consider the source, a professional design, a scientific or official touch, language, and ease of use (410), but this does not mean that impartial sources are universally favoured (408).

Clinicians are increasingly aware of the small but growing proportion of patients who obtain information from the Internet (392), but many are not familiar with the content or range of information aids provided for, distributed to, or accessed by their patients. GPs are the most likely health professionals to recommend a health website to patients, most particularly male doctors over the age of 50 (411).

### **6.3.2 ACCESSING GOOD QUALITY INTERNET SITES**

If information materials are to be used to support treatment decisions, they must contain scientifically reliable information and be presented in a form that is acceptable and useful to patients (412). One study suggests that the numbers of hits to paediatric sites or their incoming links are related to the quality of site (as measured by two assessment tools-Health AtoZ and Medical Matrix). Internet users had an ability to discriminate between higher and lower quality information (413). If this is true for other conditions or groups, then with time, the more reliable sites will appear higher on search engine picking lists. Readability of Internet sites is often poor e.g. only 1% of the top 100 Parkinson's disease sites could be read by the average adult (414).

**Table 4: information needs identified by consumers (NHMRC)**

High priority needs	Medium priority needs	Low priority needs
Chances of cure	Self-care at home	Effect on sexuality
Spread of disease	Impact on family	
Treatment options	Social activities	
Family risk		

**Table 5: information needs identified by consumers (after Coulter et al (412))**

Understanding	Disease management	Consulting	Learning
What's wrong	Self care	Making the most of consultations	Services and sources of help
Processes and likely outcomes of possible tests and treatments	How to prevent further illness	Legitimise health seeking behaviour	Identify further information and self help groups
Help others understand		Legitimise concerns	Identify the "best" healthcare providers
Gain a realistic idea of prognosis		Provide reassurance and help to cope	

## 6.4 METHODS

### 6.4.1 METHODOLOGY

For the qualitative assessment we used the 'emergent coding' method of content analysis, and for the quantitative assessment we developed a new scoring system based on EU criteria on the quality of websites (415). Since we began, there has been a marked increase in studies of quality of health-related websites, but the assessment methods and tools vary.

### 6.4.2 RESEARCHERS

In a three stage process Dr James Larcombe (JL) searched the Internet, and undertook the final data analysis; V.Emma Larcombe (VEL) undertook the initial stage of coding.

### 6.4.3 INTERNET SITES SURVEYS

We looked for relevant sites on four of the most popular search engines: Google, Microsoft Network (MSN), Yahoo, and Ask (previously Ask Jeeves). Globally, Google is visited by 587 million people every year, MSN by 540 million and Yahoo by 485 million (416); figures for the UK weren't presented separately. For the qualitative survey we limited the assessment to the two most popular independent search engines at the time: Google and Yahoo. As Internet resources, and, in particular, medical use of the Internet is steadily increasing, we repeated the same exercise after one year (summer 2006 and 2007).

### 6.4.3.1 Keyword search

For the searches, we replicated keywords that women appear to use. From our study of patient experiences we discovered that most women were happy with the term “cystitis” and indeed used it in preference to others. Some used “urinary infection” and a few “waterworks”. The keyword “cystitis” was used for the basic searches. We applied no limits geographically or with respect to further terms related to “cystitis”. The effect of alterations to the search strategies is discussed in the results section.

### 6.4.3.2 Selection and categorisation of sites

I identified the top hundred “hits” for each site and categorised these according to their source. At first, I tabulated these according to sixteen separate categories. For further analysis and statistics I amalgamated the categories, producing five major groups. These were based on the major feature or primary purpose of the website e.g. a site on guinea pig cystitis was classified as animal data and thence as an ‘irrelevant site’. Educational sites hosted by private health providers could be attributed to ‘commercial’ or ‘health organisation education’ depending on whether the site used information as a vehicle for to access private care or whether the prime purpose was the provision of an altruistic source of information. The category ‘duplicates’ included closely related articles hosted on the same site - thus the second or further sites could easily be accessed through the first site.

**Table 6: categories of Internet sites**

Major category	Original Categories			
Commercial sites	Commercial: pharma	Commercial: Complementary medicine	Commercial: treatments	Commercial: others
Educational (health organisations)	NHS bodies/ GPs	Overseas and charities	Private health providers (UK)	Non-commercial pharma
Webinfo	Medical websites	General websites	Links only	
Irrelevant sites	Interstitial cystitis	Other diseases	Research protocols	Children, men and animals
Duplicates	Duplicates			

#### 6.4.3.2.1 Sub-selection of sites for the surveys

For both the qualitative analysis of information and quantitative assessment of quality we analysed the top 20 sites identified by Google and Yahoo. Both anecdotal discussions and evidence suggest that people searching the Internet are unlikely to look further. Most look at the first search page (10 hits) or fewer (410). We recorded the Internet sites appearing in



each search engine's top twenty hits in each year, awarding the most popular site in each search 20 points, and the 20<sup>th</sup> most popular, 1 point. Thus the maximum score (four searches: two search engines) was 80. We ranked the sites (1 to 20) based on their total score, applying a tie-break to those on equal points and favouring the site with a highest individual rating on any of the searches.

#### 6.4.3.3 Assessment of sites

We assessed the sites for transparency and honesty, authority, privacy and data protection, updating of information, accountability, and accessibility according to guidelines in the European document: 'Quality Criteria for Health Related Websites' (415). This lacks an explicit quantitative assessment mechanism, but is much simpler than the 98-point checklist of the WebMedQual scale (417). We adapted individual criteria from subdivisions of quality in the EU document (415):

**Table 7: criteria for assessment of the quality of websites**

1	the site the purpose and objective of the site is transparent provider is transparent and can be identified by name and physical or electronic address
2	the purpose and objective of the site is transparent
3	the target audience is clearly defined
4	the funding of the site is transparent
5	sources of information/ references are clearly stated, including dates of publication
6	the credentials of all providers of information are listed (preferably, including dates)
7	the reviewers and editors of the site are clearly identified by name and background
8	the data protection policy and protocol for handling of information are clearly stated
9	there is a clear statement noting the last update to the site, and to individual pages/ items
10	there are arrangements for obtaining user feedback
11	there is evidence of independent accreditation
12	there is a policy for ensuring linked sites are trustworthy (responsible partnering)
13	there is a clear editorial policy
14	the information on cystitis was immediately obvious from the link given by the search engine
15	the information contained on the site was easily readable

#### 6.4.3.3.1 Selection of criteria

We included all the criteria in the EU guidelines. Criteria 6 and 7 form a single statement in these guidelines, but many websites dealt with them independently and we, therefore, considered them separately. We also considered criteria 14 and 15 separately as we needed to use a different method of scoring. Quality marks for Internet sites are a relatively new phenomenon; they post-date the EU directive, but appear to share its purpose so criterion 11 was added to the scoring.

#### 6.4.3.3.2 Additional notes on the criteria

Criteria 1,2, 3: the reader should be able to place the site provider and its intended audience in context, conceptually, and geographically

Criterion 12: many sites included a disclaimer, but this is insufficient as the guidelines ask that “all efforts should be made to ensure partnering or linking to other websites is undertaken only with trustworthy individuals.”

Criterion 15: Readability was assessed using the Fleisch Kincaid (FK) score, a standard feature on Microsoft Word. Scores produced by this method reflect the necessary reading age to cope with the language used in the information sheets. The score is equivalent to year of school i.e. FK 7= reading age of 11(year 7 at school). A score of 7 is taken as the gold standard by both advice sheets on website production and by research ethics committees assessing participant information sheets.

#### 6.4.3.3.3 Scoring the criteria

I obtained a numerical value for the quality of these websites, by scoring them against individual criteria with the exception of criteria 9 and 15, which were scored differently.

**Table 8: scoring of criteria for the assessment of the quality of websites**

score	assessment
+2	the criteria, or an explicit link, appears on the cystitis page
+1	the criteria, or an explicit link, appears on another page or is difficult to access
0	the site lacks identifiable evidence that the criteria has been met

When links weren't explicit or where the criterion was obviously met but needed up to two mouse clicks to obtain, then a score of +1 was awarded.

Criterion 9: the score for updating was determined by the years since the last identifiable update (<1 year =0). This was negatively marked so that 3 years since an update scored -3.

If the year of updating was given without a month, it was assumed that it related to January (as the assessment was conducted mid-year this penalised some sites for lack of clarity). Some sites add a copyright date on or adjacent to the lower toolbar; this was scored as the publication date if “cystitis” was the only information sheet of its type on the website. If other sheets were also covered by the copyright, they were penalised by a score of -2 for lack of clarity. This was in addition to any loss of points from the updating score up to a total maximum of -5. If no date was found, or only a general copyright date for a large site was found, then a default score of -5 was applied.

The score for criterion 15 was calculated as: Readability score = Ideal readability (7) – actual readability. For all but one site this resulted in a negative mark.

#### **6.4.3.3.4 Total scores (overall assessment)**

Total scores were obtained by adding up all the positive scores and taking away negatively marked scores

## **6.5 RESULTS**

I had expected problems from the dynamic and fast-changing nature of the Internet. The sites themselves proved surprisingly static, with few changes noted even with a year’s gap before reassessment. Few sites were updated regularly. Wikipedia, an online encyclopedia which accepts entries from internet users as well as applying internal editing, appears to update more frequently than any other site. Sites regarded as based on the Internet, or having a significant Internet function are also frequently updated. Examples of these sites are : NHS Direct, BBC, Netdoctor. These are more actively managed than sites that we considered as using the Internet opportunistically for information distribution, such as academic, NHS Trust, patient information, and commercial sites.

The results from search engines, on the other hand, proved much more changeable. On a number of occasions a search would change if repeated even hours later. On one occasion, sites were changing positions as I undertook a Google survey, some ‘hits’ seemingly leaping in from nowhere.

### **6.5.1 SURVEY OF INTERNET SITES**

All four sites used for the survey (Google, Yahoo, MSN and Ask) presented, as their default, 10 hits per page. All four sites hosted sponsored links on the same page. These links were particularly variable, and the numbers of links varied. Ask hosted the most.

### 6.5.2 SPONSORED SITES

On the surface, sponsored sites may seem a sideshow. In almost all cases, these sites are unabashedly commercial, and are, therefore, unlikely to be of primary importance for people who are using the Internet to search for medical information. Evidence from Ask, however, suggests that they may not be dismissed so lightly: this search engine featured significantly more commercial sites, and in particular, sites that gave information about alternative remedies, ‘natural’ remedies and over-the-counter (OTC) treatments. One such treatment, D-mannose was heavily promoted. Eight commercial sites relating to this product appeared in the top 100 hits in Ask compared to only one in both Yahoo and Google. Ask had 13 sponsored links in total, with varying numbers of sites per page (range 2-6); different combinations of links appeared on different pages. In contrast, Yahoo and Google hosted more sponsored links on individual pages, but repeated these links on every page, rather than varying them. Yahoo had fewer sponsored sites on the pages produced by focused searches, suggesting that advertising is targeted at Internet browsers rather than users with a specific purpose or more experienced users.

**Table 9: purpose of sites on each search engine**

	Google	Yahoo	msn	Ask
Commercial	12	17	19	31
Educational Health	22	19	27	15
Webinfo	20	28	20	18
Irrelevant	32	26	13	27
Duplicates	14	10	21	9

The featured links varied over short periods of time. In Yahoo and Google searches, sponsored links were relatively easy to distinguish from requested site search lists. In both search engines such links appeared on the right hand side of the screen and were highlighted by different background colours. In Ask they appear at the top and bottom of the requested search list and their background featured more subtle shades than those of the other two search engines. Perhaps, this contributes to their use by browsers using Ask. Interestingly, since this survey was performed , Yahoo has adopted the same format.

### 6.5.3 THE EFFECT OF REFINING SEARCHES

All four search engines allowed the user to refine their searches in different ways: Ask suggests a number of phrases to choose from when applying the keywords. Google, Yahoo and MSN, on the other hand, perform the search unhindered but then list possible sub-searches at the top or at the side of the first page.

In searches of medical research databases it is almost always helpful to increase the focus of a search. However, such databases list only in date order and do not offer any other method of separating out relevant contributions. Internet search engines employ similar but subtly different methods of producing a league table of use so that popular internet sites are ranked – thus the most popular site will be posted at the top of the search, the second most popular directly below it, and so forth.

In a medical database adding further keywords normally narrows down a search, but here the effect is to list more irrelevant sites. Most ‘irrelevant hits’ concerned interstitial cystitis, a poorly understood form of recurrent cystitis, where inflammation of the bladder occurs in the absence of active bacterial infection. Information on this could confuse sufferers of simple cystitis. Luckily, these websites turned up mostly on the third and subsequent pages, which are less likely to be viewed by patient users. The most effective search term was the simplest: “cystitis”. Yahoo was least affected by the addition of extra keywords. Some ‘off the peg’ searches automatically suggested by the search engines were more useful eg “causes of cystitis”, but didn’t improve on our original one word search.

**Table 10: effect of adding extra keywords to narrow the focus of searches**

Google keywords:	Cystitis	Cystitis+ Information	Cystitis+ Information+ sheet
Commercial	12	12	6
Educational Health	22	12	22
Webinfo	20	21	5
Irrelevant	32	43	56
Duplicates	14	12	11

A link in Google to “patient handouts” produced a very different search consisting of a mixture of information on irrelevant diseases (especially interstitial cystitis), GPs’ individual guidelines, practice/ alternative practitioner leaflets, and academic documents. Adding the term “patient” to information i.e. “cystitis patient information” produced a number of documents on the Patient UK website, as well as many obtained through the “patient handout” search. Neither of these improved on our baseline search.

#### **6.5.4 POPULARITY OF WEBSITE**

The clear winner in the popularity stakes was Net doctor, scoring 76 points, near to the maximum score of 80. Its lowest showing was fourth in the pecking order on ‘Yahoo’ in 2007, but it was first on Google for both years. Medinfo and BUPA websites (2<sup>nd</sup> and 3<sup>rd</sup>

respectively) also appeared in all searches, and the fourth to seventh placed sites appeared in three out of the four searches: BBC, NHS Direct, Patient UK, and the Natural Health Website for Women respectively.

21 sites scored more than 10 points (obtained by a single placement in the top ten of a search, or by two placements). Two sites appearing in the 2006 survey had either been removed from the Internet (New South Wales health site - ranked 9<sup>th</sup> overall) or had had their cystitis information removed (Dr Thom- ranked 21<sup>st</sup> overall).

#### 6.5.4.1 Popularity of different types of site

**Table 11: type of Internet site according to popularity placement**

	1-10	10-20
Commercial	1	3
UK Health organisations (including private and charities)	4	0
Overseas Health	2	1
Medical information websites	3	2
General web information sites	1	4

As Table 11 shows, there were differences in the types of site appearing in the top 10 and the next ten most popular sites. In fact, three of the top four are specific medical information websites, and the purpose of the first six was primarily non-commercial.

#### 6.5.5 ASSESSMENT OF TOP 20 YAHOO AND GOOGLE SITES

##### 6.5.5.1 Authorship

Many sites did not directly attribute their text to an author. Those that did predominantly used doctors as authors. Most non-attributed articles also appeared to have been written by medical professionals. A few were written by medical journalists, lay people, and those with experience of cystitis (a couple of sites were written by, or produced comments attributable to, at least one such author).

Unsurprisingly, therefore, many sites read like a medical text. A few softened their style by using the second person, but the majority were written impersonally in the third person. Notable exceptions to these styles were ‘Patient UK’, the BBC, and two sites aimed at teenagers and young adults: ‘The site.org’ and ‘RUThinking’. The latter also had a particularly good readability index). One commercial site, ‘Canesten UK’ used more day-to-day language, and also hosted a section on “myths and taboos”. Some of the better websites (from our assessment) questioned popular self-help regimes.

One commercial site (aimed at health service workers) employed a medical journalist as their author. Rather than produce new information, the site provided a review article, linked to other website articles. This produced a juxtaposition of a jaunty style of prose and some quite technical documents e.g.:

*“Similar ground is covered in slightly more detail by the net doctor site. Here, the importance of completely emptying the bladder is stressed, which is bad news for bibliophiles; sitting on the toilet and leaning forward to read makes total voiding very difficult”*

But contained in the next paragraph:

*“The cellular structure is clearly shown in this transmission electron micrograph of a single cell and this three-dimensional view of a colony”* (Allabout medical sales)

#### **6.5.5.2 Language and readability**

The complexity of language varied, but appeared generally higher than a research ethics committee might accept for a patient information sheet. Metaphors were in short supply, though a women’s health site produced the most. These were typical of metaphors used by women in their discussion of their symptoms during interviews and focus groups e.g.

*“Flushing out bugs from the bladder”*; *“down below”*; *“microscopic invaders”*

Most of the sites were single pages, though of varying length. Even sites with more pages were not especially extensive in their info – such sites used only a few paragraphs per page or larger writing.

Borrowing a metaphor from a well-known study on women’s experiences, one site opens its information sheet with: *“On the toilet every five minutes, peeing what felt like broken glass? Welcome to cystitis”* (The site.org)

#### **6.5.5.3 Further general observations on the top 20**

In 2006, Google had a few internal duplications, and more irrelevant sites. In all 17/20 Yahoo sites appeared relevant compared to 13/20 Google sites. Only five sites were common to both, which suggests that their different strategies for site-listings have a profound effect on this search. By 2007 the situation had improved, with 3 and 4 duplications respectively and no irrelevant hits in the top twenty. This suggests that the Internet health searches are improving rapidly from year to year, but whether this is due to better website production or better search facilities is uncertain.

The NHS Direct site appeared the largest (8 web-pages). The majority of sites were in the UK despite the searches being run without geographical limits. The structure of all the sites showed great similarity. Most sites organised their information in a classical biomedical manner beginning with introductions and explanations. Causes, diagnosis, treatment, and prevention followed in sequence. Some had further information, in the shape of references, related pages and books. Selected links were either given at the end or, in some cases, throughout the text. One site hosted patient narratives and opinions, though this site appeared untouched since early 2003.

### **6.5.6 INFORMATION HEADINGS ON WEB PAGES**

Since websites were structured along bio-medical lines it isn't surprising that headings reflect a familiar scientific structure. A few are problem-based.

#### **6.5.6.1 Introductions**

Almost all sites began by describing cystitis. Headings varied from the dry "Introduction" to the more colourful "A tour around cystitis". Many, using a disease-based model, set the scene with a explanation of cystitis:

*"Cystitis is inflammation of the lining of the bladder as a result of infection, irritation or damage"* (NHS Direct)

*"Cystitis is a common condition where the lining of the bladder becomes inflamed and makes urinating painful"* (BBC)

Others added a personal touch to reflections on patient experience:

*"This is an annoying and irritating condition which most commonly affects women, but can affect all age groups from either sex"* (Medinfo)

*"The symptoms are universally recognised. It can wreck marriages, careers and lives and is one of the most common and unpleasant female problems"* (Med 4U)

Anatomical differences (women's short urethra), anatomical diagrams and simple epidemiological information (such as incidences in women and comparisons to other populations- children, men, elderly etc) often featured in the introduction.

#### **6.5.6.2 Symptoms**

Most sites presented symptoms as lists. There were few attempts to rank these in order of importance. A commercial site run by a nutritionist produced the most useful advice:



*“The symptoms of cystitis make the diagnosis crystal clear, and if you have ever suffered from cystitis in the past, you'll recognise them immediately”* (Marilyn Glenville)

and ranked the most important symptoms:

*“The two most common symptoms of cystitis are:*

*— An overwhelming urge to urinate every few minutes, normally with little urine to pass.*

*— Burning pain during urination”* (Marilyn Glenville)

#### **6.5.6.2.1 Confusion of symptoms**

In the study of patient experience, it was quite common for women to mix up the symptoms of thrush and cystitis especially if their symptoms persisted after taking antibiotics. Two sites addressed this dilemma:

*“Cystitis can be confused with thrush. As a general rule, cystitis is not itchy whereas thrush is”* (Canllaw Online)

*“Cystitis and thrush often get confused and the two are so common in women that they often co-exist. To help differentiate, a new vaginal discharge is not likely to occur with cystitis alone”* (Univ of Surrey)

#### **6.5.6.3 Causes**

Causes were included in most web pages. The BBC and Patient UK sites are two examples of websites that omitted this section. Both are written in a more personal style, using the second person, and both scored better on readability statistics. Thus, the appearance of this section appears to be a feature of biomedical model information sheets but not the potentially more patient-friendly websites.

Lists were common. Two medical sites further split individual causes into sub-headings, though neither logically from a medical or lay perspective - thus: infective/ non-bacterial (logically it would read infective/ non-infective or bacterial/ non-bacterial) and bacteria/ chlamydia/ sex/ other causes (mixing microbiological causes and risk factors).

On the positive side, a number of sites were informative and relevant. This wasn't limited to sites with medical authors or medical sites, and some obviously medical sites included apparent myths. Health service organisations such as NHS Direct, or Trusts produced accurate information, though sometimes a little bland.

#### **6.5.6.4 Diagnosis**

This section appeared in most but far from all sites, though others alluded to taking urine samples to doctors. Headings “*diagnosis*”, “*tests*”, or the more patient-friendly “*how do I know it’s cystitis*” (or similar) were the most popular titles.

Unsurprisingly these sections contained less diversity than many others, reflecting a consensus amongst the medical profession, and a lack of alternative options (e.g. folklore tends to relate to causes and treatments, and alternative medicine tends to concentrate on treatments). Most websites suggested the more traditional dipstick and culture of the urine for making a diagnosis. A few sites reflected more modern evidence-based thinking, which considers that assessment of symptoms is sufficient:

*“Most often this can be based on the story alone. If there is doubt, then a urine specimen can be examined by the doctor...”* (Med info)

In many websites, this section was characterised by a more inflexible and didactic approach to information. Authors say what GPs will do, rather than what they may do. This may lead to incorrect or unreasonable expectations, and pressure to drop evidence-based medicine for the most popular, or commonest practice:

*“If you think you have cystitis and you go to see your GP they’ll ask you about your symptoms and do a urine test. This will either be using a dipstick in your urine sample, or by sending your sample to a hospital laboratory. Here they will find out which bacterium is causing the infection so you can be prescribed the right antibiotics to treat it”* (NHS Direct).

This suggests that tests are important, and antibiotics best given once the correct treatment has been established, neither of which reflect modern practice.

#### **6.5.6.5 Treatment and prevention**

I have included these two sections together as there was a fair degree of crossover in their messages. Non-antibiotic treatments often double as early management strategies for a bout of cystitis and as preventative strategies in the longer term.

Treatment was universally addressed, usually under a specific heading (“*treatment*”, “*how is it treated*”, or sometimes as sections such as “*what to do*” or “*self-treatment*”). Prevention was dealt with less explicitly: it appears as a heading in about half the sites, though is addressed to some degree in almost all.

#### 6.5.6.5.1 Antibiotics

Antibiotic treatment is promoted and discussed in greater detail by more specialist medical sites e.g. the Mayo Clinic site gives a very comprehensive overview of hospital-based infection as well as community-acquired infections. In contrast, only one website in the “top twenty” suggests that no treatment may be an option:

*“Not taking any treatment is an option if you are not pregnant. Your immune system can often clear the infection. (Studies have shown that in about half of cases, the symptoms and infection go within three days without treatment.)”* (Patient UK)

The appearance of balanced or evidence-based advice is unusual and only two sites mirror advice in Prodigy (now CKS), an NHS-sponsored evidence-based medical support website. As GPs are nowadays expected to discuss options, and pros and cons of management strategies with their patients in a ‘patient-centred approach’ it seems an anachronism that a modern invention, the Internet, when giving advice to patients often does so in a paternalistic manner within a biomedical model and written in an impersonal style.

*“If the cystitis is caused by bacteria the treatment is antibiotics that are prescribed for a variable amount of time, depending on the severity and length of the infection and on the condition of the patient”*(Kent hospitals)

#### 6.5.6.5.2 Self-treatments

Most sites made reference to simple painkillers and alkalinising the urine, usually through Potassium Citrate sachets available from chemists, as well as drinking more fluids:

*“Drink half a pint of water every 20 minutes for the next three hours*

*Take cystopurin or a teaspoon of bicarb each hour to make the urine alkaline*

*Take 2-3 strong painkillers”* (Med4U)

The latter sentence, however, lacks specific details on what is “strong”, or the dose (most painkillers are taken in twos, and I can’t think of any taken in threes)

Some mentioned cranberries. Again, few websites addressed the evidence: cranberries are one of the non-antibiotic treatments that have been thoroughly researched, and found to have some (limited) benefit. One site addresses this in a very balanced way:

*“Drink cranberry juice or take capsules of cranberry concentrate. There is some scientific evidence that cranberry helps to prevent but not treat cystitis. However, it won't do you any harm to try it as treatment”* (BUPA)

#### **6.5.6.5.3 Mechanical and lifestyle treatments**

Common suggestions were to avoid sex, as well as alcohol, coffee, tea and fizzy drinks (leaving few options for drinks!), and urinating frequently. Another piece of advice, not addressed in other web pages or our studies, suggests ways to ensure complete voiding:

*“During urination the bladder should be emptied completely. It is a bad habit to sit on the toilet bent forward and reading while urinating...a trick is to place yourself backwards on the toilet, so you lean against the wall. This posture is more suitable in securing a complete emptying of the bladder than the usual sitting posture”* (Net doctor), but it is uncertain whether this helps.

#### **6.5.6.5.4 Sites that convey the truth of uncertainty**

One site, producing mostly bullet-pointed advice, tries to convey a lack of certainty for some treatment options. This example, however, illustrates a reluctance to dismiss a popular but unhelpful strategy:

*“Passing water shortly after sex is probably a good idea in women with recurrent cystitis”* (Medinfo)

#### **6.5.6.6 Further information on Internet sites**

Many had selected links. A few included references, often from reliable medical sources. Others listed contacts, and related books, though it was common for the latter to be related to the commercial interests of the site host(s). A couple mentioned complications: this is uncommon. A few sites hosted opinions and patient narratives.

*“Then, once you actually manage to squeeze some urine out....you find that some b\*st\*rd has slashed your insides with a knife, or that is how it can feel anyway!”* (Doo yoo )

*“sometimes antibiotics work sometimes not, the doctors never seem to give me a straight answer as to why I am suffering from it so often and they just continue to dish out the antibiotics which are not good for you in excessive amounts. I am so sick of it and it's bringing me down, it is starting to control my life and I'm worried it is getting in the way of work and my relationship. Ahhh!”* (Patient UK)

On Patient UK, there was little use of this facility at the time of this survey, but since then use has increased (19/21 submissions were posted in the second year of operation).

### **6.5.7 HOW ARE 'HEALTH BELIEFS' ADDRESSED ON THE INTERNET?**

Most sites didn't venture here. They retain a conservative biomedical structure and follow the "logical" pattern described by the headings above. Few addressed women's beliefs and gave explanations based on these ideas very much in the manner promoted by consultation models. This university health centre site is a notable exception:

*"For most women, though, sexual intercourse is the underlying common factor. This seems the most probable explanation since cystitis is most common in women who first have intercourse (the so-called "honeymoon cystitis") and those who have it infrequently because their partner is away much of the time."* (Univ of Surrey)

A few sites questioned standard advice usually within sections on self-help treatment especially regarding drinking water. Most of those that included such a section perpetuated folklore identified in the study of patient experience. Popular and independent websites seem just as guilty as less popular or commercial sites.

#### **6.5.7.1 Myths and folklore**

The following excerpt illustrates the breadth of unproven advice that is given on Internet sites. This is not to say it is harmful, merely unproven, and probably unhelpful:

*"It can be prevented by drinking a lot of water (around eight glasses a day), drinking a glass of cranberry juice daily, by wiping yourself from front to back after going to the toilet, by wearing loose clothing and cotton underwear and by washing before and after sex"* (Canllaw Online)

Cranberry, above, is an exception to the 'unproven' tag – it appears to have some effect on recurrent UTI. Another site specifically suggested cranberry as a folk treatment, equating it to barley water, which has no evidence to support its use:

*"For similar reasons the folklore remedy is barley water or, these days, cranberry juice"* (Medinfo)

##### **6.5.7.1.1 Drinking more fluids**

From our study on patient experiences it seems unlikely that drinking large amounts of fluids will have any effect: our participants felt it caused more frequent, larger volume urination without any effect on (dis-)comfort. Both treatment and preventative advice

encourage women to drink more fluids, or specifically more water, some quite emphatically (colours –maroon- similar to website):

*“The best first aid treatment is to **drink, drink, drink**”* (Medinfo)

#### 6.5.7.1.2 Hygiene

Improved hygiene- ‘wiping front to back’ was also a common preventative suggestion – unproven but with a certain logicity and requiring no extra effort.

Websites, in a rather contrary manner (sometimes on the same webpage), also list a number of modern aids to hygiene as potential causes of cystitis. Shower gels, bubble baths, perfumed soap, vaginal deodorants and other similar irritants are listed as troublesome. Thus women are encouraged to wash well, but are limited by further advice in their means to do so. The approach of one website appears to steer clear of criticism from either side of the argument, but as a result runs the risk of appearing to promote an obsessive approach and is unlikely to be observed by any but the most severely affected:

*“Wash your perineum with bottled water before sex and pass urine afterwards; Make sure your partner also showers and washes thoroughly before sex”* (Med4U).

The same site suggests avoiding crowded swimming pools. None of these strategies has supporting evidence but most are widely believed to increase the risk of UTI.

#### 6.5.7.1.3 Heat and cold

In our qualitative interviews we came across a number of examples of folklore on this issue. Two medical (rather than lay sites) in our Top 20 offered advice along these lines:

*“Tuck a covered hot water bottle between the legs and one against your back”* (Med4U)

*“Warm clothes on the lower part of the body will also help prevent cystitis”* (Net doctor)

thus supporting our suggestion that health professionals are as open to, or susceptible to, folklore as everyone else!

#### 6.5.7.1.4 Truthful representations of myths

A University Health Centre was very keen to scotch the myths that UTIs are sexually transmitted or contagious. Since this myth was mentioned a few times in our patient interviews this seems to be a particularly relevant point:

*“Cystitis is not "caught" through sexual intercourse. i.e. is not a sexually transmitted disease (STD)- you cannot catch cystitis from unhygienic toilets”* (Univ of Surrey)

Drinking more water to help flush the infection out appears to be a universal myth, in both medical and lay circles, and these two websites address the issue in a way that puts many professionals or evidence-based sites to shame:

*“Have lots to drink is traditional advice to 'flush out the bladder'. However, there is no proof that this is helpful. Some doctors feel that it does not help, and drinking lots may just cause more (painful) toilet trips. Therefore, it is difficult to give confident advice on whether to drink lots, or just to drink normally” (Patient UK)*

*“Some doctors recommend that you drink lots of water to help flush out the infection, to dilute the urine and reduce the burning sensation. There is no evidence that this is helpful, although drinking at least two litres of fresh water per day is generally good for your health” (BUPA)*

#### **6.5.7.1.5 The mythical nature of the discussion of myths**

One commercial site listed and explained some ‘myths’. This is a useful innovation, at least in concept. The first ‘myth’ is, however, a medical fact. The second is probably journalistic licence, though could generously be described as a ‘noble myth’: it uses a common idiom to illustrate the fact that UTI isn’t sexually transmitted, even though the general understanding of this idiom is that it reflects sexual activity not transmission. Interestingly the webpage has since been renamed ‘frequently asked questions’:

*“Myth: Regular drinking of cranberry juice has long been recommended for cystitis as it can prevent the bacteria that causes cystitis from sticking to the wall of the bladder.*

*Fact: Some recent studies have shown that Cranberry juice may help maintain the health of the bladder. Cranberries contain substances which are thought to prevent bacteria from adhering to the bladder wall”*

*“Myth: Cystitis is often known as 'Honeymoon Disease', but this does not mean that it is sexually transmitted*

*Fact: What it does mean is that in the case of serious or bacterial cystitis, sexual intercourse can pass bacteria from the anus to the bladder. In mild or non-bacterial cases, sexual intercourse can cause bruising resulting in cystitis symptoms”*

#### **6.5.7.2 Expectations**

Some sites predict medical management. The quality of information is variable: though along the right lines, management has changed subtly over the last few years and this

wasn't always reflected in the advice. On the other hand, one site apparently written by doctors for their student patients has an open style, which allows for medical judgement and patient needs to be met without any prior expectations:

*“If the problem carries on, then please bring a specimen of urine for the nurse to test. The doctor will prescribe antibiotics to kill the bacteria in the bladder if this is what is needed. We do not normally send every specimen to the laboratory but always do so in a male, or where female cystitis recurs after medical treatment.”* (Univ of Surrey)

### **6.5.7.3 Use of evidence**

Few websites listed references. A variety of levels of evidence were proffered. Some quoted high level evidence such as systematic reviews (Cochrane etc); other relied on medical textbooks. Some concentrated on particular studies e.g. on cranberry. Commercial sites selling or promoting alternative advice and treatments were very likely to reference alternative literature and books. Interestingly, more mainstream commercial sites didn't follow this pattern, and tended to include no references.

## **6.5.8 QUALITY OF WEBSITE INFORMATION**

No site met all criteria and no criterion was met by all sites (see Table 12: quantitative assessment of quality criteria)

### **6.5.8.1 Transparency and honesty**

All current providers had a valid electronic address. Physical addresses were less common, but this wasn't assessed separately. Explicit details about the site provider (criterion 1) were unusual but commoner on popular sites; details of the purpose (criterion 2), on the other hand, was available for 16/19 current websites, though on quite a number it was merely an identification of the provider or a one-line explanation. Defining an audience (criterion 3) was commoner in the most popular sites.

Funding statements were missing from all commercial providers (criterion 4) and, more surprising, from most associated explicitly or by inference with the NHS or other government departments. The best were web-based information providers and charities.

### **6.5.8.2 Authority**

Statements on authority: sourcing and referencing; credentials; and reviewer listing were all much commoner in the more popular sites (criteria 5-7).



### **6.5.8.3 Privacy**

Most included statements on data protection, and information handling (criterion 8), though the links to these statements could be improved – commonly, they read “privacy statement” rather than more explicit phrases such as “how we handle your data”.

### **6.5.8.4 Updating**

Most popular sites were updated regularly and listed dates explicitly. In contrast only two of the sites 10-20 in popularity had explicitly updated in the last year.

### **6.5.8.5 Accountability**

Most included the opportunity to feedback (criterion 10), though it was often termed “please send us your comments” rather than being more explicit. A few included an opportunity to contact for further advice (commercial and non-commercial) but this wasn’t thought to be sufficient for this criterion.

Few sites gave reassurance on the quality of their hyperlinks and links to other sites, though most had disclaimers, absolving them of responsibility (criterion 12). Editorial policies (criterion 13) were common in the top 10 but not thereafter. Only four sites listed independent accreditation; three of these were in the 10-20-popularity list. I did not check the validity of the accreditation kite-marks.

### **6.5.8.6 Accessibility**

Usually, the search engines identified the relevant page of information instantaneously, meeting criterion 14. One provider failed to achieve this criterion: the keyword “cystitis” had to be added to reach the information on cystitis.

Readability was very disappointing. ‘RUthinking’ a government backed teenage website wins the prize for this with a Readability score of 6.3 which shows it can be done! The only other sites to come near to achieving the ideal score of 7 were the BBC and Patient UK (whose guidance on readability I followed). The range of scores were 6 to 13, and the modal and median readability score was 11, which equates to the level of a GCSE pupil. Perhaps, as these sites are aimed at adults, the writers thought this level is acceptable. As Internet use widens it seems prudent to make information accessible to as wide an audience as possible. On this criterion, there didn’t seem to be any correlation between popularity of the website and a good score, whereas for almost all the other criterion the most popular sites scored well.

### **6.5.8.7 Total scores**

The total scores ranged from -6 to +14. Appropriately, Patient UK came top in this survey, followed by the BBC and Wikipedia, the online encyclopaedia.

### **6.5.9 STATISTICS**

We calculated the correlation co-efficient of quality to popularity in this assessment:  $r_s = 0.399$  ( $p = 0.045$  for expectation of a positive correlation). Thus, popularity of a website is significantly related to a better quality assessment according to this tool.

## **6.6 DISCUSSION**

No previous work has been performed assessing the adequacy of Internet information on cystitis for patients. Since Internet use is now very widespread, improved patient website information may help to improve patient care.

Internet information sheets for cystitis usually follow biomedical patterns of discourse, confirming previous findings (418). One site, which diverged from this trend, included individual comments and blogs. A university health centre provided the best compromise between biomedical modelling and patient information.

There are some indications that Internet sites are changing relatively rapidly. The searches provided fewer duplications and irrelevant sites in the “top twenty” in 2007 than 2006. Most sites have the facility to accept feedback, and perhaps this, or changes to the methods of searching are producing more relevant articles. New to the top twenty in 2007 were Internet sites for teenagers and young adults. Their style was much more user-friendly. Perhaps, this is a sign of changes to come.

One notable change is the use of a chat-room on Patient UK, which appeared at some time after the first survey - this had had a slow start and only two blogs were present at the time of the completion of the second survey, but many more have been added since. This suggests that such methods of communication are increasingly popular and may significantly change the way that women collect information on their condition. Apart from friends, family, and colleagues, accurate information is hard to come by, and it looks as though the Internet has responded to this ‘market’. For women with good sources of information, the Internet will no doubt provide a wider source of experience and ideas, but this medium may be invaluable for women who, for whatever reason, are unable, or perhaps, unwilling to call on the support of sources closer to them.

Accuracy was generally good, though the subtleties of a doctor's decision-making were omitted. Some suggestions on the management of UTI are years out of date and may affect patient expectation and satisfaction, especially as we have found from our earlier studies that communication can be difficult in UTI consultations. It is worrying that this included NHS Direct, which gives authoritative information to the general public about their medical conditions either before or in place of a medical consultation.

The use of current evidence was patchy, and unproven or even disproved self-help theories were often given greater prominence than evidence-based facts. Myths and folklore were often perpetuated by websites, overshadowing more effective management strategies. This may be unhelpful to patients who may be lulled into thinking that these strategies should always be tried before seeking medical help. From our interviews and some web-blogs, it is apparent that women with recurrent symptoms discard many of the strategies based in folklore and rely on wisdom gained from their own experience. Newly diagnosed patients, however, may be more likely to look to the Internet as a source of initial advice. A few sites had posted well-written criticisms of popular strategies, and these could serve as shining examples for both medical and lay writers on the subject.

The uncritical use of health professionals as authors may perpetuate information being transferred in a biomedical manner. On the other hand, non-medical authors may sacrifice accuracy and holism for readability or, through a lack of contextual understanding, may present highly technical information relevant only to scientists. Perhaps, collaborations between journalists and medical professionals would be the ideal solution.

Search engines have different characteristics. The most striking is Ask, which lists more commercial sites than all the others, primarily those selling alternative therapies. This may be due to its advertising policy and a lack of clarity on the site as to what is sponsored and what are more objective sources of information. There were no apparent differences in quality of websites in Yahoo and Google searches despite another study that showed the former to be superior (419). Google searches included more duplications.

Searches that use combinations of keywords seem to have the opposite effect from that in medical databases: many relevant sites are excluded, replaced by duplicates and irrelevant sites, particularly those dealing with interstitial cystitis. The simple term "cystitis" appears sufficient to unearth the important sites. More complicated search strategies don't reveal any patient-centred gems, though more sites aimed at medical professionals appear.

Popular, and user-friendly websites meet quality criteria much more often than other sites, and this achieved statistical significance. Since most browsers will only look at the first few sites on a search (410) it is important that these are of higher quality. The reasons for some sites remaining at the top of the popularity tree however, appears obscure - e.g. the number 2, MedInfo is a single sheet of information with links (not working when assessed) to medical advice. It calls into question whether the position on search engines' lists accurately reflects volume, or whether other influences affect the ranking system. With some notable exceptions they are also more likely to score more highly on quality in 2007 than in 2006, but the association is inexact and we cannot definitely say from this evidence that quality causes sites to rise up the pecking order.

Few sites provide easily readable information, and objective readability scoring in this survey was very similar to that of advice sites for methotrexate use (420). It is interesting that groups that have a lot of exposure to the public (a teenage website, 'RUThinking', the BBC, and Patient UK) were the most readable, and compare very favourably even with better health-related websites (421). Undoubtedly others should follow their lead and experience in these matters. Another teenage/ young adult site, 'The Site.org' (a charity), whilst commendable in many other respects was much less readable than its government associated counterpart, 'RUThinking'. However, it is one of a few sites that used a bulleted format, which may compensate for the more difficult language. The use of the second person in the texts was relatively uncommon and most sites preferred the impersonality of the third person. It is probably no coincidence that use of the second person (e.g. BBC, Patient UK) was associated with better scores for readability. Both sites appeared more personal and less technical.

Regular updating, authority, and editorial policy were other areas associated with more popular websites. This perhaps, gives them greater face validity and trustworthiness; it also makes them more responsive to changing trends and feedback, which may gave them a vital edge. One website used a cast-off information sheet from one of the most popular sites, but failed to indicate this. Commercial sites scored poorly and were often less transparent than their rivals. On one commercial site the credentials of an author appeared inappropriately over-emphasised though no doubt correct. Independent accreditation marks appeared on a few sites. This development seems worthy as long as the kite-marks can themselves be independently assessed, but unfortunately seals of approval by reputable bodies are not currently a guarantee of quality and accuracy of information (422).

## 6.7 CONCLUSIONS

This survey suggests that there is plenty of scope for further improvements in available information on the Internet. Much information that is currently available follows a biomedical model, and should be redesigned to address patients' queries more effectively. A few sites are already structured in this way and we recommend that authors follow their good example. The language is often too complicated for an effective information sheet and this should be easy to address. Public service sites appear best at this.

Popular sites score well against an objective measure of quality, though the association is inexact. Further longitudinal study may reveal evidence on whether good sites rise to the top of the popularity stakes with time. Underperforming sites would not need substantial resources to improve - most of the missing data is simple and routine.

Commercial sites lack transparency and accountability, but there is no requirement compelling them to meet this requirement. If sites used independent and validated kite marks, then those that under-perform would be more clearly identified.

Internet information should be accurate and up-to-date and regular updates and adequate peer reviewing of articles should eliminate this problem. We do however, recommend that non-medical professionals are involved so that information is made user-friendlier, and an educated 'lay' input will be invaluable.

**Table 12: quantitative assessment of quality criteria**

			1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Transparency and honesty	1	provider detail	√	√		√	√			√	-					√	√					√
	2	purpose	√	√	√		√	√	√	√	-		√	√	√	√	√	√		√	√	√
	3	audience defined	√	√	√		√	√	√		-			√	√	√	√					√
	4	funding	√		√	√					√	-		√	√	√	√	√				
Authority	5	info sources	√		√	√		√			-				√	√		√				
	6	credentials	√		√			√	√		-		√					√				√
	7	reviewers/edit	√		√			√			-				√							
Privacy	8	data protection	√			√	√		√	√	-		√	√	√	√			√		√	√
Updating	9	yrs ago	0	3	2	0	0	1	2	1	-	?	?	2*	0	0	1*	3	3*	1*	5	?
Account-ability	10	feedback		√	√	√		√	√		-			√	√	√	√			√	√	
	11	accreditation								√	-			√						√		√
	12	links			√	√	√			√	-			√								
	13	editorial policy	√	√	√	√		√			-				√					√		
Accessibility	14	searchability	√	√	√	√	√	√	√	√	-	√	√	√	√	√	√	√	√		√	√
	15	readability	12	10	12	8	9	8	12	12	-	11	11	10	13	10	11	11	11	11	11	12
<b>SCORE</b>			<b>9</b>	<b>4</b>	<b>10</b>	<b>12</b>	<b>5</b>	<b>14</b>	<b>3</b>	<b>8</b>		<b>-6</b>	<b>-1</b>	<b>5</b>	<b>12</b>	<b>9</b>	<b>5</b>	<b>-2</b>	<b>-5</b>	<b>0</b>	<b>-2</b>	<b>9</b>

Key: Grey tick = +1; Black tick = +2; Red tick = potentially misleading information

\* = included a copyright date for a series of sheets but no specific details.

## **CHAPTER 7 DISCUSSION**

### **7.1 METHODS AND METHODOLOGY**

#### **7.1.1 IS THIS A NEW APPROACH?**

Previous studies used generic methodological approaches to describe patient experiences of UTI (3) and patients' and doctors' ideas about the risks factors for UTI (4). The latter study also uncovered data about interactions between patients and doctors but neither study went beyond description. A contemporaneous study (423) used analytic induction to study patient experiences, health seeking behaviour, and understanding of UTI, but its aims were limited and subsumed to the needs of a larger quantitative project (7). Latterly, and post-dating ours, there have been an increasing number of studies on information posted on the Internet about various conditions, though none have looked at UTI. Assessments of sites use qualitative methods, a variety of scoring systems, and panels of experts, though I found none that appeared to involve patients – my co-analyst was a lay researcher.

#### **7.1.2 GROUNDED THEORY**

##### **7.1.2.1 Suitability to medical research and beliefs about UTI**

Grounded theory has been widely applied to sociological, anthropological and nursing research (263) but is less commonly used in the medical arena despite its particular value in researching interpersonal processes (262). The reasons for this are uncertain, though may be due to the large investment in time (255), the common perception of grounded theory as a precursor to quantitative work through generation of hypotheses (255), or the unfamiliarity, to biomedical researchers, of inducing theories from data (280). Grounded theory is ideally suited to making comparisons, asking questions, and sampling based on emerging theoretical concepts (12). It can, therefore, test underlying beliefs and assumptions, critical to understanding lay and health professionals' behaviour and response to the changes in evidence and practice. On the other hand, we exposed some limitations in the theory: patients and professionals are more able to describe what they do rather than why they do it. This may reflect the fact that behaviour is built up over time and is influenced by a variety of people and circumstances, consciously or sub-consciously. Other methods and disciplines may help to unlock further information in this field of enquiry.

##### **7.1.2.2 Maintaining purity**

Traditionalists demand a purist approach to grounded theory (268) whereas the 'modified grounded theory approach' allows for a relaxation of this process if researchers maintain

the underlying principles (12). Constructivists allow a flexible approach to methods in order to support theory rather than to drive it (424).

For pragmatic reasons medical research more often uses mixed methodologies (273) or a ‘grounded theory approach’, though these may often best be regarded as a form of generic qualitative data analysis (270), and may lead to a perception of a lack of rigour (256). We found that mixing methodologies can be hard to avoid, particularly in the early exploratory stage of research. The early phase of grounded theory involves listening to respondents’ stories, a generic qualitative trait. Only latterly did differences emerge as we concentrated on looking for divergent or disaffirming views and testing tentative theories.

We adopted specific processes to address the inevitable difficulties of maintaining purity in the face of my biomedical influences. In all projects we used two or more analysts from different backgrounds. Independent facilitators conducted the patient interviews and a researcher with a scientific, but non-medical background, undertook the initial data collection of web-based information. The professional interviews were more difficult to manage as the status of a professional moderator aided recruitment and management of the groups. Theoretical purity was enhanced by a strict policy of non-engagement with factual discussion until after the interviews were completed, and the process of ‘bracketing’. Reductionists will argue that the perfect ‘grounded theory’ project is impossible as we all have some preconceptions, however minor, and indeed the whole process of constant comparison ensures that only early interviews can be fully objective. We subjected our intermediate findings, at the stage of axial coding, to peer review, and postponed much assessment of the literature to the latter stages of data collection and analysis.

I conclude that the keys to objectivity in our and similar situations are the application of relevant grounded theory processes to data gathering, the use of different referential points in analysis, and the maintenance of theory development as the ultimate goal. This is similar to the conclusions of a previous review (263)

### **7.1.3 FOCUS GROUPS**

#### **7.1.3.1 Sensitivity**

UTIs are mostly straightforward physical diseases. Women do feel embarrassed about some aspects of their illness, and some stigma remains, though less than in the past. Women appear happy to share their experiences with other women that they know, groups of fellow sufferers, and with interviewers. We encountered a few examples of a previously



recognised phenomenon, over-disclosure in focus groups (313, 317), rather than a lack of engagement. For this reason individual interviews may be more appropriate for in-depth discussion of borderline sensitive issues such as UTI where participants have fewer inhibitions, or where they have pre-existent mechanisms for self-disclosure (e.g. peer groups). In homogenous focus groups they are emboldened to take their discussion beyond their normal 'comfort zone'.

#### **7.1.3.2 Size of groups**

Traditionally, focus groups have consisted of 6-12 participants (317), and eight is the median ideal size quoted for general focus groups. Studies of medical topics (309), and homogenous groups appear to work well with smaller numbers (310), whilst disconfirming evidence may need greater numbers (310).

The modal number for both doctor and patient groups in my studies was five. Larger groups produced wide-ranging discussions and sometimes a broader range of opinions, but conversely the discussions could at times be superficial. It was difficult for the facilitator to complete all the group tasks and to move groups between topics, unless everyone had 'had their say', a similar finding to previous research that has shown larger groups to require higher moderator involvement (297).

The ideal size of a focus group of medical professionals varies, depending on the familiarity of the subject and its interest. When common topics are discussed smaller groups such as 4-6 participants may prove to be more manageable than larger groups. This also appears to be sufficient for groups of expert patients.

#### **7.1.3.3 Brainstorming groups**

Brainstorming groups are used infrequently in medical research even though it is a popular technique in medical education (314). We used these groups as a mechanism to survey a wide range of views early in the project and to obtain an idea of 'normality'. We were able to segment the large group into several smaller groups of similar age and sex, and we were able to learn about male opinion. With prior consent we could have stratified for previous UTI, but the success of this would be dependent on any such sub-group having an 'average experience' of UTI, which could not be guaranteed. We agree that brainstorming groups are good for exploratory information (304), and although we didn't use the technique for this purpose we think its normative influence could have a place in testing theory.

#### **7.1.3.4 Lay participants: who attends focus groups?**

Inadequate recruitment through an inability to locate participants and getting them to turn up is a major problem in focus group projects (322). As the process was difficult from the start, over-recruiting to compensate for no-shows (297) was ineffective. As the literature predicts (297) we suffered on one occasion from assembling a small group, which was then terminally affected by 'no-shows'. Feedback from women invited to the groups indicated that competing family needs, transport difficulties, and misinterpretation of our interviewer's request had all contributed to recruitment difficulties.

Theoretical sampling and use of different interview methods prevented a narrow focus of views, as those sufficiently committed to attend a focus group may not represent the 'average woman'. Lower social class and/or living in a more deprived area were associated with a preference for individual interviews rather than focus groups. We conclude that researchers should be aware of these tendencies and should use methods that are contextualised for populations rather than being led entirely by theory.

#### **7.1.3.5 Health professionals: the use of pre-existent groups**

In the first phase of the study we had decided to target three groups with different structures and background to produce a wide sample. The variable success of the sampling strategies in these groups influenced future recruitment plans such that I favoured pre-existent groups and groups that could be constructed for a dual purpose e.g. education as well as research. Recruitment was usually fairly straightforward in these circumstances, and only when I tried to bring professionals together where there was no identified common goal did the process of recruitment once again become difficult. The use of pre-existent groups is standard in social science research but is less favoured in market research (302). It appears to be a useful strategy in medical research.

Increased homogeneity reduces the range of opinions though depth of discussion is usually greater in these groups (294) and, therefore, a recruitment strategy must account for this by using more focus groups to obtain the same range of perceptions and to achieve saturation.

## **7.2 SYMPTOMS AND TREATMENT**

Women associate dysuria and frequency with a diagnosis of UTI, but sometimes describe feelings of generalised malaise and prodromal symptoms even with cystitis. This confirms previous findings (3, 7)

Women manage mild doses of illness without recourse to medical management, but we found no evidence that women respond to more severe UTIs in a similar manner. They try self-help measures and delay their attendance at surgery, so their expectation is to receive antibiotics. The success of delayed prescription strategies in respiratory illness is based on a high incidence of viral aetiologies and a tendency to spontaneous resolution, whereas UTI is a bacterial illness of variable severity. The suggestion that treatment for UTIs merely reduces the time to resolution by around one day doesn't strike a chord with women sufferers, so it seems unlikely that a delayed prescription strategy (7), will be widely acceptable for UTI at present, but further research is indicated.

### **7.2.1 EMPIRICAL TREATMENT**

95% of GPs reportedly treat UTIs empirically (6). A more recent survey suggests that 50% will prescribe empirically based on symptoms alone and 50% will prescribe immediately in the presence of a positive dipstick test (4). UK guidance varies moderately on the accuracy of diagnosis based on symptoms alone: one guideline states that dysuria and frequency are 90% predictive of UTI (10) whereas a recent algorithm suggests that three or more typical urinary symptoms are needed to reach this level of predictability (425). We didn't quantify the responses of our professional participants, but they varied from prescribing empirically to awaiting the result of cultures before prescribing. Between these two extremes, some based their immediate treatment decisions on the severity of symptoms and some on dipstick results. Many women have negative test results yet respond to treatment (54).

### **7.2.2 THE EFFECT OF PRIOR EXPERIENCE ON ATTENDANCE FOR TREATMENT**

Many women, especially those with prior experience (about half) attend their doctor when they believe antibiotics are the solution. Rarely, they are concerned that they have a serious underlying problem, but more commonly they attend in order to alleviate symptoms and to limit disruption to their daily routine (especially work), when they have run out of self-management options, or when they feel that they are suffering a more severe bout.

## **7.3 EMERGING PROFESSIONAL ROLES**

Both nurses and pharmacists have seen their roles expand in the last few years, and both seem happy with their increased responsibilities.

Nurses are able to prescribe, after acquiring a qualification, and their role has expanded particularly in the management of chronic disease (426). They more reliably implement guidelines (164) but in this study they were also considered more dependent on protocols

than their medical counterparts. This increases their readiness to incorporate evidence-based medicine, perhaps more than doctors, though they still appear heavily influenced by the medical colleagues that they work alongside.

Nurses are said to have a 'listening ear' and it is not surprising that they receive more florid descriptions of women's illnesses. Despite this, there was no indication that the increased openness was matched by any increase in revelations and discussion of embarrassing features. This could, like doctors, be a time issue, though in general nurses have been found to have longer consultations (427).

The role of pharmacists has recently expanded beyond traditional dispensing and they may now expect to take a full and confidential history, though counter assistants are frequently the first point of contact for patients. Women more commonly present with a 'ready-made diagnosis' to pharmacists than to doctors and nurses. Pharmacists manage on the smallest amount of information from their clients, but formal teaching in consultation has only recently become a recommended part of pharmaceutical training (428). Reassuringly, however, pharmacists seem through experience to have honed their diagnostic skills and manage patient narratives similarly to other health professionals.

It now seems unlikely that antibiotics will be available over-the-counter for UTI. This idea is popular with pharmacists but not medicine management teams. EU-trained doctors report the problem of antibiotic resistance in countries who have adopted this policy, and clinicians and pharmaceutical experts in the UK appear universally opposed (391, 429).

#### **7.4 COMMUNICATION, LANGUAGE AND METAPHOR**

The move from paternalism to partnership has changed consultation behaviour. Health professionals are encouraged to actively seek patients' 'ideas, concerns, and expectations', as well as their underlying 'health beliefs' in order to create a shared understanding of problems and possible solutions (249). Doctors and patients appear to use similar terms, have similar views on the markers of severity, and sub-consciously use figures of speech in consultations. They may not, however, understand the extent to which metaphors condition the ways that people conceptualise and make sense of the world (355).

Health professionals appear to understand the disruption and embarrassment caused by UTI. They are sympathetic despite women's concerns that a lack of outward signs means that it may not be taken as seriously as its severity warrants (an illness that for many combines the malaise of flu with the pain of toothache).

#### **7.4.1 USE OF LANGUAGE**

All women, without exception, and including those with a background in healthcare described their symptoms in a non-biomedical manner.

A previous study (355), found no significant differences in how women use similes, metaphors, and other figures of speech in consultations. In this study women use figures of speech in different ways. Similes often include the most florid descriptions and are reserved for more outrageous comparisons or for descriptions of more severe presentations. Florid descriptions may be a tool for legitimising consultations (355). Colloquialisms, on the other hand, may be used to soften descriptions. The classical example is that of “down below” a phrase that appears to be internationally accepted and understood.

Illness concepts may be described in quasi-technical fashion. One example, chills and colds, are said to describe below and above the waistline illness respectively (195). Anatomically placed above the waist whilst connected to structures below, perhaps the understanding of this dichotomy of the kidneys is understood by women who consequently use both the terms: “kidney chills” and “cold on the kidneys”.

#### **7.4.2 METAPHORICAL LANGUAGE**

Many metaphorical phrases encountered in patient interviews relate to symptoms, susceptibility to, and spread of, infection. A previous study suggested that metaphors are often used at the interface of physical and psychological symptoms (355), though we found little evidence of this, perhaps as this interface isn't commonly encountered in UTI. Women may, however, use metaphorical language where they have gaps in understanding and in situations where they have less control.

Surprisingly, we found no reference to militaristic metaphors that are commonly associated with ‘battling’ infection (375). Mechanical metaphors are more often the preserve of doctors (355). Only a third of women in one study of health beliefs directly attributed UTI to infection (195); on the other hand we found no evidence that women consider UTI to be a non-infective condition in our interviews. Perhaps as UTI is perceived as an internal non-contagious infection there isn't an opportunity to mount a defence against alien invaders, or perhaps since antibiotics are so effective, the ability to control the infection is assumed, so that florid description of battles is unnecessary. In their place we found conduit and directional metaphors, suggesting that women are pre-occupied with “flushing the disease

out” rather than combating the infection. Reported self-management and health-seeking behaviour contained in the patient interviews support this assertion

#### **7.4.2.1 Adding emphasis**

Women frequently use metaphors to describe symptoms, particularly when they wish to convey a sense of severity. In contrast to previous evidence (355) women readily describe burning sensations, or equivalent metaphorical descriptions, as a symptom of UTI. A few women described dysuria as “peeing glass” or “razor blades”. Such metaphors conjure up concepts as vivid and uncomfortable as “peeing barbed wire” (3). Nurses seemed to receive and remember the most florid images. They also remarked that some phrases were “cleaned-up versions”, and unfortunately for our headlines we failed to discover what the original versions were! At the opposite end of the spectrum, pharmacists recounted only straight-laced comments, no doubt due to the constraints on consultations, which may not be held in private. Most doctors were unable to recount specific descriptions, though others produced some florid descriptions: “I have a beehive down below”; “fish-hooks”. Both of these came from an overseas-trained doctor, and just like a study from Norway (3) we cannot exclude the possibility that metaphors gain something in translation.

#### **7.4.3 CAN METAPHOR SUBSTANTIATE FOLKLORE AND MYTHS?**

A few myths have attached metaphors. The idea of increasing fluids to “flush out the system” is a widely held belief of both lay and medical people (430). “A cold in the kidneys” is a common concept and is allied to the belief that changes in temperature cause infection (195, 214). Metaphorical allusions are commonly used to describe the spread of disease, which are thought to arise in vulnerable areas such as the feet.

Many associated UTIs with sex, albeit variably, and a good few participants mention the term “honeymoon cystitis”. Unlike one previous study (4) women appeared happy to use this phrase outside of the situation of wedding nights.

### **7.5 UTI AND THE HEALTH BELIEF MODELS**

By their nature health belief models are frameworks applied to research findings so that investigators can make sense of data. The fact that a number of models have been devised suggests there is no perfect framework, and that each model does not fully capture the complexity or multi-dimensional nature of health beliefs. Women’s beliefs on UTI are no exception to this rule, and whilst some ideas and behaviours match previous findings, there were many times when no pre-existent rule could be applied.

### **7.5.1 HEALTH BELIEF MODELS AND ATTENDANCE**

The original Health Belief Model suggests that women attend doctors with a particular action in mind (217) e.g. for the prescription of antibiotics to clear the symptoms of UTI. A later variation on this model (215) suggests that women consult according to severity, cues to action, and the likelihood that consultation will restrict the threat from the illness. Whilst we found that severity (or sometimes perceived severity) is not a common determinant of whether women consult, it does determine the urgency of consultation. Internal cues, on the other hand, are common triggers to seeking a consultation, especially in experienced patients who best recognise the meaning of their symptoms and variations from the 'norm'. We found that familiarity, pain, disruption, and embarrassment, all previously recognised determinants of attendance, were influential (218), though women do not often consult to restrict threat as by experience they have learnt that UTI tends to respond quickly and adequately to short courses of antibiotics. Social cues (222) or external influences such as the media, or individual informants are generally only important to women who have suffered few UTIs. With experience they rely progressively more on their internal cues.

### **7.5.2 THE FOLKLORE MODEL**

This provides insight into particular niches of women's beliefs such as lay explanations and some self-treatments (214): changes in temperature are believed to cause "chills on the kidney"; feet are considered a weak point in the body and must be kept warm and dry to prevent infection; treating a burning sensation on passing urine (perceived as indicating acidity) requires treatment with alkalis; some also suggest that ingesting acidic food or drink triggers the burning sensations.

### **7.5.3 MUDDLES OF VIEWS**

Women have multiple realities of experience. Each episode of illness may cause a different reality to emerge. Participants, lay and medical, contradict themselves and fellow participants. They entwine medical evidence with personal experience and anecdote, and often a smattering of folklore. Some health belief models predict such findings. Health understanding is shaped by collective (social) representations (222) and moreover, understanding is an iterative process and illness explanations are dynamic entities shaped by the social environment (223). Consequently, patient explanatory models are less abstract than doctors' models, more inconsistent, self-contradictory, and more often based on erroneous evaluation of evidence (203). However, the models imply that doctors' show similar but less marked behaviour, a finding confirmed in this study.

This concept emerged during the phase of external analysis (IE) of patient data. I, as a medical professional, had overlooked this, no doubt as the expressed ‘muddles of views’ are a normal part of everyday patient consultations: confusion of symptoms; medical misunderstandings; inconsistent advice from doctors; contradictions in folklore and science; linguistic peculiarities and double meanings. Despite the theory that focus groups allow insights into how perceptions emerge (303) and exploring how points of view are constructed and expressed (302) muddles remained unchallenged by other participants or interviewers. We conclude that firstly this was due to other participants sharing similar uncertainty, and secondly that contradictory ideas often appeared dissociated in time during the narratives. Either focusing on this issue alone or using different methods would be required to study this phenomenon in greater detail.

#### **7.5.3.1 How do muddles become myths?**

A number of women used and had been advised to use yoghurt. This is normally associated with treating thrush. Some had obviously mixed up their symptoms of UTI and thrush and were using it for the latter cause, but others seemed genuinely to be taking it for UTI. Some had been told to do this by friends. The initial muddle between thrush and UTI results in the adoption of an inappropriate treatment for UTI alone. Surprisingly, some women reported a reduction of symptoms: whether this was placebo or a muddle with improvement in thrush, or even a genuine benefit for UTI is unclear. This process shows how misunderstandings can become entrenched by further misunderstandings.

#### **7.5.3.2 Why myths and folklore persist**

Participants, including health professionals, are reluctant to take ‘old wives’ tales’ seriously, yet heed their messages. Some confuse folklore and medical knowledge, and sometimes there appears to be conscious rejection, but subconscious acceptance, of folklore. One woman acknowledged this contradiction, admitting despite an underlying scepticism to passing on to her children the same folk beliefs given to her by her mother.

The shared myth of increasing fluids is a common and interesting example: it is overtly transferred between doctors and patients despite a lack of evidence for benefit. Its origins are unclear - handed down from teacher to student, generation after generation, and passed into lay folklore, or else borrowed from lay folklore and perpetuated in medical circles? I submit that only when evidence of non-benefit (or harm) is found does a myth disappear. Non-benefit is more difficult to prove than benefit, or indeed harm, is unlikely to attract



research attention, and negative findings are often ignored by scientific journals (431). This may explain why the myth of ‘taking extra fluids’ for UTI has persisted.

Folklore and habits pass down the generations but the only critical appraisal they are subject to is that of experience. Mothers admonish their children for ‘exposing their kidneys’ to cold and advise that they wrap up warmly. The folklore model predicts this behaviour (214), but the young who defy the warnings are at an age where they are likely to suffer a first UTI, which can only serve to provide ‘proof’ of the folk beliefs.

At present, the Internet doesn’t address folklore, though it is suitable for debating myths. We found only one site that advertised such discussions but the issues addressed were, however, mainstream rather than folklore.

### **7.5.3.3 Myths, medical training, and incorporating evidence-based medicine**

Doctors think in uncertain, paradox-laden, judgment-dependent, rather than neat positivist ways (432). A previous study on risk factors, confirmed by this PhD, found that doctors hold beliefs on UTI unsupported by scientific evidence (4). We attempted to discover how these beliefs began and were sustained but the application of the methodology relied on retrospective self-analysis during an interview, and our participants found this difficult. Myths emerging from early teaching appear disproportionately resistant to subsequent change, so it is important that medical educators seek to maximise the accuracy and evidence-base of their material. The mechanism of learning of young health professionals appears to follow a similar pattern to children’s acquisition of beliefs from parents (433), a process that was apparent in our study of women’s beliefs.

Nurses and pharmacists more readily accept guidelines than doctors (164), but all health professionals try to weigh up management decisions on an individual basis. Whilst this may appear to be chaotic (173, 385) and result in many different management strategies, it may reflect variable knowledge of patients or their social situation (6) as well as clinical uncertainty. Experience can be used both for and against guideline implementation.

## **7.6 EMBARRASSMENT AND ITS EFFECT ON CONSULTATIONS**

Patients and professionals consider UTI an embarrassing condition (4) but beneath the surface UTIs may cause more embarrassment than is openly expressed.

Women seem happy with superficial consultations, knowing that UTI has a simple cure. Professionals, perhaps, less so nurses, seem happy to collude with this. Few other consultations in a busy surgery offer the opportunity of quick solutions. Time pressure,

therefore, further conspires to prevent deeper discussion. We learned from the professional interviews that telephone consultations, requests for prescriptions without being seen, and trips to the pharmacist to self-medicate are common. These sometimes appear to be manifestations of learned experience or avoidance of embarrassing dialogue. Focus group dynamics helped us to understand that women prefer face-to-face consultations but the potential for embarrassment encourages the use of alternative methods.

#### **7.6.1.1 Symptoms that embarrass**

Women felt that UTI was often a hidden illness with no outward signs but paradoxically worried that some symptoms (such as smell and urinary frequency) may be obvious to others, despite a lack of evidence to support their fears. Incontinence as a result of the urgency with which women are compelled to urinate is understandably worrying, though loss of control is rare. Health professionals rightly predict that frequency affects women's daily lives more than other symptoms, though may ask about it less often since it is diagnostically less useful than pain.

#### **7.6.1.2 Sharing and secrecy**

The term “an illness below the waist and above the knees” and the metaphorical allusion to “down below” both emphasise the secretive nature of urinary symptoms. Women discuss their problems with females rather than males, and closer friends and relatives rather than acquaintances. On the whole, but less obviously so, they prefer female doctors, mainly as they feel that they will have a better understanding or even previous personal experience of the problem. Women doctors seem least aware of this preference.

#### **7.6.1.3 A ‘generational thing’?**

Undoubtedly, we uncovered differences between generations. A few, mostly older women associated UTIs with sexually transmitted diseases, and this generation commented that talking about UTI used to be “taboo”, along with other “down below” problems. Their use of metaphor in describing this phenomenon, no doubt emphasises their discomfiture.

There is, however, another dimension, which has an opposing if not an equal and opposite effect. Women with recurrent problems, and also those post-childbirth expressed a feeling that previous embarrassment or “taboos” had been broken down by their experience. We reconciled this apparent contradiction by concluding that younger women are happier to talk to their peers about UTI than in the past. Older and/or ‘experienced’ women were more accepting of situations or consultations that others find embarrassing. A previous questionnaire study also found that women in their 50s were happiest talking about

sensitive issues with their GP, and teenagers were more reticent and most likely to request a female GP (364). There is scope for further research in this or other fields.

## **7.7 UTI AND THE INFORMATION SUPER-HIGHWAY?**

The Internet is changing rapidly but is it sufficiently reliable for us to encourage our patients to derive their information from this vehicle? Certainly the quality of the layouts has changed dramatically from when I viewed websites for background information, and no doubt has changed rapidly since.

We looked at a vast number of sites in four search engines. Of the search engines, 'Ask.com' had a substantially different profile that reflected their advertising strategy, posting many more alternative health sites, the majority commercial. In contrast to another study which favoured Yahoo over Google for quality (419) we judged there to be no significant differences. After the first page, the relevance and quality of the sites dropped and duplicates increased. Most people look at the first page (ten 'hits') of a search and just 71% will follow a link in the top five (410), so it is important that reliable and informative sites rise to the top. Measuring website quality is crucial in building a website that is fit for purpose and helps users to achieve their goals (434), but few sites measured well against objective criteria, though the quality scores of the most viewed sites were generally higher. Sites hosted by patient groups had higher scores. Most sites used jargon and their readability scores were too high for this sort of document - levels that grace scientific papers – but this is a universal finding in studies that have assessed this criterion. Formal medical sites were often guilty of over-complicated language and a tendency to publish information 'for a purpose' rather than to meet patient need, though another study suggests that governmental sites are accurate (435). Student health centres, which accounted for around half of the local or regional medical organisations that had websites, were an exception to this rule. Quite possibly, other health centres publish similar leaflets, but if they do, their patients use these sites too infrequently for them to register on our searches.

Those who experience less patient-centred consultations are higher users of health-related technology (436). To ensure websites provide a useful source of information to support doctor-patient communication we must encourage reputable medical providers to improve their user-friendliness, and to take greater account of patients' information needs. We neither addressed doctors' perspectives on information on UTI for use in the consultation nor patients' use of the Internet for advice. These could be addressed by further research.

## CHAPTER 8 CONCLUSIONS

UTI is rarely a cause of major medical morbidity for women but it can affect their quality of life, sometimes severely. Most find it an embarrassing, ‘below the waist and above the knees’ condition, and will discuss it openly only with female friends and relatives. Doctors collude with this: they see UTI as a short and easy consultation, but are also themselves embarrassed to ask about sensitive details. Younger women are less inhibited by former stigma and are happier to share their stories with their peers, but older women (under 64) are less embarrassed in other situations, desensitised by previous experience, especially pregnancy.

The symptoms of dysuria and frequency are highly predictive of the diagnosis, and tests only add value when symptoms are less typical. Women with recurrent UTI can accurately predict the diagnosis from their symptoms. Medical management of UTI is logical and suited to the use of algorithms and empirical treatment. Complications and the need for referral of acute or recurrent UTI are unusual, and pharmacists and nurses can manage UTI. Both groups welcome this opportunity. Pharmacists’ capacity to absorb more work, their ability to improve privacy to facilitate consultations, and the opposition of other groups are potential hurdles.

Fears about antibiotic resistance are hierarchical: PCT advisers and doctors express the greatest fears. Luckily, most uropathogens remain sensitive to common antibiotics, and cystitis is more responsive than laboratory tests suggest. Delayed prescriptions are unlikely to be readily accepted in UTI as women have usually tried simple remedies first, spontaneous resolution is slow, and tests may be negative despite infection. Guidelines on management and antibiotic use have been slow to permeate but medical professionals feel most comfortable with changes in their management of UTI when experience, evidence, and previous teaching do not contradict each other.

Sex is commonly linked to UTI, and UTI is much commoner in adults than children and in nuns, but nevertheless the association appears variable. Barrier methods of contraception are a risk factor, especially where spermicides are used.

Metaphorical language helps women to discuss UTI in greater depth, but unusually these metaphors do not refer to combating infection. Doctors rarely notice the use of metaphor, but it is unclear whether this is because they regard it as ‘normal’ speech or because they attach less significance to non-clinical descriptions.

Women are sceptical about folklore but are reluctant to dismiss it. Their beliefs fit previous research, ‘chills on the kidneys’ causing UTI, and the feet are seen as the portal of entry for cold. Medical professionals are not immune to folklore.

Women’s health beliefs of UTI fit previously recognised models but no single model provides an adequate explanation.

Self-management of UTI appears broadly uniform except where there has been prior adverse experience, or in response to different protocols or healthcare systems. In our sample, there was limited use of complementary therapy to self-manage UTI, with the exception of reflexology, which is based on the feet.

We unearthed ‘muddles of views’. These are understandable given the similarity of symptoms between clinical syndromes, and contradictory messages, sometimes from professionals as well as from the media, friends and relatives.

Lay use of the Internet for medical information is steadily rising. Quality assurance has always been a concern but the best websites, as adjudged by internationally-recognised criteria, are creeping higher up pick-lists obtained by a simple search for the keyword “cystitis”, a term widely used by medical professionals and patients alike. A ‘quality mark’ agreed by medical and informed lay input would highlight the more trustworthy sites.

Grounded theory is well suited to clinical research involving doctors despite its previous lack of use in this context. Focus groups of health professionals are easier to recruit when a common goal to meet can be identified, so the advantages of pre-existent groups may be sometimes outweigh the methodological disadvantages. Such groups produce less diverse opinions and increased numbers of groups are needed to reach saturation. Lower numbers of participants (four to six) is sufficient for groups of health professionals as discussion is rapid and open. Focus groups attract a less diverse spectrum of women patients, and one-to-one interviews are good for social balance. Brainstorming groups are an underused form of focus group, and are useful to establish issues early in grounded theory projects.

This PhD confirms, and expands on, previous accounts of women’s experiences, providing new information on beliefs, expectations, and the use of language. It summarises medical knowledge and provides unique insights into health professionals’ ideas and available information on the Internet. Few, possibly, no pieces of research are definitive, but further enquiry is probably best directed towards generic issues that have arisen and the information needs of women in the changing environment of the management of UTI.

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## **Appendix A: Study rigour: a retrospective audit trail**

The trustworthiness of a piece of qualitative research can be assessed according to four elements: credibility; transferability; dependability; confirmability (280). The structure of this audit has been further informed by two web-based documents (437, 438) based on the application of the Lincoln and Guba rules. Criticism of the checklist states that activities do not translate easily to every qualitative methodology and some specific elements such as member-checking, peer review, and external audit may be inappropriately carried out by anyone unable to be fully immersed in the data (348).

### **CREDIBILITY**

This is a measure of the truth of the findings, equivalent to internal validity. Prolonged engagement, persistent observation, and triangulation are activities that make it more likely that credible findings and interpretations will be produced. Four other techniques are proposed: peer debriefing; negative case analysis; referential adequacy; member checking.

#### **Prolonged engagement**

This requires an investment of time to see distortions, learn the culture, build trust, and test for misinformation. Although this criterion seems to favour an ethnographic approach, I took two main steps to 'get a feel' for both patient and professional perceptions before the studies: discussions about UTI with professional groups and a pilot 'brain-storming group'. I also discussed patients' illness in greater depth than usual during consultations both before, and during, the studies (triangulation without research consent that couldn't be reported). Observing distortions and testing for misinformation is integral to grounded theory and early themes and theories are fed back to subsequent participants.

#### **Persistent observation**

Prolonged engagement provides breadth whilst persistent observation provides depth. Grounded theory, a highly iterative methodology lends itself to this criterion. There were 35 participants in the study of women's views, and the health professionals' study involved 70 participants from three professional groups. Initial groups often provided breadth whereas later groups provided depth through adding detail, deviant case analysis and checking theory. 20 sites were selected for in-depth assessment in the Internet study; evidence suggests that women would be unlikely to look beyond these sites.

## **Triangulation**

Triangulation can involve multiple and different sources, methods, investigators and theories. The study on women's ideas used three interview methods, two different facilitators, and three initial analysts with different backgrounds and external materials e.g. newspaper cuttings. The extensive use of triangulation increases the credibility of the research on a smaller sample size. The professional interviews predominantly used only one method, focus groups, and as a result needed more participants. The benefit to the process of triangulation of interviewing three professional groups was less than expected, since new themes were as much in evidence as commentary on the results from other professional groups, but this often happens in health care research (299).

In the other two studies, triangulation took place at the level of investigators and analysts. In the study of websites qualitative analysis was undertaken according to a framework derived from the initial phase of analysis, which showed a very biomedical approach to the presentation of information and triangulated with quantitative assessments of readability, using an internationally recognised, computer-based score, and a check-list developed for this project using criteria defined in European Union guidance.

## **Peer debriefing**

A qualitative supervisor was an integral member of the analytical team, but a lead supervisor contributed only to analysis after the production of written drafts, thus providing a role that incorporated an essence of 'dispassionate observer'. The PhD viva and submission feedback also approximates to the process of peer debriefing.

## **Negative case analysis**

Deviant case analysis is integral to grounded theory, and many of the later groups and participants in studies were chosen for this purpose.

## **Referential adequacy**

Constant comparison appears to be contradictory to a process of referential adequacy, but we re-analysed texts on a number of occasions to build up greater depth and to question earlier assumptions, thus partially meeting the principles of this criterion.

## **Member checking**

This technique is a subject of disagreement (348), and is considered less useful in health research due to its complexity (299). It is also considered unnecessary for grounded theory

(269). I used member checking to aid the coding of individual health professional interviews as I needed to ensure the accuracy of their accounts for the purposes of effective triangulation, and in the second focus group after an equipment failure in the first group.

### **TRANSFERABILITY**

This is a measure of the applicability of the research and is equivalent to external validity. The obligation of determining transferability in qualitative research rests with recipients who must determine whether they can apply it to their context. Thick description and purposive sampling help to provide the information necessary to meet the requirements of this assessment. Generalisability is considered to be inherent in grounded theory projects when a formal theory is produced (255), but some areas of uncertainty remain in this research: these are explicated so that readers can decide on transferability.

### **Thick description**

The results sections of the projects with transcribed interviews contain plenty of direct quotes from respondents, a luxury afforded by the length of a PhD. Grounded theory generally encourages a more interpretative approach to the presentation of the results, but this deviation increases readers' ability to decide on the relevance of our interpretations.

### **Purposive sampling**

This ensures a spread of views and maximises the chances that similar views will be encountered in other social and geographical situations. Sampling in grounded theory is theoretical, a further refinement of purposive sampling. Initial interviewing was broad-based to obtain a feel for emerging data, but sampling of later respondents was based on emerging theory. The Internet study sampling strategy was highly inclusive, purposively identifying all sites that would be viewed by patients using a simple search strategy, and was thus highly reproducible and superior to a more selective sampling strategy.

### **DEPENDABILITY**

This is a measure of consistency and reliability of the research. It is contested that if the research is credible it will be dependable, and furthermore triangulation, important in the establishment of credibility, is also considered a measure of reliability. An inquiry audit, such as this is a useful tool for determining dependability.

## **CONFIRMABILITY**

This is a measure of the neutrality and objectivity of the research and is traditionally measured by a confirmability audit, an audit trail, triangulation (again) and reflexivity.

The assessment of neutrality and objectivity appears to cover similar ground. For the purposes of the audit, I have considered neutrality mainly in terms of data collection, and objectivity in terms of the interpretative parts of the projects.

### **Neutrality**

We used external facilitators for the interviews in the patient study and avoided prior discussions of my perceptions of UTI. Neutrality in the study of professionals' ideas was harder to establish, as there is an inherent dilemma in grounded theory interviews. An impersonal and detached moderator style avoids introducing preconceived ideas into the discourse, a Glaserian imperative (267); however, this style eliminates the benefits of 'experience and knowledge that sensitise researchers to significant problems and issues in the data' (269), introduced in the 'modified grounded theory approach'. 'Bracketing', a technique that health professionals deploy daily when consulting with patients who do not share the same belief system, and avoiding unnecessary intervention during interviews were used to minimise pollution of ideas. For the Internet study initial analysis was performed on a handful of pilot sites by both researchers. The lay researcher developed an initial framework for data collection that fitted her early impressions of websites and only minimal adjustments were made to produce a final version.

### **Objectivity**

Each study included two or more analysts, with at least one from a non-biomedical background. All analysts in the grounded theory studies independently produced open and axial coding. We met to discuss selective coding – either all together, or in pairs. Only codes and theory that emerged during further iteration were developed individually. The different viewpoints for both grounded theory studies were displayed on a computerised document coding stage. We further enhanced objectivity by subjecting interim findings, established during the process of axial coding, to peer review of groups of researchers and professionals. The analytical processes for the studies of metaphor and the Internet, whilst using different methodologies, were undertaken in a similar shared manner.

External interviewers discussed their thoughts and/or produced summaries after their interviews. These contained their overall impressions and a précis of the major content to

help with the first stage of analysis, and to contribute to constant comparison where interviews were held in quick succession. When I had been present the interviewers' findings were compared with my field notes.

### **Reflexivity**

Grounded theory encourages the use of specific literature reviews as part of data analysis rather than prior to data collection. Research planning and grant application necessitates more extensive reviews of the literature than is ideal for Glaserian grounded theory (263) but I kept these to a minimum, concentrating on methods and methodology, and on the clinical background to UTI. Having informally built up a picture of the literature over a number of years, I was already sensitised by much of the available biomedical research. I postponed extensive literature searches and in-depth analysis of previous qualitative research till the later stages of, or after, data collection. As a result, I missed a few potential lines of enquiry, underlining the tension between objectivity and inclusivity.

Reflexivity was an essential part of the interview summaries produced by the independent facilitators, and was interrogated at supervisor and analysts meetings so that biases were accounted for early in the process of producing theory. My motivators and potential biases are included in the introductory chapter and in the methods sections of the studies of patients' and professionals' views.

Prior to the PhD I was ignorant of metaphor in medical discourse and came to the subject fresh. As regards, website information, I had looked at a few patient websites early in the grounded theory interviews, but sites had developed rapidly in the interim, Additionally my bias towards Yahoo was neutralised by VEL's preference for Google.

### **Confirmability audit**

This is an external audit and suffers similar problems as peer debriefing where both independence and an understanding of the data and its context are necessary.

### **The audit trail**

This requires a clear description of the research path, research design and data collection decisions and the steps to manage analyse and report data sampling, clarification of the role of different research team members as well as the role of different data sources. These are summarised in Lincoln and Guba's criteria using Halpern's categories (280):



- Raw data e.g. tapes and transcripts, written field notes and related documents have been kept for all studies.
- Data reduction and analysis products: summaries and condensed notes are a feature of the study of women's views, and all data collection processes are documented in the relevant chapters of the PhD.
- Data reconstruction and synthesis products: all stages of the analyses have been retained – a mixture of paper and computerised documents; all versions of the final report have also been retained and connections to current literature are explicit.
- Process notes: all written interview schedules have been kept and can be found in the appendices. Minor changes of emphasis were agreed on a one-to-one basis and weren't formally written down. Methodological discussions are included in each chapter, and there is an overview of methods and rigour in Chapter 2.
- Materials relating to intentions and dispositions: the proposals and early plans are available. Intentions are theoretical and by nature grounded theory projects shouldn't start with expectations. Personal notes on the inquiry proposal are found in the Chapter 1 (Introduction)

## **Appendix B: Interview schedules**

### Brainstorming Session Schedule

These questions will be posted on the whiteboard for students to work on in their mini-groups:

1. What symptoms do you think urinary infections/ cystitis cause?
2. Who do you think they affect?
3. What do you think causes them?
4. How important do you think they are (in terms of people's health and well-being)?
5. What do you think people who have these infections worry about?
6. What do you know about the ways of treating them?

Groups will write down their responses on paper sheets and present them to the other groups after around half-an-hour or a similarly suitable period. Further group and individual discussion will involve the facilitators in order to clarify points. A mini-seminar (with content effectively determined by the learners) will then be given by Dr. James Larcombe to fill in gaps in knowledge, which have not been addressed by the group work.

## PLAN OF FOCUS GROUP QUESTIONS

- We talk about “Urinary Infections” and “cystitis”. Do you use these terms, or do you call them something else?
- What do you know about urinary infections/ cystitis?
- What do you know about the symptoms of urinary infection/ cystitis?
- Who do you think it affects?
- What do you think causes it?
- How important do you think it is?
- What would worry you about having a urinary infection?
- What might you do about it (if you have an infection)?

*Notes for the Ethical committee:*

- In common with other focus group research using a “Grounded Theory” approach, these questions may differ, or may be added to if the themes identified in previous groups suggest

### PRE- FOCUS GROUP “MINI-QUESTIONNAIRE”:

Name .....

How many attacks of Urinary Infection/ Cystitis have you had in the past (including those where you haven’t seen a doctor)?

*(if you’ve had a lot, an approximate number will help)*

How many times have you been to your doctors’ for treatment?:

If you have had a lot of infections you may find it easier to put a ring round one of these phrases to describe how often you visit the doctors’:

I have gone to the doctors:

**All / Most / Quite a lot / About half / Quite a few / few / none**

of the times I have had a urinary infection/ cystitis

Finally (if you feel you can share this information with us):

Your job:.....

Your husband/ partner’s job:.....

PLAN OF FOCUS GROUP QUESTIONS FOR WOMEN WITH UTI (*Modified 7/7/02*)

**Introduction (JL/AD):**

Introductions to JL/ AD  
Ground rules  
Filling of initial questionnaire

**Questions to be asked during focus group (AD):**

Warm-up questions (Q1-3) / Establishment of terminology (Q2):

7. How do you feel about being here?
8. We talk about “Urinary Infections” and “cystitis”. Do you use these terms, or do you call them something else?
9. Can you tell me about your experiences of your urinary tract infection(s)?

*Terminology needs to be established so that we are all on the same wavelength. Does everyone use the terms cystitis/ kidney infection or is there a variety of terms?*

*We are using narrative (Q3) primarily as a warm-up. Whilst there may be interesting information here, this study has already been well done (“Peeing Barbed wire”) albeit in Sweden(sic) (though I suspect their UTIs are the same as ours!) Suggest using only as a brief intro.*

Core questions (Q4-9):

10. What do you know about the symptoms of urinary infection/ cystitis?
11. What effect do you think it has on women?
  - During the day
  - At night
12. Who do you think it affects?
13. What do you think causes it?
14. Importance for current and future health:
  - How important do you think it is?
  - What would worry you about having a urinary infection?
15. What might you do about it (if you have an infection)?

*These are the major questions for the study:*

*Importance lies both in their answers and the effect it may have on the other two studies (one on the diagnosis of UTI from patients’ symptoms, and one on doctors’ management)*

Warm-down questions (Q10-11):

16. Is there anything else you want to tell us about UTIs?
17. How has it felt being here?

**Conclusions:**

Thank yous  
Indication of feedback on outcomes of study (if interested)  
Filling expenses form  
Goodbyes

## PLAN OF SEMI-STRUCTURED INTERVIEW QUESTIONS

### 1. Initial question

*An initial introduction which may help as an ice-breaker .We also used narrative descriptions in the focus groups, but as this stage I doubt whether they would help the research.*

Women seem to talk about cystitis, urinary infections, and water infections.

- Do you use these terms, or do you use anything different?
- Do they all mean the same to you, or do they mean different things?

### 2. Factual “mini-questionnaire”:

*Women in focus groups gave answers to these question on a sheet filled in after the interviews. The initial question has been added as this information was often proffered in the group chat. The others are for background information and to help purposive sampling.*

- When did you first have cystitis/ a urine infection/ water infection?
- How many episodes have you had in the past? (if a lot, an approximate number will do)
- How many of these have resulted in you going to your doctors’ for treatment?:
- All/ Most/ quite a lot/about half/ quite a few/ few/ none
- What is your job/ your husband’s job (*explaining that this is been asked so that we can ensure an appropriate spread of people in our sample*)

### 3. Proposed questions for semi-structured interviews:

*At this stage I’m interested in the whys and wherefores of people’s ideas. Please probe as you see fit!*

*The Focus Groups have been good on breadth, but haven’t always produced depth and understanding. I have set out some general questions and followed them up with some suggestions on more specific, but still open, questions. The general questions relate closely to those asked in the focus groups. The probing questions may be redundant depending on what you get from the general questions. I have included them, however, as they are areas of interest that have come from initial analysis of the transcriptions. They may be beneficial where interviewees are less forthcoming. However, this is not meant to blunt your style, so please ignore them if they get in the way!*

- What symptoms do you get with your infections?
  - a) do you get any warning of when an infection is going to come on?
  - b) what symptoms do you get first?
  - c) do some symptoms indicate that the infection is more serious, or that you should seek medical help earlier?
- What do you think causes it?
  - a) is there anything that triggers your infections off?
  - b) how do you think you catch it?

c) consider questions on specific triggers: sex?; getting too cold/ too hot?; stress? hygiene? diet or fluid intake (lack of)?

- How important do you think it is?/ Why do you think it is important?

*I would be interested to compare it to respiratory infections, something most people can relate to: minor illness e.g. a “head cold”; moderate e.g. a dose of flu; serious e.g. “pneumonia”; (if UTIs are recurrent) a chronic illness e.g. asthma*

- What would worry you about having a urinary infection?
  - a) would you worry that it might cause other illnesses
  - b) would you worry it might have some long term effects?
- What might you do about it (if you have an infection)?
  - a) would you treat it yourself at first? (if so, what with?)
  - b) what would make you go/ when would you go to the doctors? \* if this hasn't been answered in question 1
  - c) have you tried alternative medicines? (which?/ benefits?/ problems?)
  - d) (if recurrent UTIs) do you do anything to try and prevent infections?
- Have you had any side-effects from your treatment?  
how does this affect the way you deal with your infections?  
do get thrush with antibiotics? Do you sometimes find this is as bad as the cystitis?
- Do you find UTIs embarrassing:
  - a) to have? (possible reasons: frequent trips to loo; smelly urine; urgency, though not usually incontinence; perception of an association with (poor) hygiene; “down below” factor)
  - b) to talk about? (with other women, husband or partner, nurses, doctors)Warm down question: How've you found this? *or whatever you think is appropriate*

#### 4. Questions for women invited to Focus Groups but unable to attend

- Did you change your mind?
- was it being in a group that put you off?
- was it something else?
- Was it inconvenient for you to attend?
  - a) place?
  - b) time?
- was it just bad luck that the focus group was awkward for you at that time?
- Was the setting a problem (above a doctors surgery?)
- How could we have done it differently so that you could have attended? (if this has not already been answered?)

## PLAN OF SEMI-STRUCTURED INTERVIEW QUESTIONS (DEC 04)

*I've moved the questioning around- but please feel free to alter the order or the precise method of questioning to fit the situation. The initial narrative question you used in previous interviews has taken on more significance since our interest in metaphor developed. As it probes more deeply, it may be better placed after the initial chats.*

### 1.Factual “mini-questionnaire”:

*This remains useful for background information and to help purposive sampling.*

- When did you first have cystitis/ a urine infection/ water infection?
- How many episodes have you had in the past? (if a lot, an approx. number)
- How many of these have resulted in you going to your doctors' for treatment?:  
All/ Most/ quite a lot/about half/ quite a few/ few/ none
- What is your job/ your husband's job (*explaining that this is been asked so that we can ensure an appropriate spread of people in our sample*)
- Discovering Ethnic background would be useful, but this may be more appropriate in the “field notes”

### 2? (or at the end?) Questions for women invited to Focus Groups but unable to attend

- a) Was it inconvenient for you to attend?  
place? time? just bad luck on the particular day?
- b) Did you change your mind?  
was it being in a group that put you off, or something else?
- c) Was the setting a problem (above a doctor's surgery?)
- d) How could we have done it differently so that you could have attended?

### 3.Initial question

The previous initial question on terms and definitions has been scrapped (saturation of ideas reached). Instead an expanded narrative question is suggested:

- Can you describe your last UTI?
- What did you feel about this UTI? and/or
- How did you feel after this UTI?
- how do you 'see' or 'imagine' the UTI and its symptoms
- what range of images come to you? Are these different depending on severity?
- How relaxed do you feel about it?
- How would you tell this story to different people? (e.g. friend/ daughter/ mother/ husband/ son/ doctors/ nurses/ pharmacist)
- Would you tell men and women different things?
- Would you tell different stories to medical and non-medical people?

*This may help with further insight into women's different explanations depending on gender, generation, ethnicity, position power: both “self” and “target” factors will be relevant. In particular, are male doctors treated the same as women doctors, and differently from their male non-medical peers (“honorary female” status)?*

### 4. Proposed questions for semi-structured interviews:

*I'm particularly interested in the whys and wherefores of people's ideas. Please probe as you see fit! The general questions are listed 1-9 and relate closely to those asked in the focus groups and previous interviews. The probing questions (listed as a, b.. etc) may be*

*redundant depending on what you get from the general questions. They may be beneficial where interviewees are less forthcoming. However, this is not meant to blunt your style, so please ignore them if they get in the way!*

- 1. You've kindly described your last UTI to me. Do you always get the same symptoms with your infections? If not, how do they differ?
  - a) do you get any warning signs of when an infection is going to come on?
  - b) what symptoms do you get first?
  - c) do some of your symptoms indicate that the infection is more serious, or that you should seek medical help earlier?
  
- 2. What do you think causes it?
  - a) what sources do you use to get info. about UTIs (people/ mags etc)
  - b) have you received advice sheets/ leaflets? Do they help?
  - c) what sources do you trust the most? Do you act only on these, or would you still act on sources of information that you think are less reliable?
  - d) do you think it can be passed on? (e.g. to/ from husband, from loo seat)
  
- 3. Is there anything that triggers your infections off?  
specific triggers: sex? (*medical folklore suggests that sex is the major cause- but women so far have been as concerned re- the effects on their sex life as much as it being a cause of their symptoms- could you clarify this!*); cold/ heat?; stress? hygiene? diet (e.g. acid foods)? lack of fluids?
  
- 4. Is there anything else that makes you susceptible to infections?
  
- 5. How important do you think it is?  
perhaps, compare it to respiratory infections (acute infections that most people can relate to): minor illness e.g. a "head cold"; moderate e.g. a dose of flu; serious e.g. "pneumonia"; (if UTIs are recurrent) a chronic illness e.g. asthma
  
- 6. Why do you think it is important (or unimportant)?
  - a) would you worry that it might cause other illnesses (or not)
  - b) would you worry it might have some long term effects (or none)?
  
- 7. What might you do (if you have an infection)?
  - a) would you treat it yourself at first? (with what? and why do you choose particular treatments e.g. alkali to combat acid or vice-versa, heat/ cold etc?)
  - b) what would make you go/ when would you go to the doctors?
  - c) have you tried alternative medicines? (why?/which?/ beneficial?)
  - d) (if recurrent UTIs): do you do anything to try and prevent infections?
  
- 8. Have you had any side-effects from your treatment?
  - a) how does this affect your actions in dealing with your infections?
  - b) do you get thrush with antibiotics? Is this as bad as the cystitis, or worth the trade-off?
  
- 9. Do you find UTIs embarrassing?
  - a) why? (e.g. always at loo; smell; hygiene; "down below" factor; others?)
  - b) to talk about? With whom? (*overlaps with narrative question, but may at the end of the interview provide further insight*)



c) If you don't talk about them, does making sense of your symptoms/ the treatment become more difficult?

- 10. What do you think of the way Drs/ nurses approach/ discuss your problems?
  - a) do they accord it sufficient importance?
  - b) are you afraid to be honest about the way it affects you?
  - c) do you tell the doctor what you think they want to hear rather than what you want to tell them?
  - d) would you prefer to discuss your problems in a face-to-face consultation or over the telephone? *It might depend on perceived severity* Would you have a problem with either of these approaches?

Warm down question:

How've you found this?

*or whatever you think is appropriate*

## FOCUS GROUP QUESTIONS for HEALTH PROFESSIONALS

- Warm-up/ Background and introductions (level dependant on group cohesion-new/old group)
- Can we check on whether your terminology fits mine/ each others: Cystitis/ Pyelonephritis/ Lower UTI/ Upper UTI? (Ask one and check for discordant views)
- How do you diagnose UTI/ Cystitis/ Pyelonephritis? (check re-use of symptoms/ dipsticks/ MSUs)
- Are you happy with current methods of diagnosis? Is there anything else that would be useful?
- What symptoms presented by patients are important in making your diagnosis?
- Are you more influenced by patient symptoms or test results?
- How do you think patients view their symptoms?
- Are you concerned about UTIs/ serious effects? (steer away from children's UTI? or use for material for Child UTI project?)
- How do you treat Cystitis/UTI? (in particular checking on antibiotic type, dose and duration of treatment)
- Why do you treat in this way?
- Warming down; further plans

## FOCUS GROUP QUESTIONS FOR HEALTH PROFESSIONALS v2

- Warm-up and introductions (level dependant on group cohesion-new/old group)
- Background – especially where trained and previous experience and any issues/ differences that this causes for management of UTI? Any differences in health care systems that cause you to approach UTI differently?
- Do you treat women empirically/ blind? If so, do you perform any investigations? Why have you decided to manage UTIs in this (or other ways)?
- What antibiotics do you use and for how long? Why? Can you remember why you decided on this management strategy? Teaching/ guidelines/ reading and evidence?...particularly looking at early influences in medical school or training practices
- Are women's symptoms typical? Do they have a good idea of their diagnosis- especially with experience? What are their expectations and how does this influence your management? Any particular concerns that they express? Any interesting beliefs?
- How do you think patients view/describe their symptoms (include questions about metaphor)?
- Do patients talk about self- treatment, folk remedies, complementary therapy (and /or Ayurvedic)? Do you give any such advice?
- Do you think women are embarrassed to talk about UTIs? Are consultations for UTI quick? Generational differences?
- Warming down; further plans