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SEXUALLY TRANSMITTED INFECTIONS: A MIXED METHODS STUDY OF STIGMA, SYMPTOMS AND HELP-SEEKING

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DECLARATION BY CANDIDATE

I, Fiona Louise Mapp, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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ABSTRACT

Sexually transmitted infection (STI) stigma persists and can delay or prevent seeking care at sexual health clinics but help-seeking in response to genito-urinary symptoms is not well-understood and often clinically framed. I explore perceptions and social representations of STIs and how these influence lived experiences of genito-urinary symptoms and help-seeking responses. I focus on non-attendance at specialist sexual healthcare services in women and men in Britain.

This is an explanatory sequential mixed methods study. I conducted secondary analysis using data from Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3), a probability sample survey carried out 2010-2012. Prevalence estimates and logistic regression models were used to calculate population patterns of genito-urinary symptoms and help-seeking preferences and behaviour. Sequential semi-structured interviews took place 2014-2015 with 16 women and 11 men who had participated in Natsal-3 and reported symptoms in the past month and never having attended a sexual health clinic. I developed and implemented an image-elicitation method to produce data about social representations of STIs and used thematic mapping and framework analysis to understand perceptions of STIs, individual sense-making processes and lived experiences of symptoms and help-seeking responses. I integrated key findings using matrices and joint displays to connect and extend understanding of the phenomena.

From the semi-structured interview data, dirt emerged as a common social representation of STIs and key component of STI stigma. My findings suggest there were moral and physical dimensions to dirt, which were often conflated by participants, and a range of strategies to deal with STI dirt were described: silencing and concealing; distinguishing STIs from other health issues; preventive and help-seeking strategies. Dirt framed participants' experiences of symptoms and help-seeking which were themselves often concealed, silenced and dissociated from STIs.

Survey analyses showed symptoms were more commonly reported by women (22%) than men (6%) and I proposed a new model - the Cause-Concern Cycle - to explain how participants interpreted sensations and symptoms based on qualitative data. Symptoms are sensations that cause concern and have a suspected underlying medical cause. The meanings attributed to experiences mediated subsequent help-seeking responses. Non-attendance at sexual health clinics in the past year was common in both women (86%) and men (88%) as reported in Natsal-3 but participants sought help from healthcare and other sources to gain control and emotional reassurance rather than prioritising medical needs, determined from analysis of semi-structured interview data.

The data highlight that current sexual health service provision is sufficient in terms of accessibility and choice and convey a number of messages for sexual health policy makers about managing untreated STIs and unmet sexual health needs. However, these are discussed in the context of the current climate of huge funding cuts to public health budgets which is already drastically altering the landscape of sexual health in Britain.

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LIST OF ABBREVIATIONS AND ACRONYMS

aAOR	Age-adjusted odds ratio
AIDS	Acquired Immune Deficiency Syndrome
BASHH	British Association of Sexual Health and HIV
CAPI	Computer Assisted Personal Interview
CASI	Computer Assisted Self Interview
ESRC	Economic & Social Research Council
FCA	Flash Card Activity
GP	General Practice / General Practitioner
GRAMMS	Good Reporting of A Mixed Methods Study
GU	Genito-urinary
GUM	Genito-Urinary Medicine
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency virus
LSHTM	London School of Hygiene & Tropical Medicine
MG	*Mycoplasma genitalium*
MMAT	Mixed Methods Appraisal Tool
NATSAL	The National Survey of Sexual Attitudes and Lifestyles
NATSAL-3	The Third National Survey of Sexual Attitudes and Lifestyles
NCSP	National Chlamydia Screening Programme
OR	Odds ratio
PHE	Public Health England
SHC	Sexual Health Clinic
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
UTI	Urinary Tract Infection
VD	Venereal Disease
YP	Young people

USE OF TERMINOLOGY IN THIS THESIS

Term	Explanation of how I have used the term
Genito-urinary	Relating to the external and internal area around the genitals and urinary tract of both women and men
Help-seeking	Encompasses seeking care at formal healthcare services but also includes processes that involve seeking information, advice or help from other non-medical sources
STI	In some contexts I have used STI to cover sexually transmissible infections such as thrush as well as confirmed STIs
Symptom	A sensation causing concern with an underlying medical cause (see chapter 4) but also used to mean sensations and/or health issues more generally (as discussed in chapter 4)

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CHAPTER 1 INTRODUCTION

1.1 Chapter Overview

This study explores how individual perceptions and social representations of STIs influence the interpretation of symptoms and associated help-seeking responses to better understand the key public health issue of untreated STIs and unmet care needs. It is a research-paper style thesis linking published papers, pre-publication papers and traditional thesis chapters to form a cohesive argument about the subject. In this first chapter, I introduce the main ideas and background literature which support this thesis. I start by describing the origin of the study, drawing on my own professional and personal experiences to position myself in this work from the very start. I then weave together some of the key theories and empirical findings about genito-urinary symptoms and help-seeking to supplement the paper introductions in chapters 3-5. Following this exploration of the literature, I present the first research paper, a debate piece making the case for a broader research perspective to understand sexual healthcare-seeking behaviour, which leads into my description of the rationale for this research. After introducing the overall aim and research questions that guide this work, I locate this thesis within the discipline of public health and delineate the parameters of my investigation. The chapter summary consolidates the key ideas and facilitates links with subsequent chapters.

1.2 Origin of this study

My academic background is in neuroscience (biomedical sciences) and public health and I have always been fascinated with the relationship between behaviour and health, particularly infectious diseases. Causes and routes of transmission are universal but differences in prevalence are socially determined. Taboo subjects like

sex, genitals and bodily fluids are inherently interesting to me so this study stemmed from basic curiosity about bodies and behaviours, which was shaped and refined through observations and practical experience. I observed a range of different care-seeking behaviours amongst peers, from the worried well who visited services and tested for STIs frequently, irrespective of STI risk factors, to those with no perceived need for sexual health care and no experience of attending services. These initial observations were consolidated through practical experience volunteering for various sexual health and HIV projects and then more formally working for the London Sexual Health Programme, an NHS organisation coordinating the commissioning of sexual health provision across London. As ideas for this study developed and I started thinking about genito-urinary symptoms, my own experiences came in to play. I started reflecting on symptoms that I had experienced and the situated decisions I had made about my own care needs and if, when and how to access healthcare services. I have carried these reflections through my PhD study and they have been integral in sensitising me to certain elements of the data which I feel has strengthened my thesis overall (these experiences are discussed in more detail in terms of reflexivity in chapter 6). I have used my PhD as a learning experience to improve my knowledge and practical understanding of different types of word and number data and learnt the value of integrating findings to expand the explanatory potential of results.

1.3   How to read this thesis

I have written this thesis as a hybrid of traditional thesis chapters and the research paper format, an option offered by the London School of Hygiene & Tropical medicine (LSHTM). This thesis includes three published papers, work prepared for publication and linking narrative text to connect and develop my arguments. Using this approach enabled me to achieve a pragmatic balance between detailed discussion of the content and wider dissemination of my work. All papers (regardless of their publication status) are preceded by an introduction to the paper

and followed by further discussion of the content to contextualise the paper within this thesis. I have chosen to present my empirical results by concept rather than method, to consider stigma, symptoms and help-seeking holistically and not artificially cleave these concepts into numerical and text data. This approach is favoured by Goetz (2006) and Bazeley (2015) to focus on the substantive responses to the research questions posed rather than paradigms or methods. Note that I present data about women before men throughout this thesis, partly due to personal preference to disrupt the status quo of social science reporting (and more broadly) but it also made sense in terms of my data as more women participated than men. The main downside of a research paper style thesis is repetition, particularly for the empirical results papers (in chapters 3-6); I have tried to minimise this as much as possible whilst maintaining consistency across empirical results and taking account of particular journal requirements. As the research papers are written for different journals, with different audiences in mind, there are some inconsistencies in terms of presentation, language used and referencing style. I hope you can look past these stylistic differences to appreciate the overall story of this thesis.

1.4   Thesis outline

This research paper style thesis comprises seven chapters. The first chapter introduces the thesis, includes some of the relevant background literature and presents the first research paper, a debate piece, followed by the aims, research questions and disciplinary home for this work.

In Chapter two I describe my methodology for this mixed methods study. This chapter includes the study protocol paper and the flash card activity methodological findings paper as well as details about epistemology and ethical considerations.

Chapter three uses data from the semi-structured interviews, including the flash card activity, to describe social representations of STIs and explore STI dirt and stigma in the qualitative results paper.

In the second of my empirical results chapters, chapter four, I present findings from the survey and semi-structured interview data and the integration of results exploring the prevalence, lived experiences and sense-making about genito-urinary symptoms in a mixed methods paper.

My final results chapter (chapter five) is another mixed methods chapter drawing on both datasets to examine help-seeking responses to symptoms. In the research paper I focus on the prevalence of non-attendance at sexual health clinics and then explore and integrate data about different help-seeking strategies used by participants.

I use chapter six to integrate my findings and answer the five research questions of this thesis. I synthesise empirical themes that cut across the main concepts of stigma, symptoms and help-seeking and suggest conceptual links between these concepts that have emerged from my analyses. I then reflect on using mixed methods in this study.

Finally, I collate and summarise the different aspects of this thesis in chapter seven, highlighting the implications of my findings for STI service provision, public and sexual health policy, and future mixed methods research as well as input for Natsal-4 data collection. I discuss the limitations and include a short conclusion to bring out the key points of this study and highlight my contributions to knowledge.

1.5 Background literature

This thesis explores the connections and intersections of the concepts of stigma, STI symptoms and care-seeking behaviour (or help-seeking more generally to

encapsulate responses that do not include formal healthcare), using empirical evidence. I have already conducted a literature review bringing together quantitative and qualitative data about these concepts as part of my MSc in Public Health (Mapp, 2013). My findings highlighted the pervasive effects and manifestations of STI stigma as a major barrier to attending sexual healthcare services but almost no further explanation of stigma in relation to sexual healthcare-seeking. I found very little evidence of synthesis within empirical research about stigma, STI symptoms and care-seeking and much of the data came from studies carried out within healthcare services using samples of patients attending for care. Men's experiences were particularly poorly represented (Ibid). This prompted me to think critically about current understanding of the processes involved in seeking sexual healthcare from the experiences of individuals and wider public health implications and what new knowledge is needed to address this aspect of the broader issue of unmet need and untreated STIs. Summaries of the key literature about stigma, STIs, symptoms and seeking healthcare are included in the introduction sections of each of the empirical papers (chapters 3-5). Here I provide an overview of ST symptoms and sexual healthcare in Britain to contextualise my empirical chapters.

1.5.1 Symptoms

Symptoms are used in different ways in relation to health: they have social functions and clinical functions. Socially, symptoms are a way to talk about illness – they mean something to us and are an important part of illness experience conveying aspects of the physical manifestations of infection and disease (Ahlzén, 2008). Symptoms also form an important part of clinical health information provided (e.g. in information leaflets about STIs and on the NHS choices website). Sexual health clinics (as well as other types of services) use symptoms to triage patients (see figure 1), and a focus on symptoms is common across healthcare for both patients and healthcare professionals and forms part of medical history taking (even if they are not described specifically as symptoms). Therefore despite the lack

of specificity, symptoms are still commonly used in sexual healthcare (Medical Foundation for HIV & Sexual Health (MedFASH) on behalf of British Association of Sexual Health and HIV, 2014).

Figure 1: Excerpt from the registration form used at Mortimer Market Centre sexual health clinic to triage service users.

All references to symptoms are circled in red

Natsal-3 data showed that half of participants recently diagnosed with chlamydia had had their last test because of symptoms or having a partner with a known STI or symptoms (Woodhall *et al.*, 2015).Although symptoms were not commonly reported among participants, 44% of women who tested positive for *Mycoplasma genitalium* (MG) reported STI symptoms in the past month and there was a strong association between MG and post-coital bleeding (Sonnenberg *et al.*, 2015). However not everyone with genito-urinary symptoms has an STI. Whatever the underlying cause of symptoms is, they have the potential to disrupt sexual activity, reduce sexual pleasure and influence overall sexual well-being leading to poorer sexual health (World Health Organization, 2006).

There are other things we can learn from examining genito-urinary symptoms in society. The abnormalisation of bodies and bodily functions, particularly for women is becoming increasingly common, particularly in capitalist cultures where manufacturing and selling 'sanitary' products is highly profitable (Bramwell, 2001). These products are designed to conceal bodily fluids, particularly blood and discharge, as well as counteract odours, emphasising the uncleanliness and daily need to protect against normal bodily discharges (Kirkham, 2007b). In addition there are a range of products developed to mitigate pain, tiredness and other normal sensations related to menstruation (Eagen 1985 in Bramwell 2001). Women are increasingly subjected to advertising that frames normal physiological occurrences as problematic, dirty and abnormal and this may affect how they interpret their own bodily experiences, reporting physiology as symptoms. Therefore symptoms are already commonly used for social, clinical and research purposes and are a key aspect of sexual healthcare but are not well understood and have not been given much research attention in relation to STIs because of the high prevalence of asymptomatic infection (Farley, Cohen and Elkins, 2003; Low *et al.*, 2006) and overlap with other genital health issues. An exploration of genital symptoms may extend further than STIs and enable a broader commentary on the social influences of interpretation and meaning.

There are many different ways to define what a symptom is, but fundamentally it is understood as a subjective experience of disturbed structure or function of mind or body (WONCA International Classification Committee, no date) whilst a medical sign is considered to be more objective, often measurable and detectable by others (Evans *et al.*, 2008, pp. 125–126). Symptoms have been described as "*when we feel unacceptably odd*" (Evans *et al.*, 2008, p. 1), "*unwanted and unbidden*" (Evans *et al.*, 2008, p. 3), "*a sign to the self*" (Evans *et al.*, 2008, p. 15) and "*a change of, or difference in, self-perception that is perceived by the subject not to be normal*" (Evans *et al.*, 2008, p. 36). Hay emphasises the importance of cultural information and social legitimation of symptoms which informs her conceptualisation of a

symptom as *"a constructed and socially informed cognitive interpretation that indexes but is not itself an embodied sensation"* (Hay, 2008, p. 221). So far, all of these conceptualisations of symptoms suggest they are personal experiences, associated with changes to the body linked to disease that require some interpretation by the individual. But how are experiences interpreted and what are the precursors to symptoms? Given the diversity of definitions and descriptions in the literature, I use genito-urinary symptom as a collective term to include the range of genital health issues and sensations that are experienced. I unpack the concept of what a symptom is further in chapter 4.

Symptom interpretation depends on the disciplinary perspective, which is an important consideration given that public health is multi-disciplinary and this thesis describes a mixed methods study which integrates findings across research paradigms (discussed in more detail in chapter 2 – methodology). Biomedical perspectives focus on interpreting signs and symptoms as indicators of disease, based on their severity. Interpretation is to facilitate diagnosis and treatment of symptoms and the underlying cause (Rosendal *et al.*, 2013). Psychological perspectives concentrate on the factors governing the experience and interpretation of bodily sensations such as an individual's internal frame of reference based on previous experience, attention given to bodily sensations and cognitive models of perceived threat known as illness perceptions (Ibid). The role of historical, political and/or social contexts are examined by anthropological perspectives on symptom experiences and interpretations and how these aspects shape symptom manifestations (Ibid). Therefore symptoms are multidimensional constructs and can be interpreted in different ways with experiences embedded in a web of biological, psychological and cultural factors. These different approaches to interpretation raise questions about how research participants respond to questions asking about symptom experiences – what is their frame of reference for what a symptom is? Is there a common, lay understanding of what a symptom is, or have researchers' assumptions overlooked important aspects of the study of

symptoms leading to misinterpretation of population prevalence of such symptoms?

A rejection of biomedical assumptions about symptoms as biological phenomena occurring independently of social or cultural contexts (Dahmer 2006 in Brandner et al. 2014) has led to new research attention on the senses and sensations that occur before symptoms are experienced (Howes, 2004; Hinton, Howes and Kirmayer, 2008). This has required analytical separation and the unpacking of the nature of sensations and symptoms (Howes, 2004; Hay, 2008; Hinton, Howes and Kirmayer, 2008).

The transformation process or the emergence of symptoms has also been described as 'symptomization' (Risor, 2011) and has been examined at the level of societies as well as at the individual level. Macro factors governing the transformation of sensations into symptoms include power relations, social status and knowledge systems (Martínez-Hernáez, 2000; Risor, 2011). To date, there have been no studies that empirically research or synthesise data about stigma, symptoms, STIs and help-seeking. Combining individual and population data to understand the process as a whole from the earliest development of sensations to resolution with or without medical input will help address this gap.

1.5.2   Seeking healthcare

1.5.2.1   Seeking health, help and care: definitions and frameworks

Consulting a health care professional often results from the *"detection of somatic information that is deemed to be beyond personal control"* (Scott and Walter, 2010, p. 531). Help-seeking is driven by perceived need rather than an objective, evaluated need (Stoller and Forster, 1994; Scott and Walter, 2010). Responding to symptoms by seeking some form of help or support is posited as a common and rational behaviour in biomedical terms, particularly in high income countries where services are available and accessible and are often free at the point of access

(Department of Health, 2001; Independent Advisory Group on Sexual Health and HIV by Medical Foundation for AIDS and Sexual Health, 2008). However, sociological approaches have pointed out problems with these simplistic assumptions about health-seeking behaviour as individuals do not necessarily respond to symptoms by seeking help (Zola, 1973). To advance and apply Zola's (1973) theories to current STI care-seeking behaviour, we need to explore what resources and sense-making processes individuals use to maintain the accommodation of symptoms and avoid care-seeking for their symptoms.

Specifically considering help-seeking in relation to symptoms, Scott and Walter describe help-seeking as a behaviour which "*involves processes of symptom perception, interpretation, appraisal and decision-making in addition to having the ability and motivation to enforce the decision by visiting a HCP [healthcare professional]*" (2010, p.531). They highlight that help-seeking is not just about the decision to seek care, but also about the timing of this decision as the duration of a condition can have implications on individual and public health, treatment options and cost of healthcare (Ibid). From the different definitions which encompass the main processes involved in responding to STI symptoms (Pescosolido, 1992; Fortenberry, 1997; Ward, Mertens and Thomas, 1997; Scott and Walter, 2010), it is clear that health-seeking, care-seeking and help-seeking are multi-dimensional processes shaping and being shaped by individual and social factors which take place over defined periods of time. I use the terms care-seeking and help-seeking in this thesis to encompass responses that include attendance and non-attendance at healthcare services. The two definitions that are specifically related to care for STIs or STDs (Fortenberry, 1997; Ward, Mertens and Thomas', 1997) both consider individual behaviours and are biomedically framed although Pescosolido's (1992) sociological definition downplays the role and experience of the individual. A review of the use of health and social welfare services noted the wide range of factors shaping health-seeking behaviour ranging from the economic, geographic and organisational to the socio-demographic, social-psychological and socio-cultural

(McKinlay, 1972), therefore it is important for a public health study to take a broad and multi-faceted perspective to explore help-seeking.

1.5.2.2   Sexual healthcare in Britain: a brief history and current provision

Descriptions of symptoms consistent with current pathologies of STIs can be found in ancient and medieval history, in the bible and in Chinese scriptures (Talukdar, 2012). Clinical diagnosis and treatment of STIs is vital for the control of infections and countering unmet need and there have been attempts to control and contain STIs and genito-urinary symptoms for as long as observable symptoms have been recognised. Medical care for venereal disease (VD) was formalised in the sixteenth century as a multi-level network of services with large royal hospitals charging patients for care (Siena, 2004 p6) and those who could not afford hospitalisation relying on workhouses and re-purposed leper houses (Siena, 2004 p6). Charities working in private hospitals could also have delivered VD care but many chose to exclude venereal patients on the basis of morality (Siena, 2004 p3). The London Lock Hospital was established in 1746 (Bettley, 1984; 'London Lock hospital records (archival collection description)', 2015) as the first voluntary VD clinic. 'Lock' is thought to refer to isolation and containment and lock hospitals played a role in treating, housing and rehabilitating 'penitent' women ('London Lock hospital records (archival collection description)', 2015), suggesting a moral as well as medical function of these early healthcare services. Patients with VD were labelled as 'foul' (Siena, 2004 p15) and segregated from other 'clean' patients in specialist 'foul wards' (Siena, 2004 p12); stigma already associated with the disease was reinforced and potentially exacerbated by this social label, and shame dominated medical discussions about causes and treatment options (Hall, 2001 p120; Siena, 2004 p31;36).

VD care developed over the centuries with advancements in biomedical sciences and medical technologies contributing enormously both to the identification of causative microorganisms towards the end of the 19th century and the

development of effective treatments and cures including antibiotics and anti-virals. However, many infections remained untreated because treatment facilities were not fit for purpose; treatment was not covered under National Insurance provision and so there was still a fee associated with treating STIs (Adler, 1980). A Royal Commission was appointed in 1914 to investigate the prevalence of venereal disease and provisions for diagnosis and treatment and recommended:

> *It is of the utmost importance that this institutional treatment should be available for the whole community and should be so organised that persons affected by the disease should have no hesitation in taking advantage of the facilities* (as cited in Hall, 2001 p126)

The Public Health (Venereal Diseases) Act of 1917 ('Venereal Disease Act, 1917: prohibition of treatment of venereal diseases by unqualified persons, and the advertising of remedies', 1917) formalised this and other recommendations around free treatment at the point of access, confidentiality and non-coercion in VD care (Evans, 2001 p238 ; Hall, 2001 p127) through publicly-funded VD treatment centres ('The Report Of The Royal Commission On Venereal Diseases (Continued)', 1916; Adler, 1980; Catterall, 1980). The VD Act also recognised the 'moral stigma' of these diseases, and the fact that treatment was often 'unduly delayed' ('The Report Of The Royal Commission On Venereal Diseases (Continued)', 1916).

A more comprehensive and coordinated service for VD was consolidated through the establishment of the NHS in 1948 and run locally by regional hospital boards and governors (Hall, 2001 p132). The term 'venereal disease' was replaced by sexually transmitted disease in the 1970s (Evans, 2001 p237) and more recently sexually transmitted infection to account for asymptomatic infection or infection that does not cause disease (American Sexual Health Association, 2010). VD clinics became known as Genitourinary Medicine (GUM) clinics and more recently individual clinic names have been chosen as a more discreet alternative to reduce the stigma of attending.

England's first National Strategy for Sexual Health and HIV (Department of Health, 2001) aimed to widen access to STI healthcare; it included provision for services outside of specialist settings, improved geographic coverage of STI healthcare, increased accessibility to GUM clinics and the establishment of the national Chlamydia Screening Programme (Adler *et al.*, 2002). Until this point, almost all STI testing took place in GUM clinics (Low, 2002). The national strategy delineated sexual healthcare provision into different types: specialist (GUM) clinics are 'Level 3' services and diagnose the majority of STIs (Public Health England, 2014), primary care with expertise or enhanced services relating to STIs are 'Level 2' and general practice provides basic sexual health service provision and are designated 'Level 1.' More recent guidance utilises symptoms as a factor that determines sexual healthcare requirements: 'symptomatic' patients are recommended to be examined whereas 'asymptomatic' patients can be tested without a physical examination (Medical Foundation for HIV & Sexual Health (MedFASH) on behalf of British Association of Sexual Health and HIV, 2014).

In the national strategy for sexual health and HIV (Department of Health, 2001), a 48-hour access target was imposed to prevent delays in accessing care once professional help had been sought. Services were expected to provide appointments within 48 hours of initial contact by the person. This was scrapped in 2011 (Information Standards Board for Health and Social Care, 2011) but reinstated in 2014 (Medical Foundation for HIV & Sexual Health (MedFASH) on behalf of British Association of Sexual Health and HIV, 2014) after a national audit suggested access had worsened since 2011 (Prescott, Hayden and Foley, 2015). Furthermore, £200 million was cut from the public health budget in 2016 resulting in an estimated £40 million less spent on sexual health and there is concern this will exacerbate issues surrounding access and uptake of these services and lead to an increased prevalence of STIs in the population (Robertson *et al.*, 2017b). Some clinics have already closed or merged with other services, there are reduced opening hours and fewer staff (including cutting sexual health advisor roles in some clinics completely).

A report by the King's Fund (Ibid) suggests these cuts to sexual health services are putting patients at risk due to issues with accessing services and quality of patient care and point out that financial pressures on the NHS will continue.

Despite huge changes in social norms and sexual healthcare policies, GUM clinics currently remain accessible without referral from another healthcare professional, with no prescription charges for STI treatment (as is usually the case for NHS-prescribed medicines in England) and services are confidential. These tenets of sexual healthcare reflect the stigma associated with STIs and that barriers to services could contribute to a reduction in individual and public health benefits sexual healthcare services are able to deliver.

Self-sampling and self-testing for STIs including HIV is becoming more and more common, enabling STI checks to be conducted away from healthcare services and by lay individuals. Online sexual health service provision is now well established in Britain enabled by increasing digital literacy, availability of technology and the NHS as the main service provider (Wellings, Mehl and Free, 2017). With increasing financial pressures, sexual health commissioners are shifting the management of some patients (e.g. asymptomatic quick check cases) to online pathways negating attendance at a service and removing the opportunity for a physical examination.

Sexual healthcare provision has evolved in response to the changing nature of STI epidemics, advances in diagnostic technologies, patient need and socio-political factors which will continue to influence the sexual health services of the future. This thesis is written 100 years after the Venereal Disease Act was passed ('Venereal Disease Act, 1917: prohibition of treatment of venereal diseases by unqualified persons, and the advertising of remedies', 1917) and despite significant progress in service delivery, some deeply entrenched issues around STI care remain, particularly around STI stigma and reluctance or delay in care-seeking. It is the lack of progress in social aspects of sexual health that have resulted in the conception

and need for this study at all and it is time to address these long-neglected aspects in the quest to reduce untreated infection and improve sexual health.

1.6 Introduction to the research paper

The paper that follows is a debate article which consolidates the background literature on STIs and care-seeking and applies these to the practical problem of untreated STIs as the key public health issue of this thesis. I make the case for taking a broader research perspective in terms of the concepts examined (exploring non-attendance behaviour as part of care-seeking), the disciplines used (integrating biomedical and sociological perspectives), the type of sample (recruiting participants from non-medical settings) and advocate for methodological innovation to expand knowledge of untreated STIs. I highlight the need to link individual experiences with broader population patterns and in doing so, provide the rationale and justification for the approach used in this study.

This thesis does not contain a systematic review as my aim was to synthesise different bodies of literature to build a conceptual platform to support each paper through critical engagement with relevant literature. However, I wanted to write a paper to set the scene for this research, highlight some of the issues I had come across in the literature and make the case for this work outside the boundaries of the PhD process.

1.7 Research Paper: Debate article

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SECTION A – Student Details

Student	Fiona Mapp
Principal Supervisor	Ford Hickson
Thesis Title	Sexually Transmitted Infections: A Mixed Methods Study of Stigma, Symptoms and Help-seeking

<u>*If the Research Paper has previously been published please complete Section B, if not please move to Section C*</u>

SECTION B – Paper already published

Where was the work published?	BMC Health Services Research		
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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	FM conceived the idea for this article in conjunction with KW, CM and FH. FM wrote and edited all drafts with critical input from FH, CM and KW. FM decided when and where to submit the paper and lead on all aspects of the submission process. All authors read and approved the final manuscript.

Student Signature: ▮▮▮▮▮▮   **Date:** 14/07/17

Supervisor Signature: ▮▮▮▮▮▮   **Date:** 14/7/17

DEBATE

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Understanding sexual healthcare seeking behaviour: why a broader research perspective is needed

Fiona Mapp[1]* , Kaye Wellings[1], Ford Hickson[1] and Catherine H. Mercer[2]

Abstract

Background: Despite effective and accessible treatments, many sexually transmitted infections (STIs) in high-income countries go untreated, causing poor sexual health for individuals and their partners. Research into STI care has tended to focus on biomedical aspects of infections using patient samples and prioritised attendance at healthcare services. This approach overlooks the broader social context of STIs and healthcare-seeking behaviours, which are important to better understand the issue of untreated infections.

Main body: This paper is structured around three main arguments to improve understanding of help-seeking behaviour for STIs in order to help reduce the burden of untreated STIs for both individuals and public health. Firstly, biomedical perspectives must be combined with sociological approaches to align individual priorities with clinical insights. More research attention on understanding the subjective experiences of STI symptoms and links to healthcare-seeking behaviour is also needed. Secondly, a focus on non-attendance at healthcare services is required to address the patient-centric focus of STI research and to understand the reasons why individuals do not seek care. Finally, research using non-patient samples recruited from outside medical contexts is vital to accurately reflect the range of behaviours, beliefs and health issues within the population to ensure appropriate and effective service provision. We suggest piggy-backing other research on to existing studies as an effective way to recruit participants not defined by their patient status, and use a study recruiting a purposive non-patient sample from an existing dataset – Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) as an illustrative example.

Conclusion: STIs are common but treatable, however a range of social and cultural factors prevent access to healthcare services and contribute to the burden of untreated infection. Different conceptual and empirical approaches are needed to better understand care-seeking behaviour and reduce the gap between social and biomedical advancements in managing untreated infection.

Keywords: Non-attendance, Sexually transmitted infections, Sexual health clinics, Non-patient samples, Natsal-3, Irving Zola

Background

Sexually transmitted infections (STIs), acquired through genital contact, have deleterious effects on an individual's sexual and reproductive health and well-being and present a persistent public health problem. Prevention efforts are often thwarted by the complexity of factors involved in changing sexual behaviour [1], the stigmatization of both having STIs [2] and using sexual healthcare services [3] and moral opposition to teaching sex and relationships education in schools [4]. There remains a lack of evidence about the effectiveness of interventions to reduce STI prevalence, and cost effectiveness of STI prevention is a barrier to political support [5]. The World Health Organization estimates that every day, more than 1 million people acquire a STI [6]. It is difficult to quantify the proportion of these infections which go undiagnosed and untreated, which is part of the problem of understanding and managing untreated infections. Empirical studies suggest that less than 50% of untreated chlamydia

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spontaneously resolves without treatment [7, 8] while several viral STIs including HIV, herpes, hepatitis B and human papillomavirus are incurable. Modelling studies have estimated that if sex partners are not treated simultaneously, 19.4% of patients diagnosed with chlamydia and 12.5% of those with gonorrhoea will be re-infected [9]. Untreated infections can cause long-term health problems exacerbating the burden of STIs globally. Herpes and syphilis can increase the risk of acquiring HIV by three-fold, chlamydia and gonorrhoea have been linked to pelvic inflammatory disease which in turn can result in infertility, particularly if symptomatic [10] and human papillomavirus causes 528,000 cases of cervical cancer annually [6, 11]. Chronic pelvic pain, ovarian abscesses and ectopic pregnancies are not uncommon sequelae [12]. Mother-to-child transmission of STIs such as syphilis can result in stillbirth, neonatal death, prematurity, congenital deformities and neonatal infections including pneumonia and conjunctivitis [6]. STI surveillance in high-income countries is well established and national monitoring agencies regularly report infection prevalence, trends over time, clinic attendances [13] and undiagnosed HIV [14] (estimated using models based on population surveillance data e.g. [15] and surveys of children, pregnant women and high risk groups [16]). STIs have considerable economic impact on healthcare systems with recent estimates suggesting an annual cost of almost $16 billion in the USA [17]. Projected costs of STIs excluding HIV in the UK between 2013 and 2020 are more than £6 billion ($7.7 billion) based on access levels at the time [18], however severe funding cuts have led to reduced service accessibility [19]. Given that the potential physical, economic and emotional burden of STIs is considerable and that effective treatments for the majority of infections exist and are free at the point of access in high-income countries, an important question remains unanswered: how does individual sexual healthcare-seeking behaviour contribute to untreated STIs?

Asymptomatic infection is a major contributory factor to untreated infections. One study of 18–29 year olds in Louisiana estimated that 45% of all gonorrhoea and 77% of all chlamydia cases were never symptomatic and lack of symptoms was the most important reason for infections going untreated [20]. Similar results have been reported in other populations (e.g. [21]). These findings emphasise the importance of STI screening programmes as part of national STI management strategies. However, the problem of untreated STIs goes beyond infections which do not produce symptoms, and other aspects of STIs must be addressed to help reduce prevalence and improve sexual health and wellbeing. Mercer et al. found symptomatic individuals attending specialist sexual health clinics in England were significantly more likely to have an acute STI diagnosed than those not reporting

any symptoms [22], highlighting the need to better understand experiences of STIs. Further discussion of asymptomatic STIs is beyond the scope of this debate.

In the UK, STIs can be diagnosed and treated in specialist sexual health clinics (or genito-urinary medicine (GUM) clinics), primary care (General Practice surgeries), antenatal services, and other community settings [23–25]. Service provision has been broadened with initiatives such as the National Chlamydia Screening Programme [26] and the development of self-sampling and self-testing kits for use at home, such as the SH:24 project [27]. Accessing these services requires individuals to seek care or at least engage with opportunistic STI testing. Here we focus on seeking care in response to STI associated symptoms. We start by arguing that STI research must expand beyond biomedically dominated perspectives of infections to encompass socially oriented experiential aspects of genito-urinary health and care-seeking, using symptoms as a key example. This informs our second line of argument that focussing on non-attendance as part of sexual healthcare-seeking is important to understand why some people do not use available services. Finally we suggest that sampling strategies for STI research should be inclusive of people who do not access health services. We review different sampling approaches that facilitate non-patient sample recruitment and discuss 'piggy-backing' research on to existing studies as an under-used option to recruit participants independently of healthcare settings.

Combining biomedical and sociological lenses to prioritise symptom experiences in research

Research on genito-urinary conditions tends to be biomedically framed with a focus on developing effective treatment regimens and identifying risk factors to help target health promotion initiatives [5, 11, 21]. Although essential to preventing STIs, biomedical perspectives overlook the meaning and significance of symptoms and diagnoses to individuals, the sense-making processes that take place in response to these experiences and the implications of being treated for a stigmatising condition. The biomedical dominance in this area of health research calls for balance with other perspectives to progress understanding about genito-urinary health issues and link understanding about diseases, people and health care services.

Medical sociology has reframed health and illness research topics to focus on the experiential, social and lived realities adding a variety of lenses through which to examine phenomena [28]. The intense research efforts around HIV have shown the disease has both social and biomedical significance [29] but the two perspectives have not been well-integrated. The biomedicalisation of HIV has neglected the social significance of prevention,

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treatment and care [29] and this trend has spread into STIs. The gap between knowledge gained and direct impact on health of individuals and populations will continue to expand unless social research on genito-urinary conditions is considered in conjunction with biomedicine. There is a need to unite the physical and social body in the context of healthcare-seeking, in line with recent calls for more emphasis on the person with the medical problem, not the clinical problem itself [30].

Irving Zola started linking symptom experiences with what individuals did about them by rejecting common assumptions pertaining to health issues and service use [31]. His three explanations of the relationship between symptoms and care-seeking are well known and have been widely applied to health and social research. Firstly, Zola suggested that people will have a symptom(s) of something the majority of the time but most are considered too minor to warrant medical treatment; secondly, that the seriousness and frequency of symptoms do not predict attendance (highlighting the discrepancy between medical and social interpretations of bodily experiences); and thirdly, that most people make rational decisions about seeking, delaying or not attending care based on their own belief system and internal values (ibid). Zola was interested in the point at which symptoms could no longer be tolerated physically, personally and socially resulting in help-seeking behaviour. His work emphasises the importance of experiential aspects of conditions and he noted that *"the 'illness' for which one seeks help may only in part be a physical relief from symptoms"* ([17] p.679). This suggests that the need for a combined approach to understand the underlying pathogen as well as the social implications of the disease are well established but poorly implemented in relation to sexual health.

Experiences of disease and illness are broader than those observed in a clinical environment. The lived experience of a health condition is not the same for everyone affected by it and experiences may contradict population patterns and statistical associations, especially of risk factors. There have already been calls for an increased focus on personal experiences and data on the lived realities of health conditions [32]. Additionally, proposed changes to the International Classification of Diseases (ICD-11) emphasise the importance of subjective experiences of patients, embodying a more integrated approach to sexual health practice [33], which research should reflect. This turn towards individualising health experiences helps capture the diversity of health and illness instead of homogenising the population into a series of risk-factors or sub-groups based on behaviour or other attributes. Adding a sociological lens to biomedical insights about STIs helps expand perspectives and foreground key social factors including lay explanatory frameworks of infections and symptoms, and situated rationalities in healthcare decision-making. Combining perspectives helps align the priorities of patients and providers to better address STI management.

Symptoms associated with some STIs are a key aspect of the lived experience but are frequently overlooked in STI research because of the high prevalence of asymptomatic infection [22, 20] and focus on other factors such as sexual risk behaviour [21]. Symptoms can trigger help-seeking [34, 35] and have been reported as the most common reason for attendance at healthcare [36]. Symptoms are still routinely used to triage patients in sexual health clinics and form part of a sexual history taken by healthcare professionals during clinical consultations [37]. Certain symptoms can disrupt ideas of the self, causing feelings of self-disgust, loss of innocence and shame [34, 38]. Disruption and discomfort in day-to-day life form part of the burden of STIs as well as the more long-term harmful consequences. Symptoms, such as ulcers, painful or frequent urination and itching are often not recognised as associated with STIs and misattributed to other causes such as yeast infections or trauma [35, 39]. This trend is also reflected for gynaecological cancer [40] suggesting overlapping symptomatology combined with lack of understanding about how genital sensations and symptoms are made sense of may represent additional barriers to seeking care and receiving treatment. There is a need to improve understanding of symptoms and identify which parts of these experiences are important to individuals and their preferences for clinical intervention (if any).

A focus on non-attendance

Given that clinical evidence alone is insufficient to improve sexual health and individual preferences for healthcare are becoming a priority [30], we also need to consider those who do not attend services. This is not a common approach, as health research tends to use patient populations and report the experiences of those who attend services. Zola's work [31] exemplifies the patient-centric focus of studying help-seeking and treatment issues. Non-attendance or decisions to abstain from medical care are less well researched but important in the context of untreated infections. Does non-attendance equate to an absence of help-seeking or are choices about sexual healthcare bound up with other social, psychological, cultural and biomedical factors that warrant further investigation, as Zola hinted at but did not fully explore [31]?

An alternative approach in healthcare research is asking participants hypothetical questions about their behaviour such as that posed in Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3): *"If you thought that you might have an infection that is*

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transmitted by sex, where would you first go to seek diagnosis and/or treatment?" ([20] p.77). This question highlights the inherent expectation of a link between infection uncertainty and seeking diagnosis and/or treatment. Here we see the research process itself reinforcing the privileging of professional perspectives. There is a wealth of literature evidencing the discrepancy between aspirations or intentions to act and actual behaviour or action [41] and requires participants to project themselves into a different situation and imagine how they would respond, which may be influenced by social desirability bias. Aspirational or hypothetical questions have only limited potential for understanding the individual and social processes that take place to make sense of experiences and seek healthcare.

Care-seeking is a well-documented, complex social process involving symptom perception, interpretation, appraisal and decision-making linked to the ability and motivation to access healthcare [42]. The end-point of care-seeking is often viewed in terms of attendance at healthcare services or resolution of a clinical issue [43]. STI stigma is implicated in sexual healthcare-seeking and has been cited as the most significant barrier to accessing sexual health services [44]. Clearly not everyone with a need for care reaches a service [42] which is a major aspect of untreated STIs, but the social processes of not attending, or avoiding seeking care, have been overlooked in favour of reporting outcomes of care-seeking behaviour. In part, the lack of critical examination of not seeking care results from an over-reliance on service-user populations in health services research and the difficulty of identifying individuals who have a need for care but who have not attended services. This mis-represents the population in need of care by privileging the characteristics, needs and opinions of those who have attended services over those who have not. Little progress has been made in examining symptom experiences and care-seeking responses outside of medical settings. We therefore need new approaches and different types of data to investigate stigma mechanisms and the social context of non-attendance behaviour, from participants recruited independently of healthcare services.

Approaches to recruiting a non-patient sample
Much of the research on STIs and healthcare-seeking to date has used samples drawn from service-user and patient populations recruited through medical settings (e.g. general practice or sexual health clinics) and/or by using hospital records. The attractions of such designs are apparent. There is a ready-made sampling frame of registered patients, attendances within a given time frame or diagnoses of a specific condition. Service-user samples are usually simple to identify and recruit, especially if

there is an existing collaboration between service and research teams. Services may also hold other linkable medical records, which, with appropriate consent, can be used for research. Data collection can occur in the clinical setting whilst the person is waiting for their appointment or as a follow-up after they have seen a healthcare professional. However, the setting of data collection is known to influence the type and nature of the data produced, particularly for qualitative studies [45]. Medical settings tend to be formal, structured environments with inherent power relations between patient and professional, which may extend to the researcher and result in an implicit social hierarchy. Participants are viewed first and foremost as patients as well as informants on the research topic and this necessarily influences the data produced.

Using patient samples focuses exclusively on people who attend healthcare services who are known to differ from those who do not attend care [46], impacting on the data generated. Non-patient samples are vital for understanding unmet needs as well as service use and should be used more widely than they currently are. Sampling a more diverse range of individuals with healthcare needs is necessary for public health to enable better descriptions of health issues, behaviours, attitudes and decision-making. A non-patient sample is likely to mean different things in different contexts and for different research studies, as the vast majority of people living in high-income countries have experienced some clinical interaction during their life. Research looking at selective care-seeking or avoidance of specific care settings will need to accommodate the diversity of care-seeking behaviour and use innovative and opportunistic methods to define and recruit the sample.

Non-patient samples are under-used partly because of the difficulties in defining the sampling frame. The denominator may be the whole population or it may be a sub-group with a specific characteristic but if the data are not routinely collected along with contact details, the sub-group is less visible to researchers and recruitment becomes more difficult. Non-patient samples when they are used, are often convenience samples drawn from community settings such as sports and social clubs (for example Bourne and Robson's study [47] exploring experiences and social constructions of safe and unsafe sexual behaviour). Targeting events including Gay Pride as well as gay clubs and bars facilitated recruitment of participants for a cross-sectional annual behavioural survey of gay men [48, 49] and online recruitment is also a common approach [50]. Methodologically this enables data collection to take place away from a healthcare environment and can give useful insight into the topic but these sampling approaches are not systematic as they select the most accessible participants who often have a

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pre-existing interest in the topic. When considered in the context of the hierarchy of data debates in social science research [51], convenience samples lack credibility when compared to purposive, theoretical and probability samples [52].

Recent innovations in sampling techniques mitigate some of the limitations of convenience samples and balance efficient recruitment with sample representativeness. Two techniques enable non-patient samples to be recruited through approaches seeking to approximate probability sampling. Firstly respondent-driven sampling combines snowball sampling with a mathematical model that weights the sample to compensate for the non-random approach. It also introduces statistical rigor by using longer recruitment chains and by imposing recruitment limits [53, 54]. Respondent-driven sampling has been widely used for biological and behavioural studies of HIV worldwide [55] but applications of this method are limited as the population need to be socially networked with clear eligibility criteria, and equilibrium (ensuring bias is not introduced because of the snowball sampling) must be achieved [56]. Secondly, time location sampling is useful for accessing hard to reach groups by mapping locations they frequent and randomly selecting the day, time and place to systematically select participants. This method was used effectively to estimate the prevalence of STI-associated symptoms and care-seeking patterns in street-based surveys in Iran [57], taking into account cultural sensitivities and the absence of valid data about STIs. However, time location sampling is limited to people attending venues in the sampling frame during the sampling period with associated resource implications for the study [58]. Whilst a welcome addition to the toolbox for sampling different types of populations, both of the sampling methods discussed are for quantitative data collection and rely on social interaction – either through peers or at a venue. Additionally they rely on the key characteristics of interest being visible and/or easily disclosed by the population. Therefore neither approach is suitable for targeting sensitive issues in a diverse sample from the general population.

As there are limited options for sampling people who are not defined by their service-user status, there is a need for methodological innovation to create other opportunities for sampling and recruiting participants with potential unmet care needs outside of healthcare settings. One alternative approach is 'piggy-backing' additional research studies on to existing surveys of the general population (or other sub-samples) to add value and capitalise on data already collected. In this way, theoretical and purposive qualitative samples can be drawn using specific characteristics identified in the earlier survey. Providing the necessary ethics approval and governance protocols are put in place, it is possible to

follow-up with people already recruited for a study. There is a growing trend towards data re-use and secondary analysis of existing data sets facilitated by increasing opportunities to access and link data through the UK Data Archive [59]. Secondary analysis of available datasets which include relevant variables is an efficient use of existing data and can produce additional insights and add value to the original study. Myers [60] built a theoretical framework of reasons for STI testing from existing qualitative research to inform analyses of publically available data from a nationally representative survey of adolescent health, with participants recruited from U.S. schools. The findings confirmed the importance of STI symptoms as well as concerns about recent sexual behaviour as predictors of STI testing in young women, without needing to collect more data. Similarly, van Bergen [61] used sexual health questions embedded within the second Dutch National Survey of General Practice to describe the prevalence and distribution of STIs, symptoms and healthcare-seeking behaviour in the Netherlands. Both Myers [60] and van Bergen [61] used non-patient samples to quantitatively explore issues related to STIs in nationally representative data, but explanations for these behaviours and experiences from those participants who reported them are missing in single method approaches. To assess the influence of non-help-seeking behaviour on untreated STIs, we need to understand the importance of socio-cultural factors in care-seeking, the prevalence, interpretation and management of symptoms and reasons for not seeking care.

We took a different 'piggy-backing' approach to expand our conceptualisations of care-seeking for STI symptoms using a sequential mixed methods study design [62]. Analyses of data from the third British National Survey of Sexual Attitudes and Lifestyles (known as Natsal-3) [63, 64] produced population estimates of the variables of interest and helped identify and recruit a sample for follow-up interviews. We therefore identified a sampling frame for follow-up explanatory qualitative research using quantitative variables to identify characteristics of interest amongst survey participants, enabling us to recruit the same participants into a second wave of data collection and produce linked datasets. Natsal-3 is a probability survey and asked questions about STI symptoms and care-seeking behaviour as well as detailed demographic and other behavioural and attitudinal questions relating to sexual health [65]. We sampled individuals who reported one or more STI symptoms and had never attended a sexual health clinic [66]. Specifically we were able to access individuals with potential care needs and explore care-seeking responses using linked survey data and semi-structured interview data to examine areas of convergence, divergence and silence [67]. We were also able to investigate men's experience of genito-

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urinary symptoms which have been noticeably absent from the literature. Similar studies using linked data from national surveys have been carried out such as a qualitative study about growing up in step-families with participants selected from the British birth cohort study of 1958 [68].

Both of these study designs involved sequential data collection and were opportunistic uses of existing data to explain earlier findings and enrich our knowledge of the specific social phenomena being studied. More research opportunities may be created through collaborations with other national observational studies or existing sampling frames of specific populations. Additional studies using innovative sampling methods are likely to improve the representation of historically under-researched populations and help reassure potential participants of the importance of the research, encouraging participation. Researchers must be aware of the possibility of research fatigue in participants and disengagement from the process, or the development of 'expert' participants who have significant experience of taking part in research as these participant characteristics will affect the data produced. Furthermore, nesting research in existing studies can result in a time lag between different data collection phases causing high levels of participant attrition, and the sampling frame for subsequent studies is restricted to the variables included in the original dataset.

Clearly there will be specific ethical, governance and access issues to think through for using piggy-backing approaches, but the time and resource savings realised in our approach to researching people with a need for care who do not attend services, outweigh limitations. The wealth of robust data we have from national surveillance and surveys [60] could and should be capitalised on to advance our understanding of healthcare issues outside of medical settings and facilitate more sociological investigation of these phenomena. While exploring alternative sampling strategies is vital to drive progress in understanding issues pertaining to healthcare-seeking and untreated STIs, work to convince funding bodies is still needed to prioritise and invest in methodological innovation and non-patient sampling frames to facilitate empirical research.

Conclusions

STIs are common and persistent health issues requiring multi-perspective insights to increase diagnosis and treatment rates and help tackle current global trends. There is an urgent need to improve understanding about STI symptoms and the social and cultural factors governing care-seeking behaviour, in conjunction with biomedical knowledge of pathogens. These factors are not well understood due to the fragmentation of STI research and the lack of collaboration between biomedical and social scientists to address the gaps in knowledge. There is still an over-reliance on patient samples but opportunities to innovate and generate data outside of medical settings using participants not primarily identified by their patient status will help to understand the phenomena of untreated STIs in the context of care-seeking behaviours. Piggy-backing approaches offer promising new ways to sample participants whilst minimising additional resource implications and mixed methods studies in particular offer opportunities to gain comprehensive insights into issues around STI care using linked data.

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1.8   Aim and research questions

My aim and research questions for this thesis were developed to synthesise the three main concepts of STI stigma, genito-urinary symptoms and help-seeking as the earlier exploration of theoretical and empirical literature (section 1.5) showed potential overlap but very little synthesis across the three aspects in relation to addressing public health needs. They build on observed phenomena as described in the Origin of this study (section 1.2) and therefore have empirical importance, refined through locating these ideas within the public health literature.

The aim and specific research questions of this study are published in the study protocol in the methodology chapter (chapter 2). I aim to explore perceptions and social representations of STIs and how these influence lived experiences of genito-urinary symptoms and care-seeking responses. I focus on non-attendance behaviour in women and men in Britain to address the public health issue of untreated STIs and unmet sexual health needs. My main research questions are:

1. Can perceptions and social representations of STIs help explain genito-urinary symptom experiences and care-seeking behaviour?
2. What is the role of stigma in genito-urinary symptom perception and care-seeking?
3. How do people interpret genito-urinary symptoms?
4. Why do some people with genito-urinary symptoms not seek care at sexual health clinics?

These four empirical research questions each focus on expanding knowledge relating to the main concepts of this thesis, addressing specific gaps identified in the literature. They determine the findings presented in the empirical chapters of this thesis (chapters 3-5).

After the study protocol had been published, and inspired by attending and presenting at the second Mixed Methods International Research Association

Conference in August 2016 (see conference abstract in Appendix N, p.365), I added a fifth methodological research question to clearly position this work as a mixed methods study and enable consideration of the integration of my survey and interview findings (Creswell and Plano Clark, 2011c). Whilst I understand the position of other mixed methods theorists who say there should be no mixed methods questions, only knowledge aims (Sandelowski, 2016), being explicit about my use of mixed methods has helped my own understanding of how this study fits into wider academic debates. Therefore my final research question is:

5. To what extent can survey and semi-structured interview data be integrated to explain, contextualise and extend findings about genito-urinary symptoms and care-seeking responses?

A personal aim of conducting this research study was to learn and apply the theory and practical approaches of the field of mixed methods research. I am keen to conduct high quality mixed methods research projects in the future and wanted to use my PhD as a learning opportunity to try out some of the 'tools.' By including a specific mixed methods research question, methodological issues are foregrounded in this study and not incidental or tangential to empirical outcomes.

1.9 Locating this study in academic disciplines

I have situated this work within the context of academic public health research. Public health is a multi-disciplinary area including and combining epidemiology, statistics, health economics, anthropology, sociology, geography, biomedicine, psychology, geography and health services research to address population health problems. My work reflects and builds on this diversity, drawing on the work of medical sociologists, considering the epidemiology and biomedical treatment of STIs and bringing in aspects of health services research to consider service use (and non-use). Public health is *"the science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised*

efforts of society" (The Faculty of Public Health 2010). I particularly like this definition as it seems to encompass the multi-faceted approaches to addressing health issues, incorporates well-being as part of health and explicitly mentions the role of society in shaping health. Unmet need is a key public health concern in relation to STIs representing risks to individuals and others in their sexual network. Public health looks at the health of the population and for me, it has always been important to connect population patterns with individual experiences, examining the different levels of a problem together to better understand social and health phenomena. I am not just viewing symptoms as possible indicators of disease but as an experience that individuals must manage. As I argued in the debate paper earlier in the chapter, STIs have been a heavily medicalised subject given the focus on treatment and I am keen to examine the social aspects of this health issue. A perspective article for the Lancet titled "Sexual science beyond the medical" chimes with the definition of public health that guides this thesis, and makes similar points about the imbalance of biomedical and sociological sexual health research (Fisher and Funke, 2016). The authors document the cross-disciplinarity of early sexual science research, describing the clinical framing of sexual science in order to establish authority and legitimacy but note that several researchers involved in this area argued that *"a clinical approach was too narrow to understand the complexity of human sexuality"* (Fisher and Funke, 2016, p. 840). Bloch, writing almost 100 years earlier proposed: "*Let us leave the hospital and the medical consulting-room; let us make a journey round the world; let us observe the sexual activity of the genus homo in its manifold phenomena, not as physicians, but as ordinary observers"* (Bloch 1909 cited in Fisher & Funke 2016). This is what I intend to do in this study.

Locating this research within the scope of public health allows me to combine different approaches and perspectives to address a persistent public health issue – unmet need of STI care. I pick up on the meaning of my findings and implications for public health policy and practice in the final discussion chapter.

1.10 Chapter Summary

I have used this introductory chapter to set out important ideas and approaches as well as my aim and research questions to take forwards in the rest of the thesis. By engaging critically with relevant theoretical and empirical literature and through writing the debate article, I became aware of many social aspects of STIs and symptom experiences which have been overlooked. I hope to combine biomedicine with sociological approaches in this thesis to improve understandings of care needs situated in socio-cultural contexts to contribute knowledge about these individual concepts and the broader public health issue of untreated STIs.

CHAPTER 2 METHODOLOGY

2.1 Chapter Overview

Having set out the core concepts in the previous chapter and highlighted what is
not yet known in relation to STI stigma, symptoms and help-seeking, I now present
my methodology. The methods I use respond directly to the needs of the research
questions which in turn reflect absences in knowledge in the wider literature and
observed practice. By using a mixed methods approach and including an explicit
data integration phase, I was able to capitalise on the benefits of each method,
collecting different types of data to enable different types of interpretations to be
made about the phenomena being studied. One of the main methodological
considerations of this work was examining experiences outside of medical settings,
which was facilitated by using a population approach.

Here I introduce and present two published papers: a study protocol and a
methodology paper describing the flash card activity. I include additional detail to
support the contents of each paper including a summary of pragmatism, the Natsal-
3 survey and highlight some of the methodological challenges of this study. I justify
my methodological approach and articulate specific ethical considerations of this
work.

2.2 Methodological background

2.2.1   Mixing methodologies: research theory and approaches

'Mixed methods research' is the term most commonly used to describe an approach
to create knowledge that considers multiple different theoretical and practical
perspectives and positions (Johnson, Onwuegbuzie and Turner, 2007). The word
'method' in this context is interpreted broadly and its use more akin to

'methodology' (Greene, 2006). A mixture of methods has been used in early social research projects. For example, John Snow used both hospital and public records to identify where the cholera outbreak began in Soho, London in 1854. He mapped deaths around Soho, investigated individual cases by interviewing family members about access to water and took samples of water from the Broad Street Pump which was eventually removed as a direct result of his investigations, halting the spread of cholera (Tuthill, 2003). Despite early applications of mixed methods approaches, mixed methods research as a distinct field was only formalised in the 1980s (Greene, 2008); as such, multiple definitions of 'mixed methods research' exist. A synthesis conducted by Johnson et al. (2007) produced a composite statement developed from definitions from 19 leading experts about what mixed methods research is. This widely used general definition states:

> *Mixed methods research is the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration* (Johnson, Onwuegbuzie and Turner, 2007, p. 123)*.*

This definition is based on five themes that emerged through analysis of the different understandings of mixed methods research which have provided a useful conceptual framework for me when considering the approach I have used in this study. The themes are: what is mixed, when/where, breadth, why, and orientation (Ibid). I elaborate on the core principles guiding this study in the protocol paper in this chapter. Sharlene Hesse-Biber captures the essence of the applied approach I have taken by stating mixed methods uses "*numbers as well as words to generalise and to contextualise findings that show the practical relevance of macro research findings at the micro level*" (Hesse-Biber, 2015, p. 2). I would add that insights from the micro level relate back to the macro showing how individual behaviours and experiences contribute to observed population patterns.

Mixed methods research is now widely recognised as the third major research paradigm alongside quantitative and qualitative research (Greene, 2008). The boundaries between quantitative and qualitative are becoming blurred and there are calls to dispatch the qualitative/quantitative divide altogether (Symonds and Gorard, 2009) in favour of an "'*organic' view of empirical research*" focussing on using the most appropriate methods and design to answer the research question(s) (Sandelowski, 2014, p. 6). This is the approach I have taken. Mixed methods is also seen as a creative approach to research that legitimates the use of multiple approaches in order to answer the research question(s) and expand understanding of the phenomena being studied (Johnson and Onwuegbuzie, 2004). Following what has been termed a "*quiet revolution*" (O'Cathain, 2009, p. 3) in health research, mixed methods approaches have been used to address a wide range of health-related topics. O'Cathain et al.'s (2007) review of health services research studies to understand why and how mixed methods is applied showed the most commonly used methods were surveys and interviews. Two-thirds of studies were classified as explanatory instead of exploratory and there were very few studies with a dominant qualitative component. This study is designed to be explanatory, using a survey to determine population patterns of the phenomena of interest (genito-urinary symptoms and help-seeking) followed by semi-structured interviews to help explain and extend survey findings and to demonstrate the composite experiences and behaviours captured in an aggregate format in the survey. There is a dominant qualitative component to enable exploration of stigma and to help contextualise population data using individual experiences as necessitated by the research questions. I describe the purposes of adopting a mixed methods approach in the study protocol paper but include and expand on the function of mixed methods study here, to facilitate later discussion (in chapter 6) about using mixed methods. This study combines methods for complementarity (elaboration and/or clarification – methods that address different aspects of the same issue), development of the other method and expansion to extend the breadth of inquiry and address different related questions (Greene, Caracelli and Graham, 1989).

- Complementarity – survey data are used to quantify the issue of genito-urinary symptoms and non-attendance behaviour in the population and semi-structured interviews address individual lived experiences and sense-making about these phenomena.
- Development – the sample for the semi-structured interviews is drawn from a sub-sample identified from survey responses, and the topic guide was designed to include the same symptoms as were included in the survey and specifically address gaps in understanding about some aspects of help-seeking behaviour that were not covered in Natsal-3 (e.g. attendance at GP).
- Expansion – semi-structured interviews focussed on exploring experiences of symptoms over time to understand the symptoms reported in Natsal-3 in context. Interviews also produced data on help-seeking responses to specific symptoms and the outcome of seeking care at different services.

I have drawn on different aspects of mixed methods theory to tailor the approach used in this study and by doing so hope to contribute to progression of the field of mixed methods research.

2.2.2   Pragmatism

Pragmatism is a common worldview associated with mixed methods research and has been described as the *"alternative paradigm"* (Greene, 2007) enabling methods from different paradigms to be mixed to incorporate the benefits of positivist and constructivist approaches to the research (Ibid). Pragmatism overcomes paradigmatic incommensurability and enables diverse views to be combined (Johnson and Onwuegbuzie, 2004), but its use in mixed methods research is contested (Hesse-Biber, 2015). It is not my aim here to document the development of pragmatism as a philosophy or to detail the relationship between pragmatism and mixed methods research as this has already been done effectively (Johnson and Onwuegbuzie, 2004; Biesta, 2010) and does not add to the empirical story of this thesis. Instead I will focus on what pragmatism allows me to do in this study.

A pragmatist worldview is problem-centred and focusses on the consequences of research and prioritises the research question (instead of the methods) (Creswell

and Plano Clark, 2011c, p. 41). Studies use diverse approaches and multiple methods as necessary to generate data about the problem, are oriented toward real world practice (Ibid) and are committed to democratic values and progress (Tashakkori and Teddlie, 2010, p. 811). Pragmatism offers *"a set of philosophical tools"* (Tashakkori and Teddlie, 2010, p. 97) for addressing problems and encourages epistemological and methodological flexibility (Greene and Hall, 2010). In this thesis, I bring together different world views to generate findings which enable me to fulfil the aim of exploring individuals' representations of STIs and stigma and how they influence experience of genito-urinary symptoms and help-seeking behaviour.

2.2.2.1 Mixing post-positivism and interpretivism

This study combines post-positivism and interpretivism at the philosophical level, survey and semi-structured interviews as methods, and quantitative and qualitative data to answer the research questions posed.

Natsal-3 draws on post-positivism predicated on objective, unbiased approaches and a singular reality. The survey is delimited to a set of variables measured empirically (Natsal-3, 2013) despite efforts by the Natsal-3 team to incorporate and accommodate subjective experiences (personal communication with Prof. Kaye Wellings, LSHTM, 14.03.17). This approach is entirely appropriate for achieving the main objectives of Natsal-3 to examine the interplay between variables related to sexual attitudes and lifestyles (Natsal, 2015) (and the quantitative component of this study) and comparable with other survey studies (Heeringa, West and Berglund, 2010). However, a post-positivist approach does make certain assumptions about the phenomena being studied. Framed by *a priori* theory informed by biomedicine and epidemiology, Natsal-3 considers genito-urinary symptoms as clinical signs of STIs and asked a survey question about symptoms to understand symptomatic STIs better (personal communication with Dr. Nigel Field, UCL, 1.10.16). Another assumption the survey made was about the rationality of healthcare attendance

and prioritising health above other aspects of individuals' lives, a logic that has been refuted by sociological approaches that focus on lay values and beliefs (Buetow, 2007). These post-positivist assumptions informed my initial thinking and approach to the design, sampling and content of semi-structured interviews. I thought I was investigating clear-cut STI symptoms in a population who had not attended a sexual health clinic (and were therefore 'non-attenders').

The interpretive approach, rooted in phenomenology (Green and Thorogood, 2009, pp. 13–14) that underpinned the semi-structured interviews, contrasts with post-positivism and the survey data collected. Interpretivism is based on understanding people's interpretations of reality and the meaning of phenomena (such as symptoms and help-seeking). Interpretative approaches are subjective, encompass multiple realities, include inductive processes and allow for value judgements (Ibid). Very early on in the interview data collection phase, Natsal-3 assumptions about the nature of symptoms and help-seeking were disrupted by participants' accounts, and I was forced to reflect on my initial interpretations and assumptions. The neat categorisations of genito-urinary symptoms being those of STIs and people who had not previously attended a sexual health clinic being non-attenders became increasingly 'messy', and my findings developed as a result. I did not have a 'non-patient sample', as everyone reported some form of engagement with healthcare over their life course which enabled me to think more broadly about care-seeking responses. Neither was it my place to determine through the interviews whether participants' symptoms were indicative of STIs, which leads to greater focus on the lived experiences and sense-making around their symptoms. Thus, different world views are associated with different parts of the study, and by being explicit at this stage I hope to eliminate subsequent obfuscation of the nature or purpose of each type of data. In this way, pragmatism acts as an *"umbrella paradigm"* (Creswell and Plano Clark, 2011c, p. 78) for this study.

Being explicit means adding more precision to my descriptions of research processes. Instead of using the general terms 'quantitative' and 'qualitative', which tend to amalgamate a whole collection of research components and associated assumptions about design, methodology, epistemology and ontology (Tashakkori and Teddlie, 2010, p. 98), I provide exact descriptions of what I did as far as possible. For example: I conducted semi-structured interviews using a topic guide with four domains, instead of referring to this research activity as the qualitative strand of the study. This approach aligns with a more general movement in mixed methods research away from using unhelpful labels and encouraging specificity in describing what was done (Sandelowski, 2014). Occasionally it was necessary to use the terms 'quantitative' and 'qualitative' (see study protocol paper) for my study to be understood and to conform with expectations from different research communities. Additionally, the definition of mixed methods research I have used to guide this study (see study protocol paper) states that one of the core components is the collecting and analysing of both quantitative and qualitative data in one study (Creswell and Plano Clark, 2011a).

2.2.3   Integration

Integration is a core part of mixed methods research and central to the approach I have taken in this mixed methods study, as detailed in the study protocol paper. How, when and why to combine numerical and text data are a key area of innovation in mixed methods research; there are many different interpretations, although integration processes are still under-theorised (Sandelowski, 2014). The 'integration challenge' has been described as *"the imperative to produce a whole through integration that is greater than the sum of the individual qualitative and quantitative parts"* (Fetters and Freshwater, 2015, p. 116). Mason argues for a 'meshing' of methods and 'linking' of data in looser formulations to acknowledge creative tensions between different types of data. Her approach aims to create multi-dimensional explanations of social experiences rather than enforced data

integration. Sandelowski (2014) builds on ideas of linking qualitative and quantitative elements by placing them in juxtaposition to see if they confirm, refute, extend or modify each other. She differentiates this from 'actual' integration where qualitative and quantitative elements are assimilated into each other either by converting one form of data to the other or by using findings as placeholders for each other. 'Synergy' is also a commonly used term to focus on the added benefit of including more than one type of data (Fielding and Fielding, 2008; Fetters and Freshwater, 2015; Hesse-Biber, 2015) and Bazeley adopts abduction as a theoretical tool to consider how different parts of the study inter-relate in order to answer the questions posed (2006). Guest (2013) attempts to overcome simple classification schema by suggesting a focus on the timing and purpose of data integration and O'Cathain (2010) differentiates between the timing of different integration techniques that can occur at the analysis or interpretation stage of a research study.

There are many theoretical perspectives about integration in mixed methods research but relatively few examples of how you actually 'do' integration. Creswell and colleagues take a prescriptive view based on the typology of study designs they developed (Creswell and Plano Clark, 2011). They suggest integration occurs at three different levels: at the design stage, through the methods and in interpretation and reporting of findings (Fetters, Curry and Creswell, 2013). The survey and semi-structured interviews in this study are linked methodologically. Using Fetters et al. (Ibid) terminology, I have integrated through 'connecting' as my sample for the interviews was drawn from a sub-sample of survey participants. I have also integrated through 'building' as preliminary survey results informed some of the questions asked in the interviews (particularly to extend understanding of help-seeking responses to symptoms). There are also elements of 'merging' as I have brought the two datasets together for analysis and comparison and asked similar questions to understand different interpretations of symptoms, as I outline in the study protocol paper. The outputs of this merging process are discussed in more detail in section 6.2, (Integration of findings, chapter 6). In terms of

interpretation and reporting integrated findings, I have written up my thesis on a concept-by-concept basis as I explained in section 1.3 How to read this thesis. The survey and interview results are presented contiguously in the two mixed methods results papers (chapters 4 and 5) and I have used matrices (see study protocol paper) and other joint displays (described in section 6.2, Integration of findings, chapter 6) to present, link and draw out new insights from the survey and semi-structured interview findings (Guetterman, Fetters and Creswell, 2015). O'Cathain (2010) summarised the use of matrices to integrate mixed methods data, differentiating between the level of information presented. Convergence coding matrices display findings from each study component and examine to what extent findings agree, disagree or highlight silences between data sources. Mixed methods matrices exploit the availability of different types of data about the same case (in this study, individual participants) to consider data collectively and to look for patterns between cases (Ibid). I have used both approaches to integration in chapters 4 and 5 which has helped me expand the scope and deepen insight into understandings of symptoms and help-seeking by examining phenomena from multiple perspectives, thus realising the value of using a mixed methods approach (Sandelowski, 2000).

2.2.4   Background to Natsal-3

Britain's National Surveys of Sexual Attitudes and Lifestyles (Natsal) constitute some of the biggest and most comprehensive studies about sex in the world (Natsal, 2015). The first survey was carried out in 1990-1991 (Johnson et al., 1994; Wellings et al., 1994) despite political resistance over concerns it would *"invade the privacy of the 20,000 people due to be questioned"* (Durham and Hughes, 1989). Along with the second survey in 1999-2001 (Fenton et al., 2001; Fenton et al., 2005; Johnson et al., 2001; Wellings et al., 2001), data collected from Natsal has informed and influenced sexual and reproductive health policy in Britain (Department of Health, 2001; The National Assembly for Wales, 2001; Scottish Executive, 2005).

The third survey conducted between 2010 and 2012 included more questions and a greater range of variables (Erens et al. 2013) using a population-based probability sample of men and women living in England, Wales and Scotland. Data were collected in successive waves and the survey used a clustered and stratified probability sample design whereby data were weighted to represent the British population in terms of age, gender and geographic region. A total of 15,162 interviews were conducted with participants aged 16-74 years (with over-sampling of people aged 16-34 years) by trained interviewers (from the National Centre for Social Research) using a combination of computer assisted personal interview (CAPI) and for more sensitive questions, computer assisted self-interview (CASI). The overall response rate was 57.7% (Mercer et al. 2013; Erens, et al. 2013).

There were five main sections of Natsal-3 which covered: health, family and learning about sex; first sexual experiences, use of contraception and sexual lifestyle; sexual behaviour including number of partners, sexual practices, sexual health and reproduction; attitudes and risks; and socio-demographic information. In addition, urine samples were collected from a sub-sample of 4,550 sexually-experienced participants aged 16-44 years to test for five STIs (*Chlamydia trachomatis, Neisseria gonorrhoea, Mycoplasma genitalium*, Human Papillomavirus and HIV antibodies with subsequent testing for *Trichomonas vaginalis*) and 4,128 samples of saliva were provided for testosterone measurements from a sub-sample of participants aged 18-74 years (Erens et al. 2013). Note that Natsal-3 was administered through a face-to-face interview with each participant where the CAPI and CASI sections were completed in a structured approach to data collection. My follow-up semi-structured interviews also used an interview as the method of data collection but with very different aims and mode of delivery. For clarity throughout this thesis I use 'Natsal-3' or 'survey' when referring to the structured data collection resulting in numerical (quantitative) data, and 'interview', 'follow-up interview' or 'semi-structured interview' to describe the second data collection

phase producing visual and verbal (qualitative) data which were transcribed to become text data (see flash card activity method paper).

This study benefits from the linked data produced (see figure 2). The Natsal-3 survey sample was drawn from the British population living at a private residential address, from which a sub-sample of women and men who reported symptoms was identified and then follow-up semi-structured interviews were conducted with a small number of these individuals. Therefore, the participants for the semi-structured interviews are the same people as those who took part in the survey. This is uncommon in mixed methods research and greatly enhances opportunities for integration of data and explanatory value of this research.

Figure 2: Diagram of flow of participants and linked data

Population	Population living at private residential addresses in Britain
Survey sample	Natsal-3 sample = 15,162
Survey sub-sample	Symptomatic women = 1,182 / Symptomatic men = 221
Semi-structured interview sample	Symptomatic women participating in semi-structured interview = 16 / Symptomatic men participating in semi-structured interview = 11
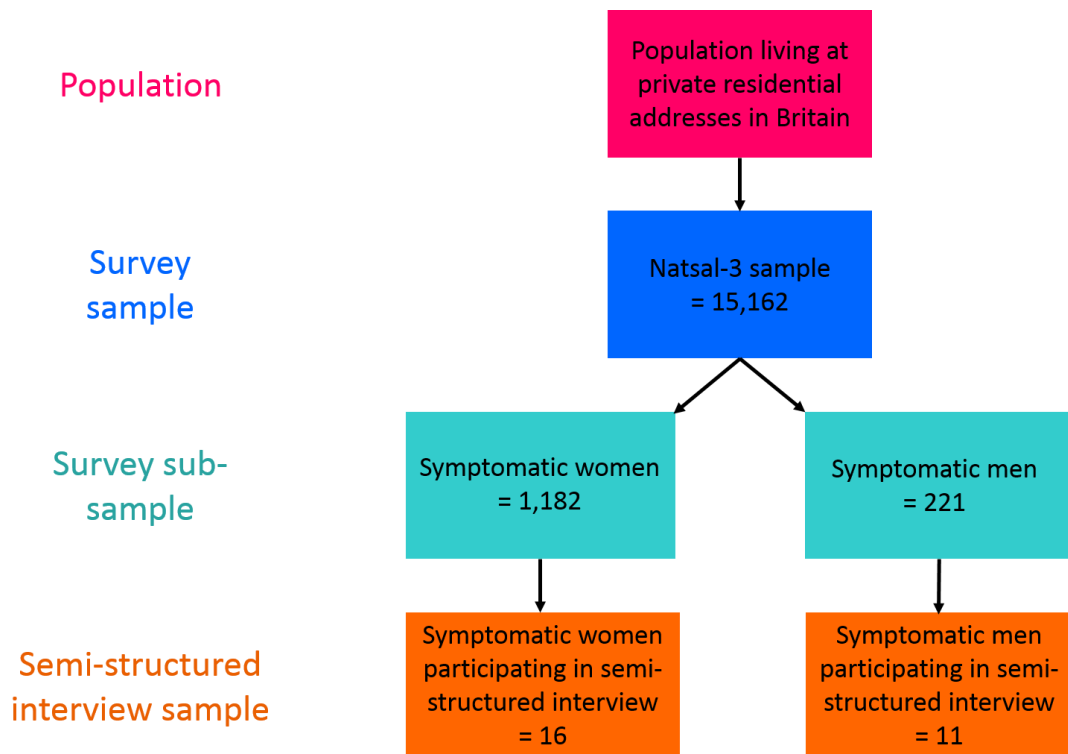
2.2.5   Discussing sex and gender

Biological sex and gender are conflated in Natsal-3, which has made accurate reporting in this thesis more difficult. The interviewer conducting data collection for Natsal-3 was asked to record whether the respondent was male or female – the survey did not ask participants directly to report their sex or their gender (Natsal-3, 2013). Therefore, the interviewer is allocating perceived gender with the assumption that their allocation maps to anatomy. For some participants, this assumption may be incorrect. Natsal-3 papers refer to women and men (e.g. Mercer et al. 2013; Sonnenberg et al. 2013) to avoid confusion between sexual behaviour and anatomy of sexual organs. I also use the terms women and men in this thesis, thereby extending assumptions about cis-genderism in survey results, which has particular implications for my findings about symptoms (chapter 4) and

related anatomy and physiology. My findings would be very different for trans-gender participants. All of the participants who participated in the semi-structured interviews I conducted referred to their gender at some point. Similarly, I discuss the theme of gender in section (6.4.1 – Integration of findings chapter) and gender differences, although I am aware much of the data refers to sex differences.

2.2.6 Methodological challenges

Walter and Scott summarised key methodological challenges in studying help-seeking for symptoms (Scott and Walter, 2010) which have guided decision-making in this study and are outlined in table 1.

Table 1: Methodological challenges in studying help-seeking for symptoms and implications for this study

Methodological challenge (Scott and Walter, 2010)	Explanation	Implications for this study and approach taken
What is being studied?	No consensus on definitions and terms about help-seeking	I reviewed commonly used definitions for STI research (section 1.5.2.1 – Introduction chapter), synthesised shared elements and focussed on what was missing – findings about how symptoms are interpreted and help-seeking responses independent of medical settings
How has help-seeking behaviour been studied?	Focus on patient populations and under-reporting of symptoms in medical records; assumptions made about patient experiences and interpretations of symptoms; questionnaires do not allow probing about	Mixed methods approach to combine standardised questions about symptoms and help-seeking (from Natsal-3) with detailed exploration of phenomena (semi-structured interviews); I am using a population sample rather than a patient sample and inductive

	type and timing of symptoms and interviews do not have standardised questions	approaches to understand lived experiences of sensations and symptoms
	Hypothetical care-seeking or intentions to seek care exclude contextual, personal, social and comorbid factors which may influence actual behaviour; minimal investigation of validity and reliability of hypothetical measures and known differences between intentions and behaviours (Armitage and Conner, 2001)	I am combining numerical and text data about previously reported experiences, behaviours and service preferences
When and where should help-seeking behaviour be studied?	Retrospective study designs after diagnosis linked to recall bias and nature of symptoms may also impact recall of symptoms; suggest longitudinal prospective study designs	Natsal-3 used retrospective reporting of symptoms in the past month independent of diagnosis, and I did not have the resources or time to conduct a prospective longitudinal study for this research. I justify the benefits of using Natsal-3 in section 2.2.4 and mitigate some of the issues of relying only on retrospective data by asking about lifetime experience of symptoms in the semi-structured interviews which may capture current symptom experiences.
Whose help-seeking behaviour should be studied?	Many studies are underpowered to detect differences in help-seeking and use patient samples, therefore excluding those who do not seek help; help-seeking research requires	Natsal-3 only asked about care-seeking at sexual health clinics, therefore I cannot quantify differences in help-seeking but instead explore them qualitatively; I am using a population sample to take a

	investigation of people who seek help but are diagnosed with different conditions to the one in question to understand what motivates and hinders help-seeking for certain symptoms	broad approach to studying symptoms and help-seeking instead of restricting the study to patients and, although framed by sexual health, this study considers a broad range of interpretations and outcomes to understand phenomena in general

2.2.7 Justification of approach

The decisions I made from developing the study design through to writing up my findings have all been governed by the research questions posed in this thesis, with consideration for some external factors that I cannot influence (for example timing of Natsal-3 data collection and response rate from participants) and acknowledging the methodological challenges outlined in section 2.2.6. It is common for research, and mixed methods research in particular, to be driven by the research question (strong advocates for this include Greene 2007; Johnson & Onwuegbuzie 2004; Plano Clark & Badiee 2010). Teddlie and Tashakkori go as far as to label such approaches as being the "*dictatorship of the research question*" (1998, p.20). As the idea for this thesis is rooted in everyday observations and I want the findings to have empirical relevance and applicability, my research questions are central to this study (see section 1.10, chapter 1).

2.3 Introduction to the research paper

I decided to write the study protocol as a paper detailing the approach I have taken and methods used, primarily to help in writing concise mixed methods results papers. By having the protocol as a citable article, I can focus on the methodological aspects that are important for each results paper and refer to the full protocol for the detail. This also helped me to overcome issues with writing mixed methods papers for public health journals with smaller word counts than more

methodologically oriented journals – an important factor when considering who the intended audience is for the outputs of this thesis.

The paper briefly describes background literature about STIs, genito-urinary symptoms and care-seeking behaviour, the rationale and aims and the research questions of this study. It details the study design, quantitative and qualitative components and approaches to integration. The discussion briefly outlines the general strengths and limitations of the study, which are revisited in discussion sections of the results papers in relation to specific data (chapters 3-5). The paper was written after data collection had ended and before substantive research findings had been produced through data analysis, therefore there are some minor inconsistencies between this paper and the results papers.

2.4   Research Paper: Study Protocol

Status: Published in BMC Public Health, 11 July 2016

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RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Fiona Mapp
Principal Supervisor	Ford Hickson
Thesis Title	Sexually Transmitted Infections: A Mixed Methods Study of Stigma, Symptoms and Help-seeking

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	BMC Public Health		
When was the work published?	11 July 2016		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

*If yes, please attach evidence of retention. If no, or if the work is being included in its published format, please attach evidence of permission from the copyright holder (publisher or other author) to include this work.

SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	FM conceived the design of this study in conjunction with KW, CM and FH. FM conducted and analysed all semi-structured interviews with support from FH and KW. CM advised on statistical analyses. FM and ST had the idea for the manuscript and FM wrote and edited all drafts with critical input from FH, CM and KW. All authors read and

	approved the final manuscript.

Student Signature: _____ **Date:** 14/07/17

Supervisor Signature: _____ **Date:** 14/7/17

BMC Public Health

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How social representations of sexually transmitted infections influence experiences of genito-urinary symptoms and care-seeking in Britain: mixed methods study protocol

Fiona Mapp[1*] , Ford Hickson[1], Catherine H. Mercer[2] and Kaye Wellings[1]

Abstract

Background: Social understandings of sexually transmitted infections and associated symptoms and care-seeking behaviour continue to lag behind advancements in biomedical diagnostics and treatment, perpetuating the burden of disease. There is a lack of research linking perceptions, experiences and care-seeking for sexual health issues, especially research conducted outside of medical settings. We aim to explore lay perceptions of STIs and how these influence experiences of genito-urinary symptoms and associated care-seeking behaviour, in women and men in Britain.

Methods and design: This study adopts a participant-selection variant of the explanatory sequential mixed methods design to incorporate quantitative and qualitative strands. We use data from Britain's third National Survey of Sexual Attitudes and Lifestyles ($n = 15,162$) to analyse national patterns of symptom experience and care-seeking, and to identify a purposive qualitative sample. Semi-structured interviews ($n = 27$) following up with survey participants include a novel flash card activity providing qualitative data about infection perceptions, symptom experiences and decisions about healthcare. Quantitative and qualitative data are analysed separately using complex survey analyses and principles of Interpretative Phenomenological Analysis respectively. Data are then integrated in a subsequent phase of analysis using matrices to compare, contrast and identify silences from each method.

Discussion: This is an ongoing mixed methods study collecting, analysing and synthesising linked data from a national survey and follow-up semi-structured interviews. It adds explanatory potential to existing national survey data and is likely to inform future surveys about sexual health. Given the current uncertainty around service provision in Britain, this study provides timely data about symptom experiences and care-seeking behaviour which may inform future commissioning of sexual healthcare.

Keywords: Mixed methods research, Natsal-3, Survey, Semi-structured interviews, Sexually transmitted infections, Sexually transmitted disease, Genito-urinary symptoms, Care-seeking behaviour, Non-attendance

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Background

Sexually transmitted infections

Sexually transmitted infections (STIs) remain a persistent public health challenge across populations, despite advancements in diagnostics and treatment options. In England, STIs disproportionately affect people under 25 years and men who have sex with men [1], although the rate of STIs in older people is increasing [2]. So far progress in the social understanding and mitigation of negative perceptions of STIs has lagged behind biomedical advancements. Stigma has been pronounced as the greatest barrier to healthcare-seeking in relation to STI care [3] resulting in increased morbidity and mortality and repercussions at an individual, health system and policy level. Despite some progress in elucidating sources and outcomes of stigma [4], the underlying mechanisms through which stigma influences individual experiences are not sufficiently explained in relation to STIs.

Genito-urinary symptoms

Genito-urinary symptoms are commonly associated with STIs but can also be caused by other urinary tract infections [5, 6] and cancers [7]. There are currently no estimates of how common genito-urinary symptoms are among the general population, who they affect, or how individuals interpret and respond to them. Generally symptoms are unpleasant, subjective experiences that alert individuals to a change within their body [8]. Experiencing sensations or symptoms does not always trigger care-seeking if symptoms are not interpreted as a need for care [9, 10]. The overlapping symptomatology emphasises the need to better understand experiences, meanings and decision-making about symptoms, underlying causes and care needs and Scott and Walter [9] advocate symptom level research rather than disease level research to better understand symptoms in relation to care-seeking.

Care-seeking behaviour

Seeking healthcare is a complex and heterogeneous behaviour and decisions about individual health needs are based on diverse motivations and information sources. Fortenberry's work on adolescent sexually transmitted disease care offers a definition of healthcare-seeking as the *"interval between recognition of a health problem and its clinical resolution and... the accompanying cognitive and behavioural responses"* ([11] p147). This incorporates a temporal dimension to care-seeking which is important in terms of early detection, diagnosis and treatment of contagious pathogens. This definition however, excludes the earlier process of sense-making that occurs before recognising a change in health and also neglects what happens if individuals do not attend a medical service.

In the UK, specialist sexual health clinics (also known as STI clinics and genito-urinary (GUM) clinics) are open access and free at the point of care. They are the best equipped service to diagnose and manage a range of genito-urinary conditions, providing more comprehensive STI screenings than community services and diagnosing and treating more STIs [12]. However some people find specialised clinics stigmatizing and unfamiliar environments [13] and so primary care is also a vital part of genito-urinary healthcare [14, 15].

We need to understand the experiences, priorities and decisions of those in need of healthcare outside of medical settings if we are to improve pathways in to care.

Rationale for this study

STIs, symptoms and care-seeking are topics which lack in-depth social examination, having been dominated by biomedically-framed research. It is unclear to what extent lay perceptions and social representations of STIs influence conceptualisations and experiences of genito-urinary symptoms, and what determines care-seeking behaviours for symptoms of STIs. Care-seeking has already been described as a complex research topic [9, 16] and there are additional complexities associated with genital symptoms and associations with stigmatised conditions such as STIs. Therefore a mixed methods approach is needed to incorporate complexities of the research topic through mixing types of methods and types of data.

There are many ways of defining mixed methods research depending on the methodological and philosophical approach. In this study we use the following core principles of mixed methods research [17] to guide our study from conception to completion:

- Collecting and analysing both qualitative and quantitative data in a single study
- Integrating the different forms of data after separate quantitative and qualitative analyses
- Study design determined by the research questions [18]
- Priority given to explanatory qualitative data
- Study is theoretically grounded drawing on pragmatism
- Using mixed methods for *"the broad pursuit of breadth and depth of understanding"* ([19] p123)

Mixed methods helps transcend single dimension and linear understandings of the topic and produce multidimensional insights [20] into symptom experiences and care-seeking whilst offsetting weaknesses of quantitative and qualitative methods. Our research questions necessitate different mixed methods reasoning to produce appropriate data including: data complementarity to

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illustrate findings from the other method; development of one method from another; expansion to examine different aspects of the same phenomenon; and some triangulation to corroborate findings where there is sufficient overlap of data [21].

Aim and research questions

This study aims to explore lay perceptions of STIs and how these influence experience of genito-urinary symptoms and associated care-seeking behaviour, focussing on non-attendance in women and men in Britain. The main research questions are:

1. What are the social representations of STIs?
2. How does stigma influence experiences of genito-urinary symptoms and care-seeking?
3. How do people interpret genito-urinary symptoms?
4. Why do some people with genito-urinary symptoms not seek care at sexual health clinics?

Our research is framed by, although not restricted to, sexual health.

Methods and design

Study design

We use a participant-selection variant of the explanatory sequential mixed methods design (Fig. 1) [18, 22]. Data collection takes place in two distinct stages to enable us to use the quantitative survey data from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) which is collected first, to identify the sampling frame for the dominant qualitative strand giving us linked datasets. Analyses of the quantitative and qualitative strands are conducted independently but simultaneously to maintain the integrity of each data. Key findings from each strand are integrated in a second stage of analysis to produce synergistic interpretations about genito-urinary symptoms and care-seeking behaviour and deepen understanding of

the research topic. Our sequential design enables identification of a sample with a potential need for healthcare, outside of medical settings. The linked datasets increase explanatory and integrative potential of the data. The study is under-pinned by public health approaches to individual and population health needs, as well as sociological and psychological theory. We draw on principles of pragmatism to incorporate different research paradigms ([23] p26) ([24] p14–16) within the study and use phenomenology to focus on lived experiences ([25] p1–21).

Study setting

Natsal-3 is conducted in Britain involving random population sampling of women and men based on household addresses. Follow-up qualitative interviews are carried out in England and Wales with a small sub-set of participants selected based on their survey responses.

Quantitative strand

The quantitative strand comprises secondary analysis of Natsal-3 survey data.

Natsal-3 survey data

The National Surveys of Sexual Attitudes and Lifestyles conducted over the past three decades have provided detailed information about sexual behaviour in Britain [26]. The third of these surveys, Natsal-3, was carried out between September 2010 and August 2012 interviewing 15,162 women and men in total. Full details of the methods have been reported elsewhere [27] but are summarised here so the survey can be understood in the context of this mixed methods study. Participants were aged 16–74 years (with over-sampling of people aged 16–34 years) and sampling took place across England, Scotland and Wales. A multi-stage, clustered and stratified probability sample design was used and data were weighted to represent the British population according

Fig. 1 Mixed methods study design

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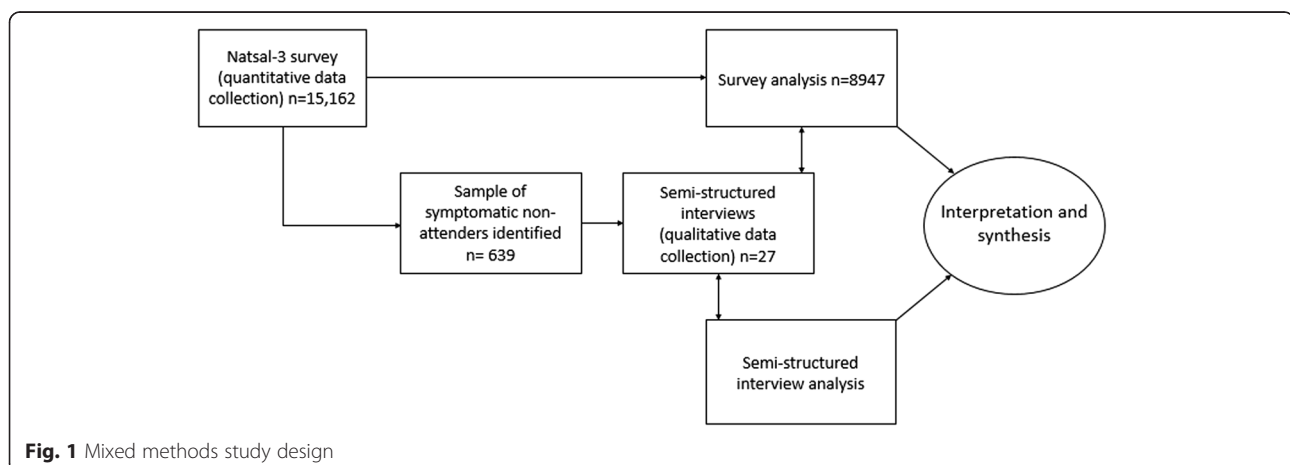
to age, gender and geographic region. Weighting the data also accounted for differing selection and non-response probabilities. A combination of computer assisted personal interview (CAPI) and, for the more sensitive topics, computer assisted self-interview (CASI) was used. Overall the response rate to Natsal-3 was 57.7 % [27, 28].

There were five main domains of questions in the Natsal-3 questionnaire which included questions on health, family and learning about sex; first sexual experiences, use of contraception and sexual lifestyle; sexual behaviour including number of partners, sexual practices, sexual health and reproduction; attitudes and risks; and socio-demographic information. Urine samples were collected from a sub-sample of sexually-experienced participants aged 16–44 to test for *Chlamydia trachomatis*, *Neisseria gonorrhoeae*, *Mycoplasma genitalium*, Human Papillomavirus and HIV antibodies, with subsequent testing for *Trichomonas vaginalis* [29]. Another sub-sample of participants aged 16–74 provided saliva samples for testosterone measurement [27].

In the CASI, questions were asked about attendance at sexual health clinics and experience of genito-urinary symptoms in the month prior to data collection.

Quantitative data analysis

This study uses data from a sub-sample of Natsal-3 participants (Fig. 2) who were aged 16–44 years and sexually experienced, defined as those who reported having had at least one sexual partner (*n* = 8947). We want to capture and compare patterns of symptoms and care-seeking across a greater age range than those at highest

risk. After initial data exploration involving cross-tabulations of key variables and basic summary statistics to facilitate choosing the sampling frame for the qualitative strand, data analysis was delayed to coincide with analysis of the qualitative data. This approach enables us to move between each dataset, using findings from one to inform analyses of the other, and vice versa, whilst maintaining analytical distinction between data types. We conduct statistical analyses on variables derived from the survey questions [30] *"In the last month, that is since (date one month ago), have you had any of the following symptoms?"* and *"Have you ever attended a sexual health clinic (GUM clinic)?"* The primary dependent variables are reported symptom experience and non-attendance at a sexual health clinic. Table 1 shows the symptoms that the Natsal-3 questions asked about. Independent variables included in the quantitative analyses are informed by qualitative findings and relevant literature. Participants with missing data for either the independent and/or the dependent variables are excluded from analysis as there are generally low levels of missing data in Natsal-3, often between 1 and 3 % [28]. We are using the survey commands in Stata V.14.1 to account for stratification, clustering and weighting of the dataset. Prevalence estimates of reported symptoms and non-attendance at sexual health clinics are calculated with 95 % confidence intervals for women and men, stratified by age-group. We are using logistic regression to examine associations between reporting symptoms and not having attended a sexual health clinic in the past year to produce crude and age-adjusted odds ratios. Analyses are stratified by sex to reflect differences in male and

Fig. 2 Derivation of sub-groups for quantitative analyses

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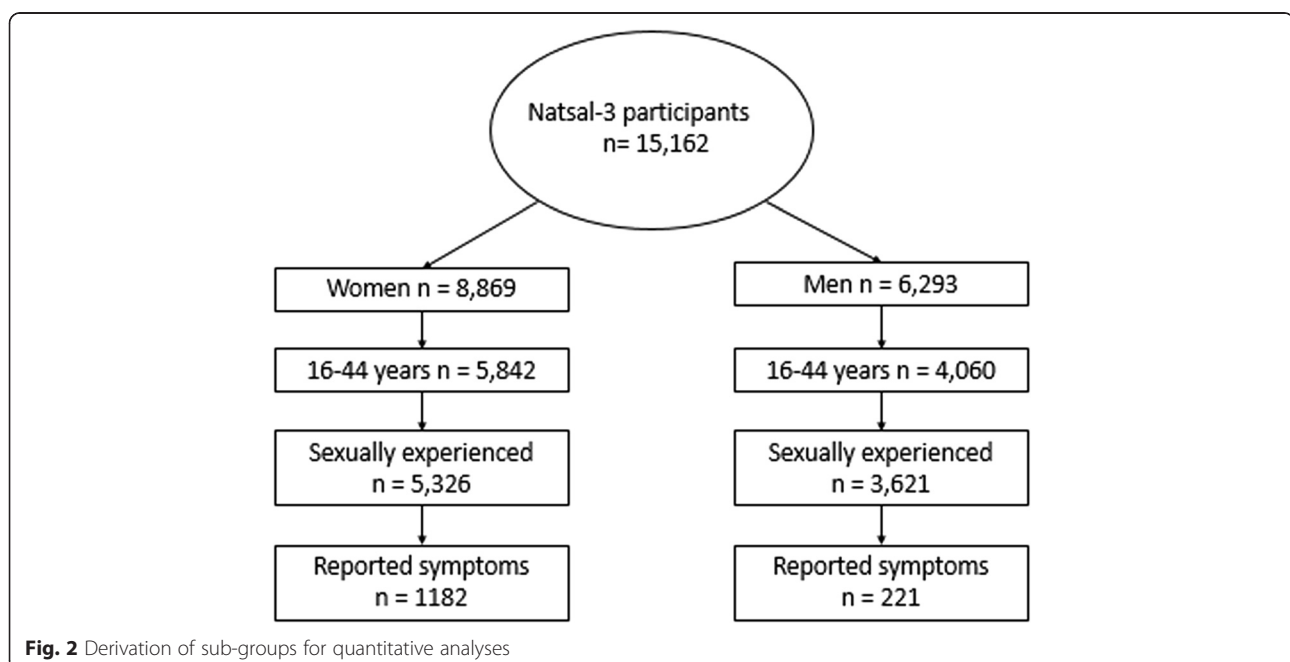
Table 1 Symptoms reported in Natsal-3 and follow-up qualitative interviews

Symptoms reported	Crude number of symptoms reported in Natsal-3 survey interview (past month)	Symptoms reported by qualitative participants during Natsal-3 interview (past month)	Symptoms reported by qualitative participants during semi-structured interview (ever)
Women			
Pain, burning or stinging when passing urine	384	2	14
Genital wart/lump	35	1	0
Genital ulcer/sore	25	3	1
Abnormal vaginal discharge	236	0	13
Unpleasant odour associated with vaginal discharge	206	4	5
Vaginal pain during sex	304	1	8
Abnormal bleeding between periods	245	4	6
Bleeding after sex (not during a period)	154	1	3
Lower abdominal or pelvic pain (not related to periods)	305	5	9
Men			
Pain, burning or stinging when passing urine	101	3	7
Genital wart/lump	27	1	2
Genital ulcer/sore	7	0	0
Discharge from the end of the penis	19	1	2
Painful testicles	93	7	8

(Two men reported no symptoms during their semi-structured interviews although they had indicated experiencing symptoms in their initial Natsal-3 interview)

female anatomy, physiology and epidemiology of genito-urinary infections [29, 31, 32] and reported gender differences in care-seeking behaviour [33–35].

Qualitative strand
The qualitative strand comprises semi-structured interviews with Natsal-3 participants (Fig. 1).

Sampling and data collection
We identified a sample of 639 Natsal-3 participants who had reported firstly, at least one genito-urinary symptom, secondly, no previously reported attendance at a clinic and thirdly consent to be re-contacted. From the Natsal-3 data, 79.9 % (95 % CI 76.0–83.3) of participants who reported symptoms and never having previously attended a sexual health clinic were women, however we are keen to ensure that the experiences of men are represented in the data, therefore we aimed to achieve a sample of approximately equal numbers of women and men. Due to the well documented experience of difficulties recruiting men for social research studies [36], we recruited as many men into the sample as possible in the study time-frame.

Our sample was drawn from a representative national survey which increased the diversity of the sampling frame, an important feature of our approach. We used maximum variation sampling, a type of purposive

sampling [37] to select participants with a diverse range of reported symptoms including different symptom types and multiple symptoms to generate appropriate data about their experiences (Table 1). Our sample consisted of those who had not previously attended a sexual health clinic as we know that past attendance can influence future care-seeking behaviour [38] and interpretations of current symptoms. We were also keen to include a variety of care-pathways and decision-making processes in our data. Sampling was iterative and responsive to feedback from earlier interviews and sampling procedures reviewed throughout the recruitment phase to ensure sufficient data was produced to answer the research questions ([39] p138). Natsal-3 participants who met our inclusion criteria were initially contacted by post then by telephone (or text message if there was no response from calling) to arrange the interview if they agreed to participate in an interview. Of 117 people we attempted to contact, 79 were uncontactable, 8 declined to take part, 2 did not meet study inclusion criteria and one dropped out before the interview took place. We recruited participants who had completed Natsal-3 most recently to help minimise attrition but included some participants from earlier waves of survey data collection to increase the variety of symptoms sampled.

The interview topic guide was piloted by FM on five participants January-February 2014. The full interviews were carried out by FM between May 2014 and March

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2015 with 16 women and 11 men. Interviews took place at the participant's home address ($n = 24$) or another convenient location specified by the participant ($n = 3$) and lasted between 35 and 108 min; the median length was 68 min. The interviews were structured around four main sections: STI perceptions; symptom meanings; care-seeking behaviour; STI stigma. The interview was flexible to the participant's experiences and needs. We also embedded an interactive flash card activity within the interview to produce different types of data about STI perceptions. The activity involved comparative ranking of STIs from most to least (or similar end points) according to different themes: prevalence, infectiousness, visibility, severity, treatability and blameworthiness. Participants were asked to 'think out loud' and a photograph of the final flash card ordering was taken. The activity produced linked verbal and visual data and overcame some of the limitations associated with participants' capabilities of spontaneously speaking about our research topic. We continued recruiting participants for interviews until the data produced was sufficient to answer our research questions and we had maximised the diversity of participants included in the study. Interviews were digitally recorded and transcribed verbatim by FM or a professional transcription company. Field notes were written to capture and reflect on the process of recruiting and interviewing participants and to inform subsequent analyses.

Qualitative data analysis

All qualitative data are imported into NVivo V11 to facilitate organization of data in different formats (audio, written transcript, written field notes and photographs). We are drawing on principles of Interpretative Phenomenological Analysis [25, 40] with attention to discourse exploring the lived experiences and meanings of genitourinary symptoms and decisions around care-seeking. This involves an idiographic approach, analysing transcripts individually, reading them through and recording initial notes, comments, questions, summaries, absences and uses of language through engagement with the data. These notes are then transformed into conceptual themes [41, 42] to capture the 'essence' of the data and these emergent themes are collated into groups to explore clustering and hierarchies of themes within the data. Organization and re-organization of these groups produces an overall coding framework composed of meta-themes, themes and sub-themes derived inductively from the data. The coding framework is then used to guide subsequent coding of other transcripts, ensuring data within each theme cohere meaningfully and themes encompass distinct concepts. We are remaining open to new codes emerging throughout the analysis process and are attentive to data that does not fit the coding framework or appears to differ from the rest of the dataset. Although we are taking a predominantly inductive approach, some *a priori* codes are developed from the topic guide and the emergent quantitative findings to facilitate cross-examination of the data. FM is coding all of the transcripts and approximately a third of the qualitative data are double coded by experienced qualitative researchers to ensure a comprehensive and rigorous analytical approach.

Quality appraisal

We have considered both the Mixed Methods Appraisal Tool (MMAT) [43] and Good Reporting of a Mixed Methods Study (GRAMMS) [44] in the conceptualisation, development and description of this study. Reporting of results and outputs from this study will also follow this guidance.

Integration of findings

This study uses quantitative survey data and qualitative data from semi-structured interviews. Integration of findings is the process through which enrichment and enhancement of each type of data occurs and greater understanding is achieved [45].

We will synthesise the data using multiple approaches for data integration [46]. The most prominent approach to integration will occur through the use of matrices. A 'convergence coding matrix' (ibid) (Table 2) will be used, adopted from the triangulation protocol [47] to present and then integrate findings from each strand of the mixed methods study, paying particular attention to areas of agreement, silence and dissonance [46]. Exploring the data in this way helps cut across the findings from each strand [47], highlight methodological discrepancy and increases the potential for gaining additional insights from using a mixed methods design.

As we have linked samples, we have both quantitative and qualitative data for a sub-set of participants. We are using the full Natsal-3 responses from each of the qualitative participants, if consent was given, to provide additional contextual analysis and create mixed method "cases" to illustrate our study and provide examples of specific symptom experiences and care-seeking pathways. As Natsal-3 contains 1792 variables (personal communication with Dr C. Mercer 4 June 2015), we will choose only those which can provide relevant additional data and focus on factors that are unlikely to change significantly over time, for example how old participants were when they first had sex or if they have previously been diagnosed with STIs. We collate quantitative and qualitative data on each participant in a 'mixed methods matrix' [46] (Table 3) to identify similarities and differences between data types for individual participants and look for patterns across individuals.

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Table 2 Example of a convergence coding matrix for integrating quantitative and qualitative findings

Research question	Quantitative findings	Qualitative findings	Integrated findings – agreement/ partial agreement/ silence/ dissonance
1. What are the social representations of STIs?			
2. How does stigma influence experiences of genito-urinary symptoms and care-seeking?			
3. How do people interpret genito-urinary symptoms?			
4. Why do some people with genito-urinary symptoms not seek care at sexual health clinics?			

Throughout the integration phase, we are looking for areas of complementarity, divergence and ways to offset the weaknesses of each method with data from the other. We move backwards and forwards between the separate qualitative and quantitative datasets and integrated findings to identify if the reasons for patterns are methodological or empirical findings for this study.

Discussion

Summary

This is an ongoing mixed methods study exploring perceptions and social representations of STIs, genito-urinary symptoms and care-seeking behaviour in women and men in Britain. We are using data from Natsal-3 and follow-up semi-structured qualitative interviews with survey respondents to produce data from linked samples drawn from the population instead of recruited from medical settings. We will integrate the results from the quantitative and qualitative strands to produce synergistic findings that give richer and more meaningful insight than a single method approach.

Strengths

Natsal-3 is a large survey of the British population with sufficient statistical power and a robust sampling strategy meaning that the quantitative results are broadly representative and therefore generalizable at a national level. This study will also provide the first estimates of the prevalence of genito-urinary symptoms in Britain and enables a unique approach to

studying non-attendance as a facet of care-seeking behaviour. Our qualitative sample is diverse, maximising experiences of different symptoms in women and men and covering a wide range of ages and geographic locations. Semi-structured interviews enabled us to explore care-seeking more broadly than have been considered in Natsal-3, and to position decisions about needs and healthcare services in a specific social and cultural context.

A mixed methods approach enables us to use and integrate quantitative and qualitative data to study a complex social phenomenon, gain comprehensive insights into underlying mechanisms of experience and help explain quantitative results [17]. This would not be possible with a single method study. The linked datasets are a particular strength of this study as there is usually a trade-off between sample size and data linking in mixed methods research. We are able to make sense of population patterns within individual lived experiences and provide multi-dimensional insights into the research topic. We also have extensive information on the participants in our qualitative sample by using their full Natsal-3 responses. This gives us further opportunities to integrate data between quantitative and qualitative strands. The sequential study design enabled us to sample individuals with potential healthcare need, outside of medical settings. This is beneficial for our study and the opportunity it affords to study non-attendance behaviour but also contributes to a gap in the literature on healthcare services which is dominated by patient samples and research undertaken in clinical settings. The mixed methods design also broadens this study's perspective of

Table 3 Example of a mixed methods matrix for exploring patterns within and across individual participants

Participant ID number	Gender	Symptoms experienced past month	Symptoms experienced ever	Previous STI diagnoses	Suspected cause of symptoms	Hypothetical preferred service provider	Actual care-seeking for symptoms
1							
2							
3							
4							
Etc.…							

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genito-urinary symptoms viewing them in other contexts besides STIs.

Limitations

The time frames of the symptoms and care-seeking questions do not correlate as Natsal-3 asked about experience of symptoms in the past month and clinic attendance in the past year. We can deduce that individuals who hadn't attended a clinic in the past year had also not been in the past month but do not have any quantitative data about care-seeking intentions or engaging with other health care providers, including GPs. Natsal-3 is a cross-sectional survey so it is not possible to determine causality of associations between symptoms and care-seeking. Survey data is self-reported (except for the urine and saliva sample testing) so there may be reporting bias, especially if the questions were perceived to be particularly sensitive. The time between quantitative and qualitative data collection ranged from 22 months to 44 months leading to high attrition of participants. It may not be possible to triangulate some of the quantitative and qualitative data because of the individual changes to behaviour and attitudes during this time.

Other operational issues

All qualitative data collection was carried out by a white British female and this is likely to have an impact on the interview data as qualitative methods involve co-creation of data between the researcher and the interviewee ([39] p23-25). Some female participants in the qualitative sample mentioned that they would have been uncomfortable discussing their symptomatic experiences with a male interviewer and the reverse may have occurred for male participants. This phenomenon has been documented in other qualitative studies [48] and introduces additional analytic dimensions to the data produced.

Application of findings

With increasing uncertainty in the provision of sexual healthcare services [49] and unknown population prevalence of symptoms, this study is timely in directly addressing gaps in the literature and answering questions relevant to public health and healthcare services. Our findings may produce new insights into lay decision-making about symptoms and healthcare-seeking behaviours by exploring individual explanatory frameworks for experiences. It may provide evidence for future commissioning of healthcare for genito-urinary health issues and inform the development of subsequent Natsal studies.

We feel that there is scope for adopting a similar approach using other national surveys to help explain quantitative patterns and trends, providing that the necessary permissions and protocols are put in place during the design and development phases to ensure ethical and data management issues are addressed appropriately.

Authors' contributions

FM conceived the design of this study in conjunction with KW, CM and FH. FM conducted and analysed all semi-structured interviews with support from FH and KW. CM advised on statistical analyses. FM and ST had the idea for the manuscript and FM wrote and edited all drafts with critical input from FH, CM and KW. All authors read and approved the final manuscript.

Authors' information

FM is currently a doctoral student in the faculty of Public Health and Policy at the London School of Hygiene & Tropical Medicine. She is funded by the ESRC, Health and Wellbeing cluster, administered through the Bloomsbury Doctoral Training Centre hosted by the Institute of Education. @fionamapp

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2.5 Introduction to the research paper

The following paper describes the flash card activity, a technique I developed specifically for this study, drawing on findings from image-elicitation methods. I was struck by how abstract some aspects of STIs seemed to me, despite having worked in the field for a number of years, such as what STI stigma was 'made of' and where cultural narratives about STIs came from. I found it difficult to articulate these in a funding proposal and quickly realised that it might be difficult to generate good data about the social representations of STIs in the context of an interview. I was also keen to use the opportunity a PhD afforded me of trying something different by exploring *"beyond the standard interview"* (Bagnoli, 2009) and embedding another technique within the data collection process.

Through discussion with one of my supervisors, Kaye Wellings, we decided on the idea of using flash cards as the basis of the additional method and using rank ordering according to specific themes as the main activity. By drawing on health psychology literature and stigma theory, as described in the paper, we devised the themes that would be included in the method, and I used the Centers for Disease Control (2013) and World Health Organization (2015) lists of STIs to decide on the STIs to include on the flash cards. I used the most common names of each infection on the flash cards to facilitate participants' familiarity with them. I piloted the flash card activity with five participants, which was a really useful experience for me to assess acceptability and interpretation of the exercise. Initially I included 19 infection flash cards (see table 2) to cover a range of STIs, other infections and diseases that affect genital health but are not transmitted sexually. The pilot indicated the need to reduce the number of flash cards included to prevent participant fatigue as well as to avoid potential embarrassment associated with lack of knowledge of less common infections. One participant in the pilot expressed concern at learning about the number of different pathogens that could affect

genital health and, on reflection, the interview seemed not to be an ideal context in which to allay such anxiety, despite subsequent provision of an information sheet.

Table 2: Infections and conditions included on flash cards in the initial version of the flash card activity

Bacterial vaginosis	Mycoplasm genitalium
Chancroid	Non-Specific Urethritis (NSU)
Donovanosis (Granuloma inguinale)	Pelvic Inflammatory Disease (PID)
Epididymitis	Scabies
Hepatitis B*	Trichomoniasis
Lymphogranuloma venereum (LGV)	

Originally, the activity contained an additional theme – curability – to assess how easy it was to cure infections with continua end points labelled 'completely curable' to 'incurable/life-long condition.' During the pilot, participants often conflated the themes of treatability and curability, leading to disruption of flow, confusion and frequent repetition which threatened the quality of the data. 'Curability' as an explicit theme was therefore removed for the final version of the flash card activity.

I wrote this up as a paper to document the method and disseminate it within the qualitative methods literature as well as gain experience of writing a methodological paper to supplement the empirical articles I had planned. It was only through writing up the flash card activity that I reflected critically on the method; I found this experience incredibly frustrating and difficult but also enlightening as I came to understand the method in greater detail and appreciate its scope as well as the strengths and limitations of using it within semi-structured interviews. I submitted the article to the International Journal of Qualitative Methods, and it underwent three rounds of revisions before being accepted.

2.6 Research Paper: Flash card activity method

Status: Published in the International Journal of Qualitative Methods 23 April 2017

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SECTION A – Student Details

Student	Fiona Mapp
Principal Supervisor	Ford Hickson
Thesis Title	Sexually Transmitted Infections: A Mixed Methods Study of Stigma, Symptoms and Help-seeking

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	International Journal of Qualitaitve Methods		
When was the work published?	23 April 2017 (online first)		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
Have you retained the copyright for the work?*	**Yes**	Was the work subject to academic peer review?	**Yes**

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Student Signature: _____ Date: 14/07/17

Supervisor Signature: _____ Date: 14/7/17

Reflections on Using a Flash Card Activity for Studying Social Representations of Sexually Transmitted Infections

Fiona Mapp[1]

Abstract
Image elicitation methods generating visual data are becoming more common in social science research to generate rich and detailed findings and access topics using nonverbal approaches. Current elicitation techniques using photos and drawing methods have limited application for studying sexually transmitted infections (STIs). To address this, I describe a novel elicitation method—the flash card activity—which involves ranking STI flash cards according to predetermined themed continua. The activity was embedded within semistructured interviews focusing on social representations of STIs and experiences and meanings of STI symptoms and care-seeking behavior with 27 participants. Participants were recruited from the third National Survey of Sexual Attitudes and Lifestyles that took place in Britain 2010–2012. This article reports on the methodological findings of implementing the flash card activity. The activity generated linked verbal and visual data that were more fluent, cohesive, and diverse than other interview data and disrupted normative accounts of infections, enabling participants to reflect on the formation and influences on their social representations. Acceptability of the flash card activity was high, although there were feasibility issues when either language comprehension or time were limited. There is scope for further methodological innovation and adaptation for different topics.

Keywords
flash cards, innovative method, visual data, image elicitation method, visual elicitation, semistructured interviews, ranking, ordering, sexually transmitted infections, joint display

What is already known?

Some topics, especially those perceived to be sensitive or personal, are not accessible through language, but verbal data are still the most common form of data used in qualitative research. Image elicitation methods introduce visual elements to research processes and can enhance analytical insights into social phenomena; they are becoming more common but have not been widely used to explore health related topics.

What this paper adds?

A descriptive overview and reflections about implementing an innovative image elicitation method to study sexually transmitted infections, situated within a review of similar methods. The flash card activity elicits verbal and visual data about how meanings are made in relation to the research topic, in this case sexually transmitted infections, using a rank ordering approach and allowed participants to reflect on the process. This article uses a joint display to integrate multimethod qualitative data, an innovation of joint displays typically reserved for mixed methods research.

Introduction

Visual methods are becoming increasingly common in social research to produce findings with more depth and analytical insight into the research topic. They help go "beyond text" and overcome the reliance on verbal data (Banks, 2001, p. 2; Prosser & Loxley, 2008). Methods producing visual data can help

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link the subject and the narrative (Reavey, 2011, p. 10) and enable patterns and associations between different components to be seen (Goody, 1986, pp. 54–55, as cited in Banks, 2001, p. 24). Visual methods offer alternatives to words and numbers data to answer research questions about human experiences (Prosser & Loxley, 2008). They have been particularly successful in studies involving vulnerable or "unheard" populations such as formerly homeless people with mental illness (Padgett, Smith, Derejko, Henwood, & Tiderington, 2013) due to their participatory nature and different mediums of expression used. However, these methods are likely to have wider applicability in terms of the types of images used for elicitation and the groups they are used with. This study builds on the existing visual methods literature, focusing on image elicitation to describe an innovative method—the flash card activity.

I address two main research questions: How can the flash card activity be used to study sexually transmitted infections (STIs) and what impact does it have as an image elicitation method on data production? I start by reviewing the literature on image elicitation methods and the challenges of studying STIs before describing the flash card activity and reflecting on its use to generate data. This work is part of a mixed methods study exploring how social representations of STIs influence experiences and interpretations of symptoms and care-seeking responses in the general population in Britain (Mapp, Hickson, Mercer, & Wellings, 2016).

Image Elicitation Methods

Image elicitation methods are a collection of techniques often embedded within other methods, particularly qualitative interviews or ethnographies (Rose, 2016). The image can be created by the researcher or respondent-generated (Prosser & Loxley, 2008). I will discuss the following common elicitation methods, giving illustrative examples of each: photo elicitation with debriefing interviews, photo diaries and drawing methods.

Photo elicitation, defined as "inserting a photo into a research interview" (Harper, 2010, p. 13), is one of the most common image elicitation methods. It was first used by Collier (1957) to address a methodological problem in categorizing housing quality in a study examining mental health in changing communities in the maritime provinces in Canada. It has since been applied to a multitude of research topics primarily within the social sciences and humanities (Prosser & Loxley, 2008) and most approaches involve research participants taking photos (Rose, 2016, pp. 314–327). Suchar (1989) suggested photo elicitation is an interrogatory process where the photo acts as a question, stimulus, or probe to elicit additional meanings and social significance. Blinn and Harrist (1991) used photo elicitation in this way in their two-part study about females returning to college after time away from education. Participants were given a Polaroid camera each and asked to take 10 photographs representing their experiences as a reentry student and write a short description of the photo and the thoughts and feelings it evoked in them. These data were analyzed using thematic content analysis and photos were categorized according to the location in which they were taken. Participants then took part in a semistructured interview using the photos and written descriptions as a basis for discussion and thematic analysis of interview data provided additional insight to the photos to reveal time as an overarching theme across photo and interview data. Combining data from the photos and interviews highlighted conflicts in the women's experiences of their role as college students and their family duties, which was not apparent from either method in isolation.

A similar approach combining photos taken by participants with "debriefing" interviews was used by Karlsson (2001) to explore apartheid and postapartheid discourse in school environments in Durban, South Africa. Karlsson was keen to gain an insider perspective and used a visual method to "fix" the fluidity of the research environment to critically engage with the research topic and facilitate learner participation in research in a culturally and linguistically complex context. Focusing on methodological challenges, her findings highlight the importance and reliance on language within visual research, which is often not anticipated when using visual data (Karlsson, 2001). Karlsson's work is methodologically important, as it emphasizes the role of images within interviews both as a prompt to elicit verbal data and as a tool to reduce eye contact with the researcher, which may induce anxiety in participants.

Another use of photos as part of a method was described in a study about street children in Kampala, Uganda, where photo diaries were used to understand the child's perspective about daily life on the street and avoid "adult" assumptions about the research setting (Young & Barrett, 2001). Disposable cameras were given to 15 children to take pictures of their activities and places they visited over 24 hr. Like Karlsson's (2001) findings, the photos were a powerful discursive tool with discussions often revealing more information than the photo itself, despite the range of content and subjects photographed. Photos were analyzed chronologically to give pictorial representations of individuals' daily lives and then collated to generalize findings. This study used a multimethod approach and carried out other elicitation methods including drawing mental maps of places street children visited, thematic and nonthematic drawings about daily life and daily time lines (Young & Barrett, 2001, p. 144) allowing for creativity and free expression. Visual data were triangulated with data generated from other qualitative methods.

Bagnoli (2009) also used visual methods based on drawing (self-portraits, relational maps, and time lines) in qualitative interviews in studies about identity and migration between England and Italy and young people's lives, identities, and relationships in England. Using image elicitation methods made the research process more "stable" and enabled a focus on participant reflexivity and gathering holistic data. By using the researcher's instructions as a "scaffolding" (Bagnoli, 2009; Prosser & Loxley, 2008), participants produced their own meanings and associations for each drawing, which became the focus of analysis instead of using preexisting theory. Including elicitation methods as part of data collection helped participants convey what they meant but could not articulate in words and was useful to overcome silences around sensitive aspects of their stories (Bagnoli, 2009).

Using Image Elicitation Methods to Study STIs

I use the term STIs to encompass a range of sexually transmissible infections (World Health Organization, 2015). STIs still tend to be negatively framed in society, highlighting the taboo nature of the topic and associations with deviant behavior (Weston, 1999, p. 4). They are not commonly discussed outside medical settings (Hood & Friedman, 2011) and for some participants, the topic is not accessible through language (Eisner, 2008) because it is too abstract and unfamiliar, which presents some unique methodological challenges for studying STIs. Visual methods using elicitation techniques seem to offer a solution, but current image elicitation methods are not well suited to investigating personal health issues such as STIs. Taking photos of symptoms on and around genitals is neither feasible nor appropriate for this study. Similarly, as existing medical images of STIs and symptoms are often very graphic (Holmes et al., 2008), using these images may cause strong emotive responses, distorting individual's perceptions of their own experiences. Creating a drawing of STIs or related symptoms is unlikely to result in good quality data because of the unfamiliarity of what infections look like and may instead reproduce stereotypical images of infection and elicit superficial narrative.

However, image elicitation methods still offer methodological potential when the specific challenges of the research topic are identified and addressed creatively, an approach encouraged by Mason (2006). The flash card activity described in this article draws on image elicitation principles to ground the research topic through the creation of a visual image by the participant using predetermined conceptual themes and text-based flash cards. The method is designed to simultaneously mitigate the lack of appropriate language about STIs (by providing named infections and relevant themes to focus discussions) and explore the process of forming representations and making sense of these infections through verbal and visual approaches. The activity is an experimental method, developed specifically for this study, which is common in image elicitation approaches to meet the needs of the study aims and participants involved (Rose, 2016, p. 319; Young & Barrett, 2001).

The Flash Card Activity

Participants

The third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) was a large probability survey in Britain (Erens et al., 2014) and I used participant responses to the survey to identify my sampling frame for this study. I recruited participants who reported recent STI symptoms (see Table 1), never having attended a sexual health clinic, and who agreed to be recontacted about further research. These survey questions were asked to a subset of sexually experienced participants aged 16–45 years. I used a purposive sample to ensure the inclusion of different types of symptoms in women and men, to explore how these influenced representations of STIs (Mapp et al., 2016).

Table 1. Sexually Transmitted Infection Symptoms Asked About During The Third National Survey of Sexual Attitudes and Lifestyles Data Collection.

Male Symptoms	Female Symptoms
• Pain, burning, or stinging when passing urine	• Pain, burning, or stinging when passing urine
• Genital wart/lump	• Genital wart/lump
• Genital ulcer/sore	• Genital ulcer/sore
• Discharge from the end of the penis	• Abnormal vaginal discharge
• Painful testicles	• Unpleasant odor associated with vaginal discharge
	• Vaginal pain during sex
	• Abnormal bleeding between periods
	• Bleeding after sex (not during a period)
	• Lower abdominal or pelvic pain (not related to periods)

There were 16 women and 11 men in the sample. Most were White British/other, three were Asian/Asian British and one was Black/Black British. Five participants did not speak English as their first language. Sixteen were employed and six were in full-time education; less than a quarter of the sample were educated to degree level and two participants did not have any educational qualifications. Eight participants were from the two least deprived quintiles and 12 from the two most deprived quintiles in Britain (Payne & Abel, 2012). One participant reported having only 1 lifetime sexual partner and eight reported having more than 10 partners. Three participants reported they had previously been diagnosed with an STI.

Data Collection

Semistructured interviews took place a median of 30 months after survey data collection, in England and Wales. Two participants did not complete the flash card activity, one due to time constraints and the second because English was not their first language and they did not understand the term STIs. Participants were shown cards with the names of eight common STIs (Table 2; Centers for Disease Control and Prevention, 2013; World Health Organization, 2015), removed cards they were unfamiliar with, and then ranked them according to thematic continua (Table 3). Themes were informed by the public health literature on STIs and care-seeking behavior (Malta et al., 2007), psychological theories including the health belief model, theory of planned behavior, and Jones et al.'s (1984) six dimensions of social stigma, particularly "concealability," "aesthetic qualities," and "peril." Each of the six themes was dichotomized into extremes, for example, the prevalence theme was divided into the most and the least common, to simplify complex epidemiological, biomedical, and sociological concepts and to facilitate flash card ranking. I took a photograph of the participant's card arrangement for each theme. These photographs constituted the visual data alongside the verbal

Table 2. Flash Cards Included in the Flash Card Activity.

Infection Flash Cards Included in the Final Activity	
Chlamydia	HIV/AIDS
Genital herpes	Pubic lice/crabs
Genital warts (human papillomavirus)	Syphilis
Gonorrhea	Thrush (Candida/yeast infection)

Table 3. Flash Card Activity Continua Themes.

Continuum Theme	Explanation	Labels
Prevalence	How common is the infection?	Common—uncommon
Infectiousness	How easy would it be to catch the infection?	Easy to catch—hard to catch
Visibility	How visible is the infection?	Visible—hidden
Severity	How severe would the infection be if you had it?	Mild—severe/life threatening
Treatability	How easy is the infection to treat?	Easy to treat—hard to treat/untreatable
Blameworthiness	How much is it the fault of the person with the infection?	Completely the person's fault—not at all the person's fault

data generated by participants "thinking out loud" followed by discussions to elicit further justification for their positioning of the flash cards. I emphasized that it was their opinions I was interested in rather than specific knowledge about infections.

The flash card activity was carried out halfway through the interview following general questions about STIs, experiences of symptoms and care-seeking responses, and it preceded a discussion about STI stigma. The activity lasted between 14 and 38 min and the complete interviews ranged from 44 min to 1 hr and 48 min in duration. The whole interview was digitally recorded and transcribed verbatim.

I chose flash cards as the basis for the method to allow repositioning of the cards during the ranking process. Rank order exercises are flexible and useful tools for studying individual differences in opinion, decision-making, priorities, and preferences (Hudelson, 1994, pp. 19–20). The ordering and grouping of flash cards during the activity mirrors similar information sorting tasks such as Peterson and Barron's (2007) use of sticky notes in focus groups. They asked secondary school students to use the sticky notes to write their own ideas about the definition, purpose, and personal responses to assessment and feedback in school. They then asked them to organize the sticky notes into groups reflecting common and differing views on large sheets of paper. This stimulated more "engagement, interaction and discussion" (Peterson & Irving, 2008, p. 241) among students, generating contextualized explanations of common themes.

Ethical Considerations

All participants provided written consent agreeing to participate in the study, for the interview to be audio recorded and for anonymized data to be used. Ethics approval was given by National Research Ethics Service Committee South Central—Oxford A 11/H0604/10 and London School of Hygiene & Tropical Medicine Observational/Interventions Research Ethics Committee 6538.

Analysis of the Flash Card Activity Data

Visual and verbal data were analyzed separately but concurrently using principles of interpretative phenomenological analysis to understand how individuals made sense of STIs and the meanings and social representations of these infections (Smith, 1996; Smith, Flowers, & Larkin, 2009). The photographs were collated and grouped as a set of continuums completed by each participant (see Figure 1) as well as according to continua themes (see Figure 2). This enabled comparison of an individual's social representations of STIs as well as comparison across different participants' views within each theme.

For the transcribed verbal data, each transcript was analyzed in full to situate the flash card activity in the context of the complete interview. Empirical findings from these analyzes about STIs are reported elsewhere. The text relating to the flash card activity was then extracted and analyzed separately, according to the method described by Smith, Jarman, and Osborn (1999), paying particular attention to discourse. Using an idiographic approach, initial coding notes, comments, and questions were transformed into conceptual themes to summarize the "essence" of the data (Smith et al., 2009). Analyses were iterative and inductive, focusing initially on descriptive individual meanings which developed into interpretations of shared meanings and commonalities in the data (Smith et al., 2009, p. 79). The visual data were analyzed by considering the spatial positioning of the flash cards in relation to each other and the continuum end points. I developed codes to describe the pattern created for each completed continuum, referring to the transcribed verbal data to distinguish intentional variations in flash card positioning from incidental placement. I considered the content of the flash card activity and coded how participants had interpreted specific STIs in relation to the other infection flash cards and the overall theme. Analysis also focused on what impact the method had on the participant's account during the interview.

Visual and verbal data were then integrated using joint displays, a technique used to synthesize different types of data in mixed methods research (Guetterman, Fetters, & Creswell, 2015). This article represents the use of a joint display to integrate different types of qualitative data in a multimethod study, a novel application of the technique and methodological innovation in using joint displays typically reserved for integrating quantitative and qualitative research findings.
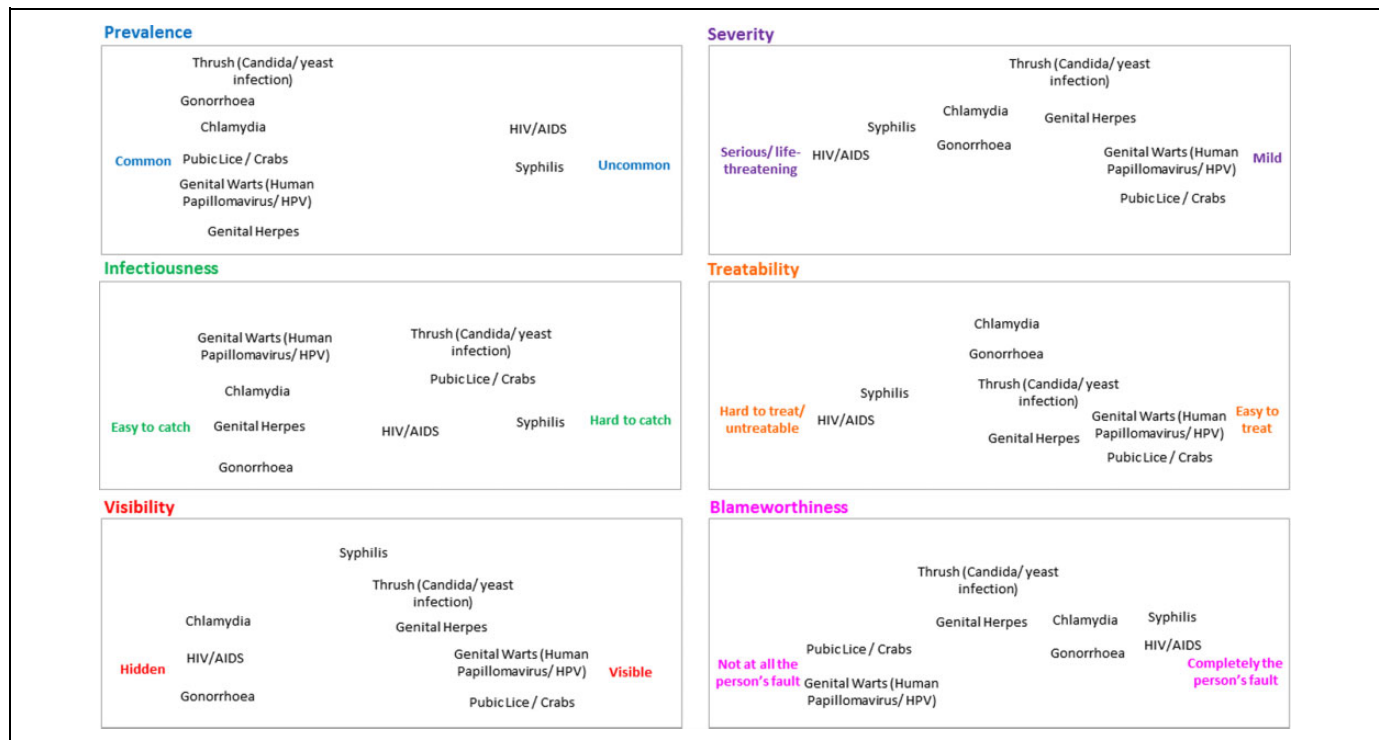
Figure 1. Ordering of the flash cards according to the six continuum themes by an individual participant (i13, man, aged 20–24).

Participants' descriptions of their ordering process were placed together with the photo of the completed continuum (represented diagrammatically in Figure 2) to look for areas of analytic convergence and divergence according to the research topic and methodological research questions (see Figure 2). Key themes were generated as the inference of data integration. This ensured photographs of continua were analyzed within the context of the interview, an analytic approach used in other visual methods studies (Blinn & Harrist, 1991; Pilcher, Martin, & Williams, 2015).

Findings

The focus of this article is on the methodological findings from using the flash card activity and does not report empirical results about STIs. Participants showed good engagement with the activity and 22 participants used all eight flash cards in their ordering process; the lowest number of flash cards used in the activity was five. All participants completed at least five of the six continuums and the blameworthiness theme was the most frequently refused continuum with 6 of the 25 participants either not attempting it or positioning all of the flash cards together (usually in the middle of the continuum extremes).

Verbal Data

The text element of the flash card activity gave participants specific terminology, which they could choose if and how to use. Specifying particular words offered a clear framework for participants to respond and helped structure the activity. Some

participants immediately adopted the language of the flash card activity as their own and became more confident in what they were saying, such as this participant who used the names of specific infections as she ordered the flash cards.

> I'm not sure about syphilis but I know herpes is untreatable and so is AIDS and pubic lice you could rid of easily. (i3, woman, aged 20–24, treatability continuum)

Incorporating the terminology of the activity helped participants make sense of STIs and consider the attributes of individual infections instead of collective meanings about the category of STIs. Before the flash card activity, narratives were fractured and less fluent, as participants searched for language to convey their views coherently. There was little evidence of preformed narratives about STIs, meaning participants had to make sense of their thoughts spontaneously when prompted during the interview. In most cases, participants struggled to describe their views about STIs. For example, in the following quote, the participant's response falters and his uncertainty about what to say is exposed.

> Interviewer: And what comes into your head when I say sexually transmitted infection, or STI to you?
> Participant: You shouldn't really say it 'cos anyone can get them but kind of, more it's perceived as slightly, not dirty people but kind of more promiscuous, stuff like that... (i24, man, aged 16–19)

The introduction of terminology, that is, the names of infections and specific themes, during the flash card activity opened

Figure 2. Joint display showing the integration of verbal and visual data from four different participants for the visibility continuum to produce key themes.

	Verbal data	Visual data (Hidden → Visible)	Inference (Key themes)
i27	*I'm thinking about what you can see like AIDS it affects you from the inside and I think these kind of infect you from inside so you wouldn't really know it unless they were really, really ill. With thrush because it's something physical and these are more physical things like the lice it affects you, you're itchy and people would be able to tell there was something wrong…you'd be very uncomfortable and so you'd know that there was something not right.*	**Hidden:** HIV/AIDS; Chlamydia; Genital Herpes. **Visible:** Pubic Lice / Crabs; Thrush (Candida/yeast infection); Genital Warts (Human Papillomavirus/ HPV)	• Heterogeneity of infections within category of STIs • Degrees of visibility of STIs depending on the context • Symptoms and social clues as key determinants of visibility • STIs visible to society through cultural reference points • Medical diagnostic tests make hidden STIs visible • Genital warts and genital herpes as visible STIs; HIV/AIDS and chlamydia as hidden STIs
i28	*I think they're all visible because they are out there, like I said the three that I didn't know they have come up on adverts on TV so it is out there, and again, the HIV and Chlamydia, I mean sort of Thrush, so, yeah, I think they're all visible…in terms of society…If like in terms of if I knew I had it I wouldn't be so sure, so it would be hidden.*	**Visible:** HIV/AIDS; Chlamydia; Genital Herpes; Gonorrhoea; Thrush (Candida/yeast infection)	
i8	*I was always get stuck on the middle ones, I can always think of the most visible and the hidden, or the most common and like that, but it's the middle ones that I get a bit like, ooh, what goes where…with HIV you can look ill as well, whereas chlamydia you don't…I think it's probably more common not to have symptoms, but then I suspect people do have symptoms because otherwise how would anyone know.*	Chlamydia; Genital Warts (Human Papillomavirus/HPV); Genital Herpes; Syphilis; Gonorrhoea; Thrush (Candida/yeast infection); HIV/AIDS	
i3	*I think they're like the most visible ones but because I've obviously read up on like the herpes one I know that sometimes it can be hidden and people don't know they have it or they mistake something for like something else so that's why I would say it's more hidden than say something like pubic lice, that's obviously…[HIV] it's hidden so you have to get tested in order to find out that you have it, unless you have symptoms.*	**Hidden:** Chlamydia; Gonorrhoea; HIV/AIDS; Genital Herpes. Thrush (Candida/yeast infection). **Visible:** Pubic Lice / Crabs; Syphilis; Genital Warts (Human Papillomavirus/ HPV)	

up a greater narrative range (beyond that which was given as part of the exercise) for participants and enabled more cohesive ideas to emerge. The quote below is from the same participant during the flash card activity.

> It could take a while for symptoms to show and then on some they can or can't have symptoms … I think HIV, AIDS can take years for it to have any detrimental effects on you, and the symptoms you get from that are not from the virus itself, they're from immune deficiencies. (i24, man, aged 16–19, visibility continuum)

Therefore, the flash card activity catalyzed verbal data production, as is common with other elicitation methods (such as Karlsson, 2001; Suchar, 1989; Young & Barrett, 2001). This resulted in richer data being produced facilitating understanding of STIs.

The flash card activity was particularly successful at disrupting normative discourses about STIs and helped overcome "clichés and ready-made answers" (Bagnoli, 2009, p. 566), such as STIs only affecting promiscuous people. This occurred as participants were choosing positions for the STI flash cards and justifying their reasoning. They often

reordered flash cards reflecting the reformulation of ideas about the infections and this added depth and additional meaning to the data collected similar to Young and Barrett's (2001) findings about how street children created and amended their mental maps of Kampala. The flash card activity also gave participants the opportunity to reflect on how their social representations were formed and influenced, which added a reflexive element to the method and highlights another advantage of including visual components (Bagnoli, 2009).

Visual Data

The flash card activity was semistructured, with predetermined flash card contents and themes that were interpreted and ranked by participants, creating different spatial patterns. I have included the original photo of a completed continuum in Figure 3, but other figures show diagrammatic representations for clarity. The patterns that participants created through ordering the flash cards were diverse (see Figure 2). Some participants interpreted categories as dichotomous, that is, infections were common or uncommon, severe or mild, and visible or hidden (Figure 2, i27). Other participants responded
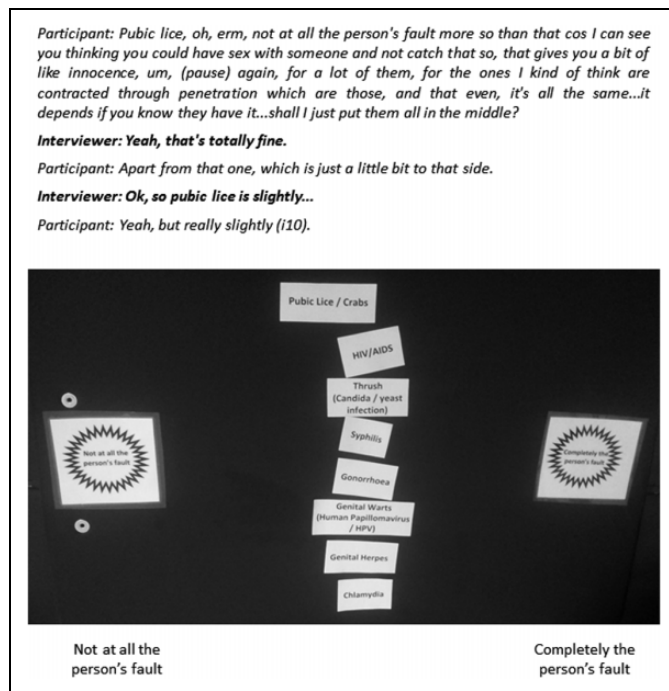
Participant: Pubic lice, oh, erm, not at all the person's fault more so than that cos I can see you thinking you could have sex with someone and not catch that so, that gives you a bit of like innocence, um, (pause) again, for a lot of them, for the ones I kind of think are contracted through penetration which are those, and that even, it's all the same...it depends if you know they have it...shall I just put them all in the middle?

Interviewer: Yeah, that's totally fine.

Participant: Apart from that one, which is just a little bit to that side.

Interviewer: Ok, so pubic lice is slightly...

Participant: Yeah, but really slightly (i10).

Figure 3. Participant (i10, man, aged 20–24) quote about ordering the flash cards for the blameworthiness continuum (top). The same participant's completed blameworthiness continuum showing differential positioning of pubic lice in relation to the other infection flash cards (below).

to the idea of a continuum very literally and there was strong linearity to their organization of the flash cards (Figure 2, i8). For other participants, it was a more complex pattern of relative relationships of the different infections, with marginal spatial differences conveying distinction in their social representations of one infection compared to another, which was only highlighted when verbal and visual data were considered together (see Figure 3).

The ordering or grouping of different infections gave some insight into the relativity of social representations of STIs. The flash card activity enabled participants to build up visual depictions of their social representations and circumvented the linearity of verbal speech (Gauntlett, 2007, p. 126). The visual aspect of the flash card activity accounted for and allowed the fluidity of the subject of STIs to be incorporated; it generated and organized data in a more tangible way than giving a verbal account and "fixed" the fluidity within the research process (Karlsson, 2001). Additionally, the physical presence of the flash cards and continuum themes in front of the participants provided a focus to discussions and made a complex topic more accessible. They acted as visual prompts to stimulate additional narratives that verbal prompts may not have elicited, performing a similar function to the photos in photo elicitation methods (Harper, 2010).

Other Methodological Findings

A valuable and novel outcome of the flash card activity was the insight it gave into the process of meaning making and the

forming and reforming of social representations of STIs. By asking participants to think out loud as they ordered the flash cards, additional explanatory data were produced that were not apparent from the visual data alone. Sources of cognitive dissonance were revealed through doing the activity, which the participant often reconciled as they went along.

Syphilis I know is kind of labelled as an old disease but I'm also aware that it's something that's been on the rise recently so . . . [it's] not uncommon really, just less common than the others. (i6, woman, aged 35-39, prevalence continuum)

The social context in which views about infections were created and revised was often incorporated within narratives, and participants drew on experiential knowledge to inform their decisions about ordering the flash cards. Some individuals disclosed personal experiences that they had not previously mentioned, suggesting the flash card activity was a useful way of accessing sensitive information which enriched the data set overall.

(Interviewer going through the infections listed on the flash cards)

I should say, I've actually had thrush . . . I thought I might have left it out. (i10, man, aged 20–24)

This participant then used their personal experience of having had thrush to help them complete the activity.

Thrush as I say, I've had, more than once so I'd say that's quite common . . . because, I have experience with that [thrush], those are obviously visible . . . thrush [is] mild, real mild as well, cos I had that as well and I'm fine . . . thrush you have one of those tablets and you get some cream and that's it . . . it's over in 2 days. (i10, man, aged 20–24, prevalence, visibility, severity, and treatability continua)

Disclosing personal information in the flash card activity may have been easier than in other parts of the interview as the method diverted attention away from the researcher–participant relationship as other researchers have found (Karlsson, 2001; Young & Barrett, 2001). While including the flash card activity broadened the data in some areas, it potentially restricted it in others. This activity relied on relative ordering of flash cards in relation to other cards and the continuum theme so is not necessarily generalizable to social representations about STIs in other contexts. The data were created within the setting of the interview and produced for the purposes of this study.

The flash card activity was a text-based exercise (similar to most qualitative data) rather than an expressive visual method and, in its current form, required specific knowledge that was not shared by all participants. Despite emphasizing it was the participants' own opinions and views that I was interested in, some participants were uncomfortable with gaps in their knowledge being revealed and tended to place that flash card in the middle of the continuum rather than removing it from the activity (see Figure 4).

Figure 4. Completed treatability continuum by i16 (woman, aged 25–29) with gonorrhea positioned in the middle of the continuum.

I'm putting gonorrhoea in the middle because I don't know any-thing about that. (i16, woman, aged 25–29, treatability continuum)

This led to some partiality in the flash card activity data. Placing flash cards in the middle of continua shares similarities with responses to quantitative scales and the central tendency (Tourangeau, Rips, & Rasinski, 2000), whereby respondents are unlikely to answer using the extremes of the scale and commit themselves to a specific viewpoint. Participants some-times employed guesswork or arbitrary flash card positioning which may have influenced the quality of the visual data and in turn, the verbal data produced. Despite the visual component, the flash card activity also required some language comprehen-sion about the research subject to understand instructions given, evidenced by the participant who did not complete the activity as they did not understand the term STI.

Some participants considered the themes too broad, vague, or abstract. Before starting the ordering process, a few imposed certain considerations that determined how they responded to the activity; themes were restricted to specific populations, geographical locations, behavioral determinants, or other con-textual social factors.

Oh we haven't spoken about protection, it depends whether you have protected or unprotected sex then [. . .] so we are talking about somebody who stays at home and has got a normal lifestyle. (i25, woman, aged 45–49, infectiousness continuum)

The scope for differential interpretations of the themes gave the flash card activity flexibility and potential to adapt within the parameters of the method (Bagnoli, 2009) and distinguished it from structured quantitative ranking exercises.

Acceptability of the Flash Card Activity

Other authors have reported the fun, interesting, and engaging aspects of using visual methods with participants (Pilcher et al., 2015) as well as enabling participants to have some autonomy and control of the research process (Young & Barrett, 2001). Overall participants enjoyed the participatory elements of the flash card activity and the change from the standard interview format. Although there was no formal evaluative component of

the activity, several participants gave spontaneous feedback about their experience of participating in the activity.

I'm enjoying this bit. (i2, woman, aged 35–39)

Okay, I like this game, to do [*sic*] my knowledge. OK, that's interesting. (i25, woman, aged 45–49)

Despite being a positive experience for most, a few partici-pants were not comfortable using the tool and in these cases, including the method in the interview may have artificially driven the process of deriving meaning about the subject matter and deviated from the core principle of "naturalness" within qualitative inquiry (Green & Thorogood, 2009, pp. 22–23).

Concluding Comments

The flash card activity is an innovative, text-based image eli-citation method, producing rich data in the form of photos of rank orders of STIs and associated verbal discussions about the ordering process in a sample of British adults. The duality of data generated different perspectives about STIs and contex-tualized new knowledge in meaning making processes. Con-sidering each completed continuum in conjunction with participants' explanations about how and why they had decided on the positioning of cards gave new insights into salient themes in relation to STIs and is a key advantage of using the flash card activity. Through the activity, the topic of STIs became more accessible; participants built up complex accounts using visual representation; and narratives were more fluent, cohesive, and diverse than those elicited in standard interviewing. This demonstrated the value of including an experimental image elicitation method within interviews, which was specifically designed to accommodate complexities of researching STIs (Hood & Friedman, 2011). Other visual methods have been shown to "prompt" data production (Pros-ser & Loxley, 2008) and photos in particular have been described as an "anchor point," a "springboard," and as a "safety net" (Hatten, Forin, & Adams, 2013). The flash card activity fulfilled all three roles, as it anchors the subject and makes an abstract topic easier to articulate, catalyzes data pro-duction, and provides language to participants, minimizing dis-comfort when articulating their views about STIs.

Development of the flash card activity aligned with the shift in qualitative research to embrace innovative approaches to produce data that fit the needs of the investigation (Taylor & Coffey, 2009). Although it built on other image elicitation methods, the flash card activity is distinct and there were inherent trade-offs linked to its utility. As the method used cards with written words, it imported the language and certain assumptions of biomedicine, which helped minimize discomfort in talking about STIs, but was a less dimensional approach than using photos or drawings. Differences in meanings were manifest in both the visual and verbal data, although discussion about the ordering often elicited implicit assumptions behind the meanings. Therefore, the verbal data often revealed more than the photos of the continua which support methodological findings from other visual methods (Karlsson, 2001; Young & Barrett, 2001). Using a text-based method was appropriate for understanding social representations of STIs, unlike using images of the infections, but required participants to know infections by name and inadvertently inserted a measure of STI knowledge into the activity. The activity is unable to capture the dynamism and fluidity of STI social representations as it collects data at one point in time. Repeated interviews using the activity may elucidate changes in how individuals think about specific STIs, reflected in different flash card positioning. The method had a defined structure enabling comparisons across continua themes and between different participants, but the semideductive approach limited the scope of interpretations of STIs beyond the parameters of the activity.

Through the processes of developing, implementing, and reflecting on using the flash card activity, I have devised recommendations for how to use the flash card activity effectively:

- Adapt the design of the flash card activity to the specific needs of the research questions, topic, and participants.
- Derive continua themes from relevant literature and theory.
- Embed this method within another qualitative method—semistructured interviews work particularly well. This will enable comparison of data generated by different methods.
- Ensure participants have sufficient knowledge of the items listed on the flash cards, there is enough time to conduct the activity during data collection and the location where data collection takes place is suitable (i.e., has a well-lit flat surface that both researcher and participant can access).
- This method works well for topics that are not often verbally discussed and that are not amenable to drawing or photographic methods and where different types of data are needed to access different perspectives or disrupt normative or stereotypical descriptions.
- The flash card activity should be implemented part way through data collection to allow data to be collected before and after specific terminology is introduced; the change in method also engages the participant in a different way, refocusing them, and minimizing the impact of research fatigue on data quality.
- Other applications of this method should utilize its advantage of eliciting and reflecting on the meaning making process of ordering flash cards not just the final ordering.

The data elicited were coproduced through interaction between researcher and participant and were contextual to the interview. Therefore I, as the researcher, had a substantial impact on what was said and not said and how continuum themes were interpreted and flash cards positioned. My gender was likely to have had the most influence on the flash card activity as STIs and other genital infections affect women and men differently (Weston, 1999); as a cis-woman, I found it easier to relate to women in the sample than men, and several women commented that they would not have been comfortable discussing this subject with a man.

There is potential to further develop and adapt the activity for different research contexts, subgroups, and purposes, and the flexibility of using flash cards as the main component of the method would enable a variety of data to be generated. This method could also be employed for generating multiple perspectives to understand how individuals attribute meaning to other stigmatized areas of health such as mental health conditions, psoriasis, or irritable bowel syndrome. The activity would be amenable to digitalization and administering via handheld tablets, which also increases the applicability of the method to other studies and may further increase engagement, as has been found with similar technologically enhanced elicitation studies (Pilcher et al., 2015).

Supplemental Material

Details about the data used in this study are available from the author. Data will be archived after completion of the study where participant consent has been given.

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Author Biography

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2.7 Ethical considerations

2.7.1 Ethical approval

Natsal-3 was granted ethical approval by the NRES Committee South Central - Oxford A (reference: 09/H0604/27). I submitted a substantial amendment to the existing ethics approval that had been granted for the Natsal-3 work package involving follow-up interviews with participants. I was granted approval for my study by NRES Committee South Central - Oxford A 11/H0604/10 and LSHTM Observational / Interventions REC 6538. I also signed Natsal-3 data usage agreements to adhere to internal governance procedures.

2.7.2 Ethical practices

I used adapted versions of the recruitment letter, information sheet and consent form that had been developed for the Natsal-3 follow-up interviews (see Appendix E p.328 and I p.349). I considered informed consent as a process rather than a one-off event (Israel and Hay, 2006, pp. 60–75) supported by the information sheet sent to participants in advance, by the verbal description given by the member of the Natsal-3 team and by myself during telephone conversations to arrange the interviews and on the day of the interview. During my explanation of the study and of what I would be using the data for, I made it clear the participant could stop the interview and withdraw from the study at any point and they could contact me using the details I provided in the recruitment letter and information sheet at any point afterwards to see their transcript or withdraw themselves. No-one has contacted me to date. I talked them through the consent form and asked them to initial next to each statement listed. All participants consented to all statements except for two who did not consent to their anonymised transcript being added to a data repository. I will exclude these participants and their data when I archive the transcripts. I assured participants of the confidentiality of what they told me and anonymised transcripts, removing names of people and places. I decided to use a

number based system for the transcript identification instead of pseudonyms which are commonly used in social research. This decision was based mainly on what felt right for my data. Names come with baggage related to social values, morals and inferences about class, ethnicity and age which all cluster around the name and influence perceptions about the person. Names are a big part of social identity, and whilst I didn't want to de-humanise my participants or detach the social context of my findings from the selected quotes, I didn't feel it was appropriate to import a different set of values with a pseudonym when all I wanted to do was differentiate my participants.

I was careful to balance the expectations of participants and my role as a researcher. In situations where I was asked for clinical information I made it clear I am not medically trained and re-iterated the purpose of the study. I gave participants the infographics that the Natsal-3 team produced based on the findings of the first six articles published in the Lancet November 2013 which included sign-posting to sources of help and support (see appendix H, p.341). The interview had a therapeutic aspect for some but was more difficult for others and may even have acted as a sort of intervention, raising awareness about STIs and prompting participants to seek information or visit a healthcare provider, although this was not something we discussed.

2.7.3 Data management

I established data protection measures to protect the identity of participants in this study before generating or receiving any data. The data usage agreement I signed with the Natsal-3 team necessitated data to be transferred via a secure FTP server only accessible by members of the team, and any transfer of data took place using encrypted devices. The audio recording of the semi-structured interviews was made on a password-protected device and transferred to my password-protected LSHTM desktop computer at the earliest opportunity, then deleted from the mobile device. I transferred files for transcription by an external company (approximately two-

thirds of the dataset) via encrypted software and asked them to sign a confidentiality agreement relating to the data. Audio and transcripts of the semi-structured interviews were stored on my password-protected LSHTM computer and backed up via the LSHTM servers. Printed transcripts were stored in a locked filing cabinet along with the signed consent forms from my participants. I only shared excerpts of my data with supervisors and those involved in double coding as per the consent form. As mentioned above, I will transfer the transcripts from the semi-structured interviews with participants who consented to a secure repository on completion of this study.

2.8   Chapter summary

I have summarised the theory of mixed methods research, the world view underpinning this study and explicated more detail about the research processes through two published research papers. I have also outlined the ethical considerations inherent within the study and the data management procedures I have put in place to ensure data security was maintained throughout the project. It was important for me to explain my methods fully instead of relying on the methods sections of the results papers in subsequent chapters as the methods shape the type of data elicited which in turn determine the robustness of my findings.

CHAPTER 3   RESULTS: SOCIAL REPRESENTATIONS OF STIS AND STI STIGMA

3.1   Chapter Overview

This is the first results chapter of this thesis and I present empirical findings about social understandings of STIs and STI stigma. These results explore STIs in a social context and start to link the concept of STI stigma to symptom experiences, seeking care and other help-seeking behaviour, which are followed up in more detail in the following two results chapters (chapters 4 and 5). Specifically, the findings presented in this chapter help to answer the first and second research questions: 1) Can perceptions of STIs help explain genito-urinary symptom experiences and care-seeking behaviour? And 2) What is the role of stigma in genito-urinary symptom perception and care-seeking?

This chapter starts by examining the social representations of STIs using data from the flash card activity (described in the flash card paper in chapter 2). I then introduce the results paper about dirt and STI stigma, stating the purpose, justification and key themes in section 3.3. The research paper itself uses semi-structured interview data to explore perceptions of STIs, specifically STIs as dirt and draws heavily on Mary Douglas' work to understand symbolic meanings of dirt in relation to maintaining the social order. I do not mix data across paradigms here (i.e. this chapter does not use Natsal-3 survey data). The discussion of the paper in section 3.5 includes empirical and methodological reflections, highlighting the emergence of dirt as a key component of STI stigma and considering the use of the methods to understand participant experiences. The chapter closes with a review of what has been discussed and an explanation of how these findings link to the results chapters about symptoms and help-seeking.

3.2 Social representations of STIs

I consider knowledge about STIs to be shared within social contexts and shared between individuals, following notions of social representations theory (Moscovici, 1961 in Farr, 1987) which draws on Durkheim's concept of 'collective representations' (Durkheim, 1898). Parker defines social representations as *"shared images and concepts through which we organise our world"* (Parker, 1987 p448) and Wagner et al. (1995) elaborated on these ideas by suggesting social representations were *"images or metaphors…created in everyday discourse between social groups"* (Wagner et al., 1995 p673). These definitions tap into the sharing of social reality and the impact this has on individual behaviour (Jaspars and Fraser, 1984 in Farr, 1987). For concepts to be shared, there must be some form of communication about the subject, but for a stigmatised and sensitive subject such as STIs, silence may speak more loudly about how the phenomena is represented in society.

STIs have long been perceived differently from other infections (Siena, 2004). This is partly attributable to their obvious association with sex, which in turn has moral associations (Hood and Friedman, 2011). STIs are still perceived and described in negative terms (Holt *et al.*, 2010; Hood and Friedman, 2011). They are often interpreted as an indicator of risky sexual behaviour, irresponsibility and lack of hygiene (Mapp, 2013), making them socially and morally unacceptable (Scoular, Duncan and Hart, 2001).

The academic literature tends to focus on individual attitudes towards specific STIs (for example Chlamydia (Duncan, 2001) or genital herpes (Barnack-Tavlaris, Reddy and Ports, 2011)) and more general descriptions of social representations of STIs as a group of infections are uncommon. This may be because social representations are formed through discourse (Wagner *et al.*, 1995) and STIs are often 'silenced' in social contexts (Hood and Friedman, 2011). Studies also tend to describe STIs as a

homogeneous category without distinguishing between different types of infections. Generalising and assigning characteristics at an aggregated level risks overlooking specific determinants that may influence social representations and conceptualisations. Studies have revealed differences in narratives about STIs with visible symptoms such as genital warts and herpes, and those that are predominantly asymptomatic such as chlamydia (Balfe, Brugha, O' Donovan, *et al.*, 2010). Holt et al. (2010) discovered that gay men perceived differences between chronic viral STIs and more treatable bacterial STIs, and HIV is often viewed as a distinct infection (Arkell *et al.*, 2006; Balfe, Brugha, O' Donovan, *et al.*, 2010) probably influenced by memories of rapid declines in health and significant fatalities before the availability of effective treatment (Obel *et al.*, 2011). These studies suggest some variation in current social representations of STIs although these have not been fully explored in a range of different infections.

Participants in the semi-structured interview component of this study told me that they did not often think about, or talk about STIs, suggesting full or partial concealment of the topic in everyday discourse and social settings. However, all participants were able to describe the manner in which STIs were represented socially, when prompted, with one exception (i18) who did not have English as a first language and did not understand the term. Descriptions of STIs were generally spontaneous and unrehearsed, often articulated through fractured sentences and sometimes by single, negatively valued descriptive words such as *"dirty"* and *"disgusting."* Participants often made sense of the topic as they went through the interview and became more comfortable over time in talking about the subject. This gave valuable insight into the process of meaning-making and the sources of knowledge and information they drew on to form and re-form ideas.

Given the recognised difficulty in talking about STIs (Hood and Friedman, 2011), I incorporated an additional data collection technique within the standard interview which is an increasingly common approach used to study research topics that may

be difficult to express verbally (Bagnoli, 2009). Embedded within the interviews was a visual method based on image-elicitation techniques and developed specifically for this study (see the flash card activity paper, chapter 2) to explore dimensions of stigma (Jones, 1984) and related concepts. Participants were asked to 'think-out-loud' as they ordered flash cards with the names of sexually transmissible infections from the most to the least of each pre-specified theme derived from the stigma literature (Jones, 1984; Malta *et al.*, 2007), (see tables 2 and 3, flash card activity paper, chapter 2). I then took a photo of each completed continuum with the STI flash cards positioned along it to create visual data linked to the verbal data also collected. The activity was designed to elicit rich data about the social representations of STIs and how individuals made sense of them as well as enabling a different way of accessing a topic that is quite abstract and often hard to articulate in words alone.

Transcribed text and visual data from the flash card activity were analysed in combination using thematic analysis (Braun and Clarke, 2006) focussing particularly on sense-making about STIs. Together, this generated insight into the meanings generated about STIs from the sense-making processes that occurred to complete the activity. These meanings in turn framed and contextualised participants' accounts at other points during the interview about their symptom experiences and help-seeking behaviours. Additionally, descriptive summaries of all collated responses for the six continua and for each of the eight STIs that were included were developed to highlight convergence and divergence of individual and collective views.
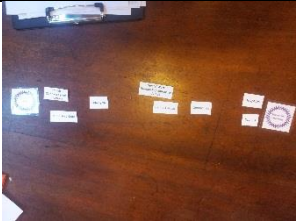
The flash card activity (see flash card activity paper, chapter 2) elicited valuable comparative data about specific infections and key dimensions of STIs, including aspects of stigma (such as blameworthiness which relates to the components of stigma identified by Link and Phelan (2001) and Jones' (1984) dimensions of stigma

particularly concealability, aesthetic qualities, origin and peril) as shown in tables 4 and 5.

Table 3 brings together the transcribed verbal data describing interpretations of STIs, and the visual data of the photograph of the final flash card positioning along each continuum according to each of the continua themes. It constitutes a joint display of data from different methods, a technique used to present and integrate data in mixed methods research (Fetters, Curry and Creswell, 2013a; Guetterman, Fetters and Creswell, 2015). The flash card activity enabled me to access individuals' perceptions and comparative views about named STIs, more general views of STIs as a group of infections, and collectively, looking across flash card activity data from all participants, to interpret the social representations of STIs according to key themes.

Table 3: Summary of verbal and visual data from the flash card activity data for each themed continuum

Continua theme	Continua end-points	Summary of flash card activity data	Example completed continua	Example quote
Prevalence	Common - uncommon	Thrush and chlamydia were consistently positioned as two of the most common infections and HIV/AIDS and syphilis as the least common. There was a tendency to group infections around the common end of the continuum which suggested STIs were perceived as common health issues	(i20)	*"Thrush is more common than the other ones, I would have said, it's more common than genital warts and genital herpes and chlamydia, but I think pubic lice and crabs could be on the same as thrush"* (i20, man, aged 30-34)
Infectious-ness	Easy to catch – hard to catch	Similarities to the prevalence continuum with those perceived as common also generally considered as more infectious and easier to catch; pubic lice in particular considered easy to catch. There were groupings of infectious at the easy to catch end of the continuum but greater variation in overall flash card positioning across participants and more of a tendency towards placing flash cards near to the middle. Genital warts and syphilis were perceived as hard to catch.	(i16)	*"From what I've heard Chlamydia's quite common so I'm guessing it's fairly easy to catch…genital herpes I know you've got to have like skin-to-skin contact so I think that would be hard to catch…If the infection's active at the time I don't think they're really going to be wanting to be getting down."* (i16, woman, aged 25-29)

Visibility	Visible – hidden	Interpreted as more distinct categories – STIs tended to be interpreted as either visible or hidden but there are degrees of visibleness depending on the context – self-examination compared to someone else seeing symptoms, or whether the person is wearing clothes or not. Genital warts and genital herpes were consistently positioned as visible and to a lesser extent pubic lice, although these were sometimes considered to be hidden due to their physical size. HIV/AIDS and chlamydia were predominantly construed as hidden infections.	 (i7)	*"Chlamydia, we know that the symptoms are not very obvious. Well this I would think again, very visible. This, thrush, yes also visible, genital warts as well, genital herpes as well"* (i7, woman, aged 40-44)
Severity	Mild – serious/life-threatening	Linked strongly to how easily treated the infections were and if they could be cured through treatment. Thrush was the most mild of the infections included and HIV/AIDS placed in the most extreme position at the serious/life-threatening end of the continuum by all except two participants.	 (i6)	*"So HIV and AIDS, syphilis I'd say are serious and life threatening. Thrush is mild and pubic lice. Chlamydia isn't life threatening but you, I think you need to probably get it treated"* (i6, woman, aged 35-39)

Treatability	Easy to treat – hard to treat	Chlamydia and thrush were perceived to be the easiest to treat with participant explanations based on how treatment was accessed i.e. over-the-counter medication compared to prescribed treatment and the amount of treatment or duration of the regimen i.e. one dose compared to multiple pills over an extended period of time. HIV was interpreted as the hardest to treat as everyone knew it was not curable and similarly genital warts and genital herpes were also positioned nearest the hard to treat end of the continuum.	(i29)	*"I think syphilis is quite hard to treat, HIV hard to treat. This probably, this gonorrhoea is always my problem. These are probably easier to treat and the human papillomavirus is easy to err monitor and eventually to treat. But probably it's more on the hard to treat, yeah because it's more invasive whatever you get is more invasive than the rest, I think the rest you can do with tablets and antibiotics and creams."* (i29, woman, aged 40-44)
Blame-worthiness	Not at all the person's fault – completely the person's fault	The majority of participants clustered the infections around the not the person's fault end or that half of the continuum. The amount of blame related to how treatable the infection was and the long-term consequences. Blameworthiness was also linked to visibility as symptoms acted as a visual warning and it was perceived to be irresponsible to continue having sex if you had seen any abnormalities.	(i12)	*"Don't think it's anyone's fault that they get something unless obviously, they're just stupid…if they went out, and they were just sleeping with all, absolutely everybody with absolutely no protection and, then that's just stupid"* (i12, woman, aged 25-29)

The flash card activity shows that participants were able to distinguish between the different STIs according to the themes, placing the flash cards at different points along each continuum. Groupings at the end-points (i.e. most and least extreme of each themes) and in the middle between the two extremes were common pattern formations. The positions along each continuum chosen for each STI allowed participants to consider the different attributes of each infection, something they had not done elsewhere in the interview, where the tendency was to treat STIs as a homogenous category.

> *Like gonorrhoea is completely different to crabs. You can't put them in the same bracket at all, because gonorrhoea is inside, crabs is on the outside…[it's] like chalk and cheese…but they are the same because they're a nuisance as well (i11, man, aged 16-19)*

In this way, they built up multi-dimensional representations of each STI throughout the course of doing the flash card activity. I then synthesised the information about each STI across the six themes for all participants to create a meta-narrative of the eight STIs included (presented in Table 4). I looked for commonalities in positioning of STI flash cards between participants across all themes and focused on description of the STIs rather than more interpretative analysis at this stage. STIs were constructed as complex and multi-dimensional infections, with meaning created along intersecting themes (those of the six continua). This multi-dimensionality is explored in more detail in table 4.

Table 4: Summary of participants' views about specific STIs from the flash card activity data

STI	Meta-narrative from flash card activity data
Chlamydia	All participants considered chlamydia to be common, second only to thrush in some cases. This was linked to chlamydia being easy to catch (i.e. highly infectious). There were mixed views about how visible it was: some thought of it as hidden because it is an internal microscopic infection with few symptoms therefore cannot be seen, but the social visibility increased awareness of it and

	contributed to how visible chlamydia was. The normality of chlamydia testing demonstrated the tension in interpreting visibility of chlamydia: on one hand testing was necessary as the infection was invisible and a diagnostic test was the only way to know if chlamydia was present. On the other hand, testing increased the visibility of infections, illuminating aspects of experience not visible by other means. Chlamydia was described as fairly mild, particularly by younger participants (under 25 years) but some did mention long-term complications relating to fertility. Chlamydia was thought of as treatable and a few mentioned only having to take one pill to cure the infection. Five positioned chlamydia as completely the person's fault but others thought of it as similar to other STIs, grouping them together.
Genital herpes	There were very similar views about genital herpes as there were for genital warts and often participants indicated they did not know the difference between them and/or thought they were the same. Slightly less was known about genital herpes than warts but it was often linked to cold sores which tended to minimise ideas about severity. There were mixed views but also a lot of fairly neutral views about genital herpes being neither extremely common nor uncommon. Again, participants exhibited mixed views about infectiousness but more thought of genital herpes as hard to catch and treat. It was considered as very visible but also mild and was grouped with other STIs in terms of blame.
Genital warts/ HPV	Genital warts and herpes were often conflated as described in the row above. Warts were frequently linked to cold sores and cervical cancer (because I included HPV on the flash card). The defining feature of genital warts was their visible appearance and most understood warts in terms of their presence on other body parts. Similar to genital herpes, genital warts were considered to be neither common nor uncommon, quite hard to catch, mild and fairly easy to treat (although the length of time to treat was noted as a factor in considering them to be harder to treat). Genital warts incurred similar amounts of blame as other STIs.
Gonorrhoea	Gonorrhoea was the least well known STI, however only one participant removed it from the activity. It was frequently placed in the middle of all continua, representing the uncertainty about specific information about gonorrhoea, rather than being thought of in terms of being at a mid-point between the extremes because of its innate characteristics. Symptoms were not mentioned by participants (due to lack of knowledge) and it was grouped with other STIs in terms of blame.
HIV/AIDS	HIV constituted an extreme example of STIs and the social aspects of HIV were far more commonly described than for other STIs

	making it an exceptional case as has been documented elsewhere (Bayer *et al.*, 1999). This reflected greater social understanding and representations of HIV beyond the field of biomedicine, which influence perceptions. HIV was thought of as uncommon but well known, therefore several participants noted it was probably more common than most people thought. There were mixed impressions of how infectious it was with fear of catching HIV exaggerating ideas about how easy it was to catch. Other routes of transmission were highlighted (especially sharing needles and blood transfusions) which added to the views that it could be quite infectious. HIV was considered an invisible virus with no symptoms until the end stage of AIDS and a lot of people were thought to live with it without knowing they have it, contributing to the fear of it as a silent, hidden killer. HIV was described as serious and life-threatening by all participants because of persistent ideas developed before the introduction of Highly Active Antiretroviral Therapy (HAART) in 1996 (Delaney, 2006). Most participants mentioned that you can die from it and the lack of a cure meant that everyone considered it hard to treat or untreatable, as conflation between curability and treatability was common from piloting the flash card activity (see flash card activity paper). Finally, there were mixed views about how much blame was linked to HIV. Some participants placed a lot of blame on those with HIV because of the implications of transmitting the virus whilst others positioned flash cards at the opposite end of the continuum (not at all the person's fault) because of pity for people living with HIV.
Pubic lice	There were mixed views about how common or uncommon pubic lice were – participants often linked them to head lice and understandings of head lice used to infer understanding and perceptions of pubic lice. Pubic lice were thought to be quite easy to catch and most participants understood the method of transmission which was more intuitive than thinking about the transmission of bacterial and viral STIs. Lice were generally thought to be visible but their size was a consideration (visible to the naked eye but small enough to be missed unless careful examination took place). They were mild and treatable as they were external to the body – on the surface of the skin therefore had limited potential to cause damage to bodily structures and functions. Pubic lice did not incur much blame in line with perceptions of other STIs and two participants removed the pubic lice flash card from the activity due to lack of knowledge.
Syphilis	Syphilis was removed from the activity by three participants. It was considered uncommon and quite hard to catch which linked to having more blame associated with it than other STIs in the flash

	card activity. Not many participants knew about symptoms, resulting in a mixed collective view of how visible it was. Syphilis was portrayed by participants as being an old, historical disease and several mentioned key historical figures having it as well as noting some more obvious symptoms related to loss of eyesight and neurological complications, conflating different stages of syphilis and the social and physical visibility of the infection. Most thought it was serious and/or life-threatening.
Thrush	Thrush was removed from the activity by one participant who did not know what it was but was generally considered to be common. Thrush was also perceived as being fairly easy to catch (i.e. quite infectious) and easy to treat. Most considered it to be fairly mild, although a few participants described it as more severe if they had thrush and it had lasted for more than a few days. Their perceptions were relative to their other experiences of STIs and most had not been diagnosed with other infections. There were mixed views about how visible thrush was. Some considered it highly visible because of the associated discharge and smell (although not strictly about visibility, smell did come in to some accounts, broadening the interpretation to consider other sensory experiences contributing to how easily concealable the condition was). Others thought of thrush as more of an internal issue which was not visible and could more easily be concealed to others. Finally, thrush was considered to be fairly blameless and not at all the person's fault for having it, as most people made the distinction between sexually transmitted and sexually transmissible infections (even if they did not use this terminology). Even when other STI flash cards were grouped together in the middle of the continuum, thrush was separated as an exceptional case and positioned to represent even less blame. This reinforces the tendency for infections associated with lifestyle choices to incur more blame than others (Crawford, 1977).

I have chosen not to compare the data in table 4 with other quantitative findings about the nature of STIs as I am not looking to find a specific type of 'truth.' For example, I could have used surveillance data from Public Health England (2017) and compare measured prevalence of the different STIs (of those that are notifiable and therefore reported) to perceptions of how common participants thought they were. Although interesting, this does not help me answer my research question about how social representations of STIs influence lived experiences of genito-urinary symptoms and help-seeking responses.

From this analysis of the social representations of STIs, I have evidenced the negative connotations of these infections, highlighting dirt and disgust as common descriptors of STIs as a group. I have also shown the variability of social representations relating to specific, named infections by participants. These findings may go on to form a short research paper about social representations of STIs, similar to Holt et al. (2010), after submission of this thesis. Stigma is a common shared social representation of STIs, and manifests in individual perceptions of STIs, as I have elucidated through the flash card activity. More focused exploration of sense-making about STI stigma and the impact on lived experiences is needed to understand if and how it influences health experiences. These aspects will be explored in the following research paper about STI dirt and stigma.

3.3   Introduction to the research paper

This paper draws on the data from the 27 follow-up semi-structured interviews I conducted with Natsal-3 participants. Natsal-3 did not include a measure of STI stigma and I was keen to use an exploratory approach to understand individual sense-making about STI stigma rather than quantify manifestations and individual perceptions. Therefore, I did not seek an alternative quantitative data source about STI stigma as I felt it would not add much value to this study, would require a lot of comparative analysis about the different participant samples and may limit the potential for data integration.

In this paper, I explore how STIs are perceived by British women and men, how these perceptions differ from other health issues and the implications for preventing and treating STIs. I explore, in detail, the meta-theme of "STIs as dirty" to consider STIs as dirt, sex as dirty, moral and physical dimensions of dirt and strategies for dealing with the dirt in participants' accounts. I have employed a two stage analysis process using thematic analysis which offers a flexible approach to identifying and analysing patterns in qualitative data, enabling rich descriptions of

the phenomena being studied and interpretations of individuals' experiences (Braun and Clarke, 2006). The key theme of "STIs as dirty" identified from the thematic map of the data is then analysed interpretatively using Framework analysis (Ritchie and Spencer, 1994; Ritchie and Lewis, 2003).

I have written this paper with the intention to submit it to Social Science and Medicine as an original research article.

3.4   Research paper: Stigma results paper

Status: To be submitted to Social Science and Medicine

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RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Fiona Mapp
Principal Supervisor	Ford Hickson
Thesis Title	Sexually Transmitted Infections: A Mixed Methods Study of Stigma, Symptoms and Help-seeking

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Social Science & Medicine
Please list the paper's authors in the intended authorship order:	Fiona Mapp, Ford Hickson, Catherine H. Mercer, (other Natsal-3 team members tbc), Kaye Wellings
Stage of publication	**Not yet submitted**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	FM conceived the design of this study in conjunction with KW, CHM and FH. FM conducted and analysed all semi-structured interviews with support from FH and KW. FM wrote and edited all drafts with critical input from FH, CHM and KW. The final draft of the paper will be circulated to the Natsal-3 team for approval.

Student Signature: ███████████   **Date:** 14/07/17

Supervisor Signature: ███████████   **Date:** 14/7/17

"BIG, GREEN, WARTY KNOBS": AN EXPLORATION OF DIRT AND SEXUALLY TRANSMITTED INFECTIONS STIGMA

Fiona Mapp, Ford Hickson, Kaye Wellings

Abstract

Sexually transmitted infections (STIs) remain a stigmatised health issue despite much public health practice and research attention on de-stigmatisation efforts. STI stigma can delay or prevent seeking care at sexual health services and contribute to the undiagnosed and untreated infection. Patients who are diagnosed with STIs report feelings of dirtiness and other negative connotations. We explore perceptions of STIs among women and men in Britain, how these differ from other health conditions, and how they influence actual or potential preventive practice and help-seeking. This study draws on data from semi-structured interviews conducted between May 2014 and March 2015 with 27 women and men who had experienced STI symptoms, drawn from a national population survey about sexual attitudes and lifestyles (Natsal-3). Thematic mapping identified a prominent theme about the perceived dirtiness of STIs which was explored in more detail using Framework analysis. STIs were frequently seen as dirt, interpreted as anomalies that did not fit the classification system underpinning social order. Dirt and stigma were common perceptions and participants made links between these concepts, suggesting that dirt is a key component of STI stigma. Promiscuous sex, especially when unprotected or outside of established partnerships was also seen as dirty and stigmatised. Dirt had moral dimensions relating to moral impurity and tarnishing reputations and also physical dimensions in the context of hygiene. Both moral and physical dirt can be considered as transgressions of boundaries of the body and were often conflated and amalgamated in participant accounts. Participants described three ways of dealing with dirt: silencing and concealing; distinguishing STIs from other diseases and through preventive and help-seeking strategies. The

association of STIs with dirt, dirty people and dirty sex may bias individual perceptions of STI risk, however as participants stigmatised unsafe, unprotected sex, this may have public health benefits. The relationships between dirt and stigma need exploring in other population groups, settings and types of infections to better understand how they may be levered to improve individual and population health.

Keywords**:** Sexually transmitted infections, stigma, dirt, STI symptoms, help-seeking, Britain

Introduction

A high proportion of sexually transmitted infections (STIs) are undiagnosed and unreported despite extensive public health efforts to encourage help seeking (see debate article, chapter 1). Help-seeking behaviour is heavily influenced by a person's own perceptions of the disease (Fortenberry, 1997), including how it might be seen by others, how it might reflect on them and what is entailed in the process of investigation. These factors are particularly relevant to experience of STI, yet in the past more attention has been paid to knowledge and awareness than to personal perceptions of these infections.

An exception to this generalisation is the focus on stigma in relation to STIs. Stigma has been described as a "*discrediting attribute*" (Goffman, 1963), "*mark*" (Jones, 1984) or "*label*" (Yang *et al.*, 2007) linking individuals to "*undesirable characteristics*" (Lewis, 1999). Newton and McCabe (2005) point out that it is the interpretation of the attribute that causes the negative effect rather than a property of the attribute alone. Stigma therefore acts as a physical or metaphorical sign. Jones (1984) suggested six dimensions of stigmatising conditions, four of which have particular relevance to STIs: 'concealability' (how visible infections are), 'aesthetic qualities' (how disgusting or repellent symptoms are), 'origin (the cause of infections and associated blame)' and 'peril (danger or threat to others)'. STI

stigma remains a major barrier to sexual healthcare (Kinghorn, 2001), preventing or delaying individuals seeking care and discouraging disclosure (Barth *et al.*, 2002; Fortenberry *et al.*, 2002; Lichtenstein, 2003; Mulholland and Van Wersch, 2007). Hood and Friedman's (Hood and Friedman, 2011) review of STI stigma also suggests it causes psychosocial stress to those infected and contributes to negative attitudes towards STIs. They go on to point out the absence of exploration of social dynamics in relation to shaping STI stigma and influences on public perceptions of STIs. Gaps also exist in relation to unpacking stigma as a concept to explore how it exerts negative effects on sexual health and wellbeing.

STIs are therefore stigmatising and stigmatised conditions (Piercy, 2006). When people do seek care and are diagnosed with an STI, they report negative feelings of shock (Duncan, 2001; Scoular, Duncan and Hart, 2001), self-disgust and distress (Duncan, 2001), embarrassment, guilt and shame (Lichtenstein, Hook III and Sharma, 2005; Newton and McCabe, 2005; Balfe and Brugha, 2009; Balfe, Brugha, O' Donovan, *et al.*, 2010). There are also strong themes around dirt and contamination running through accounts from those who have attended a sexual health clinic and/or been diagnosed with a STI. Several different STIs have attracted the label "dirty" including HIV and genital herpes (Waldby, Kippax and Crawford, 1993; Lawless, Kippax and Crawford, 1996; Lewis *et al.*, 1999). Scoular (2001) found that women diagnosed with Chlamydia in Glasgow felt dirty, and that dirtiness formed part of the negative feelings towards STIs along with guilt and moral judgement. Similarly both women and men described feeling dirty following diagnosis with Chlamydia in a study in the Midlands area of the UK (Piercy, 2006). The authors suggested that participants experienced and expressed their infection as a sense of bodily contamination which challenged their sense of self. The same study also found that re-testing helped those previously diagnosed with Chlamydia to manage feelings of contamination and bodily pollution; a negative follow-up test held symbolic significance as the end of dirtiness and restoration of cleanliness for individuals (Piercy, 2006a). The desire to get rid of contamination was found to be a

strong motivator for men and women attending specialist sexual healthcare in the north east of England (Mulholland and Van Wersch, 2007).

These studies suggest that ideas about dirt and contamination are important to heterosexual individuals in clinical environments and can influence subsequent behaviours. However the dirtiness of STIs has also been reported in other social and cultural contexts. Feeling dirty was a common experience for gay men diagnosed with STIs in Sydney, Australia (Holt *et al.*, 2010). STIs are labelled "dirty diseases" from a study in Laos (Sihavong *et al.*, 2011), and "dirty illness or "dirty blood" by diverse communities in South Africa (Shefer *et al.*, 2002). Perceptions about cleanliness and dirtiness of female sexual partners were fundamental in socially excluded young men's negotiation of STI risk (Limmer, 2016). These perceptions were based on dress, demeanour, area of residence, social class and perceived sexual activities. Similarly perceptions of cleanliness and dirtiness were important in perceived HIV risk in relation to injecting drug behaviour and were formed from judgements about appearance, familiarity with the person and their previous behaviour (in relation to sex and injecting practices) (Hughes, 2009). Therefore, dirt does not appear to relate only to physical infection and has broader social connotations and meanings.

Theoretical perspectives relating to dirt have drawn predominantly on the work of anthropologist Mary Douglas, who in turn drew on Durkheim's theories of social order (Durkheim, 1895). Douglas' (1966) conceptualisation of dirt is "matter out of place" i.e. material in the natural and social world that does not 'fit' the categories constructed to maintain the social order, so is residual and transgresses the boundaries of the categories. Dirt encompasses everything that blurs, smudges or contradicts accepted classifications (Douglas, 1999, p. 51), such as STIs, which are liminal to categorising the self/other, and as such, have the capacity for pollution. Dirt is dealt with by suppressing or avoiding, the latter meaning excluding dirt from sight, speech and mind. For Douglas, dirt offends against order and it is in this sense

that her thinking helps in understanding perceptions of STIs. In framing her cultural accounts of purity and impurity, Douglas dismisses "medical materialism" (Douglas, 1966, p. 36) meaning that the way in which things are classified as clean and unclean goes beyond a concern for hygiene. Ideas about purity and impurity also distinguish what is perceived as normal and acceptable or abnormal and deviant in a particular context (Duschinsky, Schnall and Weiss, 2016, p. 2). What is seen as proper sex is condoned whilst improper sex is censured (Douglas, 1999, p. 262). This perspective applies to STIs, as well as other sexuality issues such as homosexuality, transactional sex and pornography. According to Foucault, these do not fit within the category of the procreative, conjugal union and so are subject to social suppression (Foucault, 1990).

There may be conceptual linkages between dirt and stigma in relation to STIs, which are likely to have implications for sexual health and wellbeing. Shefer (2002) suggests stigmatising STIs involves stereotyping, the most pervasive of which is promiscuity including sexual looseness, dirtiness and immorality, from focus group research in South Africa. These findings are echoed by an Australian in-depth interview study with women who reported feeling stigmatised which was expressed in terms of stereotypes of women with STIs being dirty and promiscuous (East *et al.*, 2012). Coupled with Douglas' (1966) work about suppressing and avoiding dirt and theories denoting stigma as a mark that is interpreted negatively, dirt may be a component of stigma that has not been well conceptualised, particularly outside of clinical settings. We explore perceptions and meanings of STIs in the general population and implications for prevention and treatment.

Methods

This qualitative study was part of a larger sequential mixed methods study exploring how social representations of STIs influenced symptom experiences and help-seeking responses using data from the third National Survey of Sexual

Attitudes and Lifestyles (Natsal-3) (Erens *et al.*, 2013). Natsal-3 was a probability sample survey which took place in Britain 2010-2012, interviewing 15,162 women and men aged 16-74 years about sexual attitudes and lifestyle. The study protocol for the mixed methods study has been published elsewhere (Mapp *et al.*, 2016). In this paper, we focus on the data exploring how STIs were perceived by participants, how perceptions differed from those of other health conditions, and what were the implications for prevention and treatment.

Study setting and sampling procedures

Participants were recruited from a sub-sample of Natsal-3 survey participants. All had agreed to be contacted with a view to participating in further research and had reported at least one genito-urinary symptom in the survey (for example painful urination or a genital wart/lump, see appendix B, p.318). These symptoms are associated with STIs and were asked about in a module about STIs (although the question only referred to them as symptoms), however participants reporting symptoms did not necessarily have an STI. We also selected participants who reported no previous attendance at a sexual health clinic. All participants were sexually experienced (had reported at least one sexual partner in their lifetime) and were aged 16-44 at the time of Natsal-3 survey data collection. Sampling sought to identify participants from the population who had reported symptoms associated with STIs independent to healthcare-seeking experiences as those who have previously attended a sexual health clinic are known to have different experiences and healthcare preferences to those who have not attended (Tanton *et al.*, 2017).

Follow-up semi-structured interviews were conducted with participants, who were resident in England or Wales at the time of data collection. We recruited a purposive sample of 27 women and men to maximise the variety of symptom experiences included but also balance sample variation in terms of age and gender. Non-response rates were high (90/117 survey participants who were re-contacted

were not recruited to this study) as interviews took place May 2014-March 2015, a median of 30 months after Natsal-3 data collection and we only had access to addresses and telephone numbers to contact participants. Eight people refused to take part because they did not have enough time or were not interested in the subject matter.

Data collection

Permission was given by the Natsal-3 team to contact participants initially with a letter and study information sheet sent by post and then with a follow-up telephone call to answer any questions and arrange an interview if appropriate. Participants were told the interview would be about STIs and healthcare services and the researchers were looking for a range of different experiences and opinions. Data collection took place in participants' homes or another convenient location requested by the participant (such as their partner's home or a university building where the researchers were based). Before the interview commenced, the researcher explained the purpose and format of the interview, gave the participant opportunities to ask questions and read and sign the standardised consent form if they were happy to proceed. FM conducted all interviews using a topic guide designed to facilitate participant's accounts of their own experiences. Open-ended questions explored perceptions of STIs and people diagnosed with them, the language used to talk about STIs, and the meanings STIs held for them. For those who disclosed personal experiences of STIs during the interview, further discussion about lived experiences of the infection(s) also formed part of the data collected. Interviews lasted between 35 and 108 minutes, were digitally recorded and transcribed by FM or a professional transcription company.

Data analysis

We took a continuous and iterative approach to analysis in two main analytic stages to ensure breadth and depth in understanding and interpretation of the data. The

first stage comprised rich thematic description of the entire dataset (Braun and Clarke, 2006). All transcripts were checked by reading and re-reading them as part of data familiarisation to get to know the scope and diversity of the data set as a whole (Green and Thorogood, 2009a). Initial notes about the data helped generate preliminary codes inductively for all transcripts to identify important themes without imposing an existing coding framework. Coding was done by hand and emergent codes were collated and recorded using an excel spreadsheet to facilitate data organisation and grouping of codes into broad themes. FM coded all transcripts and approximately one-third were double-coded by other researchers followed by discussion to review and refine the themes to ensure they reflected the raw data. Through this process, we produced a thematic map of the full dataset and identified key themes to explore in more depth.

In the second stage, we conducted more detailed, interpretative analysis of the theme "STIs as dirty", identified from initial thematic mapping of the data. We used the Framework Analysis approach (Ritchie and Spencer, 1994; Ritchie and Lewis, 2003) to generate a matrix to classify data relating to the chosen theme. This enabled us to systematically move back and forth between different levels of data interpretation whilst keeping close to the raw data (Green and Thorogood, 2009b, p. 219). Each row of the matrix represented a participant from the study and columns were used to organise data about STI dirt into sub-categories emerging from the data. The thematic mapping informed the processes of familiarisation of data for this type of analysis and developing a coding frame for the matrix, adding additional depth and helping to unpick the complexity of the theme. Data summaries and key quotes were added to the matrix according to each sub-category of the "STIs as dirty" theme to reduce the data into manageable chunks and facilitate transparent data interpretation. The data were then synthesised within each category across all participants and illustrative quotes chosen for inclusion in the results.

Ethical approval

Natsal-3 was granted ethical approval by the NRES Committee South Central - Oxford A (reference: 09/H0604/27). The qualitative strand of this study was given ethics approval by NRES Committee South Central - Oxford A 11/H0604/10 and LSHTM Observational / Interventions REC 6538. All participants included in this study gave written informed consent to participate and for the publication of anonymised data extracts. Participants were given an additional information sheet at the end of the interview signposting them to additional information and support. Unique identifiers are used to identify participants' data and only non-identifying descriptive details are included in this paper.

Results

Participants

Table 1 summarises the key characteristics of participants who took part in the semi-structured interviews. Of note is the fact that all participants had, in Natsal-3, reported experience of symptoms which could be associated with STIs, but the semi-structured interviews revealed that not all had experienced STIs.

Table 1: Summary of participant characteristics

Characteristic	Participants in this study
Gender	16 women; 11 men
Age	19 – 47 years; median age was 29 years
Ethnicity	23 White British/white other; 4 Asian/Asian British/Black/Black British
Sexuality	25 with only heterosexual experience; 1 gay man and 1 bisexual woman
STIs and other diagnosed genito-urinary conditions*	1 diagnosed with genital warts; 2 diagnosed with chlamydia; 2 diagnosed with HPV; 1 diagnosed with an STI but could not remember which one; 1 diagnosed with bacterial vaginosis; 9 reported they had had thrush (not all diagnosed by a healthcare professional); 17 did not disclose any STI or other condition

Genito-urinary symptoms reported during semi-structured interview	**Women**: Pain urinating and abnormal vaginal discharge were the most commonly reported symptoms. Abdominal/pelvic pain, vaginal pain during sex, abnormal bleeding between periods, unpleasant odour associated with vaginal discharge, bleeding after sex and genital ulcer/sore also reported **Men**: painful testicles and pain urinating were the most commonly reported symptoms. Genital wart/lump and penile discharge also reported
Help-seeking responses to symptoms*	14 sought care with their GP; 3 attended a sexual health clinic; 3 went to a gynaecologist; 5 chose other services (pharmacist, hospital, midwife and/or contraception clinic); 1 could not remember if they had sought help and 7 did not seek any help

* Note numbers do not add up to the total number of participants as some reported multiple events

STIs as dirt

Recounting spontaneously what STIs called to mind for them, participants near universally mentioned dirt or a synonym of dirt. STIs were themselves considered 'dirty words' and were referred to as *"dirty", "skanky" "gammy", "grimy", "filthy", "nasty"* and *"gross"*. They were frequently described as "disgusting", often with reference to visceral aspects of the infections, including bodily secretions (*"pus", "discharge", "oozings", "dripping"*); sensory aspects (*"smells"*) and tangible lumps and lesions (*"lumps", "boils", "wounds", "warts"*).

> *Interviewer: What comes into your head when I say sexually transmitted infection, or STI to you?*
>
> *Participant: Warty knobs I suppose, it's not a glamorous thing at all is it an STI…So yeah probably a big, green, warty knob…a dirty thing, a shameful thing* [19F]

Body fluids – particularly blood and abnormal discharge in women – were considered particularly disgusting. Disgust related not only to sores and lesions producing the discharge, but also to their location on the body, notably the genital area. STIs were therefore seen as dirt; they were anomalies and did not fit the classification system on which the social order of our society depends (Douglas, 1999 p.5).

The dirt metaphor extended from the infection itself to the person affected: women and men with STIs were described as *"unclean", "dirty people."*

> *So, you know, you could be called names, you're thought of kind of being dirty, there's certain stereotypes that might come with it. Again you're branded names, you sleep around. A slut, slag, whore, that sort of thing.* [4F]

> *They're [people with STIs] dirty and they're reckless or they're not very well behaved* [13M]

Use of terms such as *"stain", "tarnish", "blemish"* were widespread in references to the 'dirt' of STIs and, relatedly, several participants spontaneously mentioned the terms *"stigma"* and *"stigmatise."* Some (for example, 6F) provided a definition of the term unprompted, others were asked what it meant to them (for example, 19F) but all combined the concepts of mark or stain, with its social meaning and significance.

> *What's the word I'm looking for? I'm sorry I'm being really thick and tired, stigma. Stigma's not acceptance and stigma is…Not a truthful reflection of the situation. So stigma is attaching extra meaning to a factual situation, it's attaching connotations of what that factual situation means. Yeah, it's attaching a meaning or meanings that aren't actually there in relation to that individual and that particular situation.* [6F]

> *What does stigma mean to me? I'd say it's a negative thing, obviously a stigma, it's a...does it derive from stigmata, like a sign, …stigma, it's people having prejudice isn't it or forced perceptions about something* [19F]

Others were more hesitant in their use of the term, but in several instances linked it with labelling and being labelled. One man extended these ideas to describe stigma as an instrument of social control.

> *I suppose people imposing morals and rights onto others and I don't know, is it a way of controlling the masses maybe, or it comes from ignorance, you know, I'm thinking like other forms of*

stigma, racism and things, what else, way of controlling masses,
I'm rambling, stigma? [20M]

Narratives about dirt and cleanliness were common across participant accounts and in particular, dominated the discussion by one young man about hypothetical STI transmission.

I mean, if someone's proper filthy, like really disgustingly bad,
then obviously they're at more risk [of STIs]... if a person's really,
really clean, they're not going to give it [an STI] to somebody
[11M]

And later, when he is discussing making judgements about people attending sexual health clinics:

...you start thinking, "Why are they here, what have they done,
what have they got, have they got it?" ...If you saw somebody like
clean cut, nice haircut, suit and tie on and that, you'd think, "Well,
he might have been out last night, took somebody home, she
didn't tell him" [11M]

Together, these data show that dirt and stigma are common perceptions of STIs. There was an implicit entanglement of the two terms and the meanings given to them in participant accounts. One younger women explicated the link between dirt, hygiene and stigma as illustrated in the following quote:

The stigma of STIs like's associated with like being unclean or dirty
or just not thought of as a hygienic person [26F]

Dirt appears to be a key component of STI stigma, acting as a discrediting attribute (Goffman, 1963) and stigmatising those labelled as dirty. The symbolic meaning of dirt goes beyond the physiological status of symptoms or other manifestations of STIs.

Sex as dirty

Explanations for thinking of STIs as dirt, and those infected by them as dirty, focussed predominantly on the fact that transmission was *"to do with sex."* Variations of this phrase featured frequently in accounts, and many participants sought to qualify the kind of sex that was seen as dirty. Promiscuity was seen as warranting the label [2F, 3F, 10M, 13M]; as were other variants of non-exclusive sex [16F] such as *"sleeping around"* [4F, 8F, 9F, 12F, 20M], *"one-night stands"* [2F,15M, 21M, 23M, 25F, 26F]. Transactional sex was mentioned by two participants [15M, 25F], rape by another [4F] and homosexual activity by others. Types of people seen as fitting these categories were described as *"people loose with their morals"* [18F] and were labelled *"slappers"*, *"tarts"*, *"slags"* and other derogatory terms. Some sexual practices were labelled as 'dirty', in general, those outside of established sexual partnerships and relationships for example, *'doing it dirty'* [13M], *"giving guys dirty blowjobs"* [16F] One man who had been diagnosed with an STI summarised the criteria he saw as defining *"dirty sex"*:

> *You do think perhaps you're a bit dirty or maybe you didn't*
> *behave in the right way cos otherwise you wouldn't have got it ….*
> *You're quite dirty sexually you could say …. or you do it a lot and*
> *when you do it, you do it dirty …dirty because they have the*
> *infection, dirty because of maybe the people they choose, or*
> *maybe the flippancy with how they choose their sexual partners,*
> *the terms slut and slag still applies.* [13M]

In other words, the dirt of STIs was associated with the violation of conventional rules around sex. Broadly summarised, the sexual partnerships and practices in question were those that were other than heterosexual, procreative, and monogamous, though some participants also included unprotected sex [4F, 9F, 22M, 23M, 25F, 27F, 29F]. Classifying in this way served to reinforce the social order. Attempts were made by some participants to identify the source of the classification system in which aberrant and acceptable sexual partnerships and practices were opposed. Though quick to point out that they were not believers

themselves, several attributed the underpinnings of the categorisation of kinds of sex as 'dirty and disorderly' to religious doctrine [4F, 7F, 14M, 20F].

> *It's probably because of religion…it's inconvenient. Probably mainly for the Church…you know to make people believe that sex is dirty and should only be within wedlock. I think it just sticks, it goes on down through generations, as I said, you know, society and religion…people probably don't see sex in a committed relationship as dirty but as you come out of that people see it maybe as dirty, like it's not really acceptable and not religious, all those things… I think that's probably why.* [7F]

> [in the context of HIV/AIDS] *I remember the so-called religious people saying that it was an act of God to get rid of them [gay men] … I still think people do feel like that some of them, you know, who's like still back in cave days, yeah. I still think there's people who think that it's something that's associated with homosexuality… And that's quite worrying because that's probably why a lot of people have caught it thinking that they wouldn't get it because they're not homosexual…* [14M]

> *Homosexuality and AIDS don't go down well with the church, religions. And being with more than one man, woman, you know, sex before marriage* [20M]

Such views strongly echo Foucault's description of the elaborate system of classification he described as seeking to establish a divide between "normal" and "deviant" sexual practices which, although weakened, persists because of its regulatory value in supporting a social order (Foucault, 1990).

Moral and physical dimensions of dirt

Both physical and moral aspects of dirt featured in accounts of risk and vulnerability to STIs. Dirt was mentioned by participants both in the context of hygiene and in the context of morality.

> *You can get it from anything really, in my eyes you get it from dirt, crap you know, don't wash properly, you can get it from anywhere*

really, like I said earlier public toilets, second hand car, I've heard of a woman contracting it from the seat of a car, a leather seat in a car, what that's been used for God's knows what, because it hadn't been cleaned properly. [15M]

…say, if you don't wash yourself, you don't clean yourself, then that's obviously going to improve your risks of getting one because, obviously, if you're not very clean down there yourself… [11M]

These quotes illustrate the elision of moral and physical aspects of STI dirt. They were frequently conflated and amalgamated by participants in their description of perceptions of STIs and so are considered together in this paper. Participants sometimes extended dirt to cover other behaviours that transgress social norms such as using drugs and being drunk [2F, 4F, 14M, 19F]. The elision between physical and moral cleanliness was easily understood in terms of a transgression of the boundaries of the body, a violation of personal space. This quote exemplifies the potential contagion from moral contamination.

If someone's proper filthy…really disgustingly bad, then obviously they're at more risk, because…they don't give people the boundaries…I get people that are drunk all the time, and they come over, and they're like right in your face …if they spit on you, it can land on your lip…if a person's really, really clean, they're not going to give it to somebody…see what I mean, I'm arguing my own point again. [11M]

Continuing descriptions of the dirt associated with STIs in both physical and moral terms, several participants attributed sexually transmitted infection to poor personal hygiene, to not taking care of the body, and even to unsanitary living conditions: *"infections come from unhygienic things"* [10M]; *"I would say a lot of it is hygiene, but not completely all of it…say, if you don't wash yourself, you don't clean yourself, then that's obviously going to improve your risks of getting one"* [11M]. Beliefs about contracting STIs from toilet seats were held by some. More often, dirt was seen in a metaphorical sense as 'moral impurity' but again the terms

used in accounts were drawn from the vocabulary of physical dirt and associations with moral and physical dirt were often conflated:

> *Well it [sexually transmitted infections] makes me think of dirty, maybe the guy doesn't wash himself…It makes you think of promiscuous, it makes you think of multiple partners…I think that many of these diseases may potentially come from lack of cleanliness and lack of basic hygiene and of course promiscuity…also ignorance of course, ignorance is also very important* [25F]

> *…it's how you differentiate…when I make a judgement of somebody, you look how they look…and you think, "Well, how clean is this person? Have they been doing anything they shouldn't have been?"* [11M]

> *…you're thought of kind of being dirty, there's certain stereotypes that might come with it…you're branded names, you sleep around. A slut, slag, whore, that sort of thing* [4F]

> *People always have preconceived ideas that if you get those [STIs]…you sleep around or maybe it's also associated with bad hygiene, which probably has not much to do with it in most cases but yeah, I think you think of it as dirty and you probably think of the person who's got it as, you know, dirty…* [7F]

It became apparent that often, a reverse logic was at work. The connotations of STI dirt generated a syllogism: people who contract STIs are dirty; dirty people are at greater risk of contracting STIs themselves and more risky to others. One man, for example [11], drew links between the dirty, messy houses he worked in as part of his job for the council and an increased personal risk of contamination. Similarly, dirty is promiscuous and promiscuous is sex work and so sex workers are dirty and not hygienic [6F]. Conversely, having an STI defines behaviours and people. By a process of reverse logic, just as 'dirty people' were seen as having STIs, having an STI was to be seen as dirty or debased: "*They think it's because you've been and done something dirty*" [20M]. The syllogism was implicit in several accounts.

Many participants remarked on the capacity of STIs to do damage to, or to 'spoil' reputation [12F, 14M, 15M, 17M], what Goffman refers to as "*blemishes of individual character*" (Goffman, 1963). In more than one instance the damage was seen as permanent; whether the STI was acute or chronic the effect on reputation was described as *"lifelong contamination…a factor in their life that will be there forever"* [12F], *"something that stays with you"* [2F] and in one account as likely to necessitate a change in your circle of friends [17M].

An important element of seeing STI in moral terms was a perception of someone with an STI as blameworthy, as having brought the infection on themselves. Blame and therefore shame accrued to infection because it could be avoided and so was seen as deserved not only by engaging in what were described as dirty practices and partnerships, but also to failing to practice safer sex. It was considered an individual's personal responsibility to have safer sex. Blame was seen as accruing not only to risk behaviours (e.g. having multiple partners), but also risk reduction practices (e.g. not using condoms).

There was, however, no clear consensus on the issue of fault and blame. Whilst some accounts were consistent and unequivocal in seeing STIs as the fault of the victim, others revealed conflicting and contradictory opinions. Several participants described people with STIs as seen by others as a matter of personal responsibility, but sought to distance themselves from any suggestion of judgmental attitudes on their own part.

> *I suppose it's the connotation is that it's something that you could control the getting or not getting of and that if you take precautions or don't, in inverted commas, sleep around…I'm kind of talking a little bit as devil's advocate because I don't necessarily share those views but I think they're kind of rooted in…people's perceptions.* [6F]

Many conceded that contracting an STI could be a matter of chance and outside of individual control: *"just pot luck"* [6F] *"you can't just say "oh this is your fault"… I mean sometimes you are completely innocent aren't you and you just don't know?"* [4F] *"you can have one partner and…you can catch it…''*[14M]; *"[he or she] could be clean as a whistle, and they've just had a one-night stand and they've gone with the wrong person"* [20M]. The most usual scenario used as illustration in this respect was that in which a man or woman had unwittingly been put at risk by a sexual partner who had not disclosed their risk status or were themselves unaware of it. Again, language drawn from the lexicon of dirt and disorder was often used to describe such behaviour. The term 'messing about', for example, was used to describe non-exclusive sex. *"You don't know if someone's been messing around behind your back and they've caught something…so it's a bit between."* [2F] *"I'm so busy working … I haven't got time to be messing about, especially like with my missus now you know, we've been together like nearly 6 years."* [15M]

By the same token, participants with experience of STIs did not always share the moral connotations STIs had for others. One woman described an infection she believed to have been a consequence of her own neglect of personal hygiene as being interpreted differently by others, presenting it as an illustration of the moral slant she saw as associated with STIs.

> *Here's a true story. I did get oral thrush once from inhalers and not using enough mouthwash so I got given an antibiotic and a friend found out and she went round telling everyone I'd been giving guys dirty blowjobs …she knew what had caused it, she does actually work in the medical field and she still acted like that, that just shows the perception of it'.* [16F]

Four participants' disclosed during the interview that they had been diagnosed with an STI but none considered themselves or their infection as dirty. They either viewed themselves as exceptions to the type of people who get STIs and distanced

themselves from negative stereotypes, or their experiential knowledge had changed their views about STIs and their associations.

Dealing with dirt

The 'dirt' of STIs was seen by one man as: "*obviously something there that shouldn't be there, so you're not used to seeing it*" [11M], an observation which closely corresponds to Mary Douglas's (1966) well used phrase of "matter out of place." Classifying in this way served to reinforce a social order in which aberrant behaviours, norms and physiology were distinguished from acceptable. This same man saw dirt as transgressing the boundary between the categories of self and other, and – in the reference to drunk – to controlled and uncontrolled behaviour:

> …if someone's proper filthy…really disgustingly bad, then
> obviously they're at more risk, because…they don't give people
> the boundaries…I get people that are drunk all the time, and they
> come over, and they're like right in your face …if they spit on you,
> it can land on your lip…if a person's really, really clean, they're not
> going to give it to somebody…see what I mean. [11M]

He was, ostensibly, making his point to illustrate the role of physical contamination in the risk of STI transmission. However, if his observations were only to be interpreted from a perspective of hygiene and disease avoidance, it could be argued that a greater volume of saliva could pass from one person to another through kissing than spitting. In describing socially unacceptable practices such as being drunk and spitting, he effectively draws our attention to a second kind of contagion, associated with not with disease but with social contamination and damage to reputation. In his description of the breaching of the body's boundaries he reveals an elision between physical and moral pollution.

Participants described three main approaches to dealing with STI dirt: silencing and concealing the dirt, distinguishing STIs from other diseases and preventative and help-seeking strategies.

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For most participants, the avoidance of the dirt of STIs meant banishing it from mind, from speech, and from sight, rendering the dirt silenced and hidden. There was general agreement that STIs were not spoken about.

> *If you had an STI you wouldn't particularly go out and broadcast it from the treetops… (Laughs)* [6F]

> *No I didn't [tell anyone about STI]. Can you imagine saying, you know, to colleagues or friends, or my friends, no, no.* [7F]

> *It's not like you're going to update your facebook status, "Hey guys I've got gonorrhoea"…I don't think you'd tell a whole load of people about it.* [10M]

> *You wouldn't go round with it tattooed on your forehead…(laughs)* [9F]

One way of not talking about STIs directly was to use euphemistic language; the genital area was described as *"dirty in the south"* [8F], *"your bits"* [2F] and *"big green knob that's all warty"* [19F]. The reluctance to talk about STIs was apparent not only in what participants said, but how they said it. Many lowered their voices or whispered when mentioning experiences or scenarios involving STIs. Not only were STIs not spoken about, they were not even allowed to enter conscious thought. Asked what came into their head when they thought about STIs, some were reluctant to engage at all with the subject.

> *I try not to think about it…It's like taboo isn't it? You don't speak about it, it's sort of frowned upon innit… something you don't talk about…* [12F]

STIs were also hidden from view, invisible in a social sense. Participants with experience of STIs concealed the physical marks of STIs In Goffman's (1963) terms, this can be viewed as an attempt to conceal a discredited status (abominations of

the body and blemishes of individual character). Therefore the silence surrounding STIs was maintained in individual's approaches to dealing with the dirt.

Distinguishing STIs from other diseases

Asked to describe characteristics of STIs which marked them as different from other health conditions, participants reiterated several of the themes implicit in their earlier accounts. Symptoms such as discharges, smells, sores, blemishes and rashes, were acknowledged to be common to other infections, but their social and moral meanings emerged as important distinguishing features of STIs. Blame and fault were held to be important distinguishing criteria. Parallels were drawn with other health conditions seen as being brought on by the sufferer themselves, for example, obesity, [6F] but the perceived link with personal responsibility was considered more marked in the case of STIs. As a consequence, STIs were unlikely to elicit sympathy in the same way as other illnesses. Having an STI, for example, would not justify absence from work or exemption from everyday tasks.

> *…it's a bit like a hangover really…you've made your bed and now you have to lie in it. Everyone gets superior over this in their own way…it's your fault cos you should have been more careful* [13M]

The fact that STIs were not spoken about also marked them off from other health conditions, as did connotations of dirt and sexual impropriety. The silence around STIs was in marked contrast to the ease with which many other health conditions could be disclosed.

> *They have sexual in their name so that puts them apart slightly in terms of what you talk about freely and socially. You would never hear, in the same way that somebody said "oh how you feeling?" "Oh I had the flu last week". You would never have somebody say "oh I'm trying to get over herpes."* [6F]

Comparisons were also made with other diseases in terms of the consequences of disclosure and its impact on reputation. STIs were seen as likely to generate feelings

of judgement and contempt, even ostracisation.

> *I suppose it's like having a cold but people don't say that's dirty*
> *[8F]*

> *Anything related to sex I think most people view differently, STIs*
> *make you feel dirty, contaminated [12F]*

> *It's not like I've got a cold or something like, when you hear*
> *someone's had that [STI] you think they're dirty, that's a lot of the*
> *problem….Because when you get something like that you're sort*
> *of branded with a name. [2F]*

> *…like as soon as you find out or there's a possibility that you have*
> *something that you got from having sex then … there's always*
> *some kind of worry about how other people view you and what*
> *they might think about you….someone can use it against you…*
> *they'll like ruin you. [3F]*

A further distinguishing factor, linked with sex, was the part of the body most commonly affected. *"It's because it means you've got to drop your trolleys to get checked!"* [16F] *"It's not like just getting your arm out…it's pulling down your pants…It's like your private parts isn't it - they stay private."* [12F]

Preventative and help-seeking strategies

Perceptions of STIs as dirt, the strategies used to avoid dirt, and the stigma and perceived impact on reputation of having an STI could all be seen to strongly influence preventive actions and healthcare seeking. In the context of prevention, the association of STIs with dirt served to impair risk assessment; several respondents claimed they would judge whether people were 'risky' or not according to whether they look clean, as distinct from arguably more relevant aspects of sexual history. The exclusion of STIs from everyday discourse created impediments to several aspects of prevention strategies. Participants described the consequences of the difficulty of talking to sexual partners about STI risk and this had implications not only for primary prevention but also secondary prevention. Non-disclosure had potential impact on onward transmission, notably in relation to

partner notification: *"people don't disclose these things and still go around sleeping with people without letting them know."*[4F]; *"because you're going to get a slap across the face or she's going to swear at you and walk off"* [21M].

Reflecting on her partner's failure to disclose a previous diagnosis of genital warts, one woman recounted:

> *Apparently he had it like before we were even together so I'm*
> *really annoyed that he didn't tell me because, you know, we've*
> *been having unprotected sex so like that's not fair, he's putting my*
> *health at risk as well just because he couldn't say it to me* [3F]

Perceptions of STIs also created barriers to resolving infection. The association with physical dirt explained attempts at self-care. Participants who experienced symptoms and or STIs described a need to *"to wash it away"* [29F]. *O*ne woman described her efforts to keep cleaning herself to try and remove the physical dirt of symptoms.

> *…you're quite clean and you're trying to keep yourself more clean,*
> *you just don't understand why it's happening, that, I was, didn't*
> *understand that because I was really, really sore and the more I*
> *was keeping myself clean the more sore I was and I found out I*
> *shouldn't be like cleaning myself that much* [27F]

The hidden nature of STIs, the stigma attached to them, and the need to distance oneself from the idea of infection also meant that participants were less likely to recognise their symptoms as those of STIs. One man who was subsequently diagnosed with, and treated for genital warts, described his initial difficulty in making sense of his symptoms and his use of the internet to help him to understand what was happening.

> *Initially my thought was "what the hell is that?" I hadn't gone "Oh,*
> *no, I've got one of these" I just thought "what on earth is that?" as*
> *if I'd never heard of it ever in my life…and then I went to Google, I*
> *could pick out similarities but the images completely like, it's as if*
> *they're designed to get people really, really scared but they look*
> *nothing like it so it didn't click with me originally* [13M]

Qualms relating to attending for medical treatment were not universally expressed, some participants were of the view that health care professionals were less likely than the general public to be judgemental and the view of many was that things were changing, that people were now more accepting; and that reputations were less drastically affected by having an STI. Nevertheless, expressions of apprehensiveness, retrospectively reflected on by those with experience of STIs or envisaged among those with none, were commonly expressed. Again, perceptions of barriers to seeking help again followed predictably from the perceptions of STIs as dirty, shameful and stigmatising. Some of the key features differentiating STIs from other diseases and creating a differential response in the community also created deterrents to attending for treatment *"the nature of the disease would stop you seeking help"* [i29]. The silence surrounding STIs hindered disclosure and discussion of sexual histories, the tendency for STIs not to be spoken about, it was claimed, would inhibit or limit disclosure: and the necessary exposure of 'private parts' of the body caused embarrassment. Concerns about stigma and the perceived ignominy of having an STI and the kind of sex associated with STI militated against a ready acceptance of seeking help.

> *You're happy to go to your doctor and show your tongue, it's a different thing with STDs or STIs I think. It's something that people don't really want to go and talk to their doctor's about.* [6F]

> *I'd give them minimum information until they start asking for more. I just don't tell them everything. When you go to the doctors, you say the extreme so they look at everything. When you go to a sexual health clinic, you'll say minimum so they don't look at everything, do you know what I mean?* [11M]

> *It seems such a private part of your body...I think it does stop people perhaps seeking help and stuff because they're embarrassed.* [9F]

Several participants believed ways of thinking about people with STIs determined the care they received.

*I think I would be treated differently if I went to my GP saying I
needed a course of antibiotics for chlamydia [than] what else do
you take antibiotics for, a tooth infection, so I think yes, you do
get treated differently* [9F]

Fears relating to contravening the social norms surrounding parts of the body such as the genital area were compounded by embarrassment of having to show to health care professionals visible symptoms of what might be an STI. A woman who had sought care for symptoms of abnormal vaginal discharge described her discomfort in doing so.

*I would probably feel embarrassed going and showing … because I
think if it's just pain you can say to the GP "Oh I feel pain down
there", okay he will maybe have a look, a quick look, but if it starts
showing and it looks ugly than I would feel even more
embarrassed* [25F]

Added to this was the ignominy of possibly being seen and recognised in an STI setting. Where attendance at an STI clinic was seen as stigmatising: attending General Practice community physician was seen as conferring protection since the reason for attending was not apparent. This prompted several participants to argues for a combined service, integrating STI treatment of STIs with other aspects of sexual health or with other health conditions For the same reason, pleas were made by some to extend facilities for treating STI in General Practice In terms of a preferences for health care settings, advantages were seen in attending General Practice in terms of the generality of conditions presented there.

*The doctors is so general isn't it? You know, you could walk into a
doctor's waiting room and nobody knows what you're there for*
[4F]

*It would make it easier if there was…like a clinic that was on at the
same time as the surgery or it was combined into the surgery so
people wouldn't feel as though they was being watched going into
a sexual health clinic. But I don't think there's any real bother
about it now* [14M]

Discussion

We have explored perceptions of STIs, how they differ from those of other health conditions, and what this means for policy and practice. We found that STIs are near universally conceptualised as dirt, the meaning of which was described in the contexts of both hygiene and morality. Avoidance mechanisms encompassed excluding STIs from thought, speech and sight, and individuals distancing themselves from its physical and moral connotations. Factors distinguishing STIs from other infections included the attribution of blame and shame to sufferers, the silence and invisibility around STIs, their association with irregular and illicit sexual behaviours and with failure to implement risk reduction practice, and their location on parts of the body normally concealed, all of which had implications for their prevention, care and treatment.

As we drew our sample from existing population survey participants, we were able to examine STI stigma in a social context that was independent of medical settings and therefore avoided an overly biomedicalised framing. Recruiting participants from a nationally representative sexual health survey enabled us to identify and select a non-clinical sample of participants who had reported symptoms associated with STIs. Participants were purposively recruited from those who reported in Natsal-3 symptoms which could have been those of STIs. It emerged that, because of the lack of specificity in the symptoms listed, participants recruited by this method included both those with and without experience of infection. Where initially this was had the potential to be a limitation to the study, it emerged as a strength, because of the wider range of views elicited.

We applied insights from a social constructivist perspective to the data analysis, and in particular, those from structuralist theory. Whilst acknowledging the potential for analysing the data from other theoretical perspectives, those elaborated in the seminal work of Mary Douglas (Douglas, 1966) continue to have clear relevance to

the interpretation of perceptions of STIs. Her insights are unparalleled in helping make sense of the overwhelming dominance of dirt in the accounts reported on in this paper. In two important respects, however - both reflecting the passage of time since Douglas wrote - caution is needed in applying an uncritical application of her original ideas; although Douglas recognised the contingent and socially determined nature of classification systems, her tendency to see them as an essentially unified monolith in any one setting has been criticised (Duschinsky, Schnall and Weiss, 2016, p. 6). First, our data portray men and women in a post-modern world as having considerably more access to the tacit coding of sexual conduct than was the case when Douglas was writing. There are, in the accounts of those taking part in this study, explicit references to the power relations and mechanisms underlying the control of sexual conduct, and instances of contradictions between personally held views and perceptions of rules relating to the social order. Second, it becomes clear from these data that in a multi-cultural society characterised by rapid social change, not one but several competing classification systems are at work. In the accounts of men and women participating in this study, we see evidence of parallel and co-existing discourses relating, on the one hand, to sex seen as irregular and illicit, on the other, to sex which is unprotected and unsafe. The one reflects a system of categorisation deriving largely from religious tenets, marking off acceptable from unacceptable sexual behaviours; the other reflects a rational-scientific paradigm in which epidemiological categories are privileged, and according to which it is the failure to implement harm reduction strategies that is seen as deserving of moral opprobrium.

There are parallels between our findings and those of other research examining perceptions of STIs. Dirt has been found to be associated with STIs in several other studies (Waldby, Kippax and Crawford, 1993; Lawless, Kippax and Crawford, 1996; Lewis *et al.*, 1999; Nack, 2000; Scoular, Duncan and Hart, 2001; Lee and Craft, 2002; Shefer *et al.*, 2002; Holt *et al.*, 2010; Cook, 2014). However, since many of these studies have been carried out in clinical samples, or among particular age groups,

there is less scope for direct comparison of the findings. Moreover, none of these studies have explored correspondences between the significance of dirt in a pathogenic sense and its significance for social order in any depth.

Concepts of disgust and stigma, which have featured prominently in the accounts described in this paper as a response to the dirt of STIs, have been viewed variously according to disciplinary perspective. Some environmental psychologists and biologists have interpreted them as mechanisms for disease avoidance. (Phelan, Link and Dovidio, 2008; Oaten, Stevenson and Case, 2011). Others have countered that since human children do not generally show a contamination response before age three, disgust is likely to be a socially learned response behaviour (Knowles et al. in Duschinsky, Schnall and Weiss, 2016). In relation to our own study, whilst avoiding people who exhibit signs of, or risk factors for, infection can be seen as an effective strategy for avoiding infection (Kurzban and Leary, 2001; Phelan, Link and Dovidio, 2008), it does not account for the total range of aversive behaviours seen in our data. Phenomena categorised as warranting avoidance included people behaving inappropriately in some way, those who did not look clean and tidy, people who lived in dirty environments, and even those of lower social position or education. In framing her culturalist accounts of purity and danger, Douglas dismisses (Douglas, 1966, p. 36) what she terms "medical materialism" by which such classifications are seen as forms of concern for hygiene. Psychological researchers such as Rozin et al (2009), however, see no incompatibility between recognising, on the one hand, that the human disgust response evolved as a disease avoidance mechanism and, on the other, recognition of its appropriation in a social and moral realm. It seems reasonable to consider that the perceived need for avoidance can be seen in the context of both pathogenic, and social and moral contagion.

These data on perceptions of STIs convey a number of messages for sexual health policy makers and practitioners in sexual health. In the context of prevention and

risk avoidance, the association between STIs and 'dirt', 'dirty people' and 'dirty sex' has the potential to bias assessment of risk, and to induce a possibly false sense of security based on a superficial observation of physical cleanliness and social standing. A more positive finding is the growing recognition of the need to implement risk reduction strategies. Among many men and women, practicing unsafe sex was worthy of equal, if not greater, opprobrium and this may be seen as carrying welcome messages for public health practitioners. In this respect, our findings echo the stigma related to unprotected sex or contraception failure reported by teenage mothers (Ellis-Sloan, 2014). None of our participants admitted to having unprotected sex and putting themselves at risk of STIs and stigmatising this type of risk could also be viewed as a *"defensive orientation"* (Goffman, 1967) (i.e. practices to save face).

The silence and invisibility around STIs has implications both for their prevention and treatment. A disinclination to think about STIs is likely to lead to denial of symptoms and delay in seeking health care, or failure to do so. A consequence of reluctance to speak about STIs is that conversations among friends and family/within the social circle - which might provide opportunities for symptom recognition and raised awareness of the need for help-seeking - do not take place. It is also likely to limit disclosure of relevant information in the health care setting and to deter men and women with an STI from notifying their sexual partner.

The tendency to conceal STIs also has inferences for service configuration. Reports from those interviewed in this study of a preference for health services outside their residential area such that they will not be recognised, and for services offering treatment for a wider range of health conditions than STIs such that the reason for attending is not obvious, confirms the benefits of open access clinics and integrated sexual health services.

These findings also have implications for the 'discovery' and classification of new pathogens as STIs (for example, *Mycoplasma genitalium* (Sonnenberg *et al.*, 2015a). Whilst there may be a biomedical rationale for categorising a novel pathogen within the group of STIs, our findings have shown this is likely to confer the label of dirt on the infection and the implications that come with this categorisation.

Additional exploration of dirt and its relationship with stigma is needed to understand transferability to other forms of stigma, beyond STIs to other infectious diseases, where there is risk of transmission and contamination. Empirical data about the links between dirt and the disgust it elicits in relation to STIs would augment evidence about stigmatisation processes and our findings would benefit from application to work examining power and structural forces (Parker and Aggleton, 2003; Link and Phelan, 2014) governing stigma of infectious diseases. As noted by Douglas, the physiological body is a powerful metaphor for the social body and embodied cognition translates into every aspect of STI perception, from perceptions of cause to predisposition to seeking help.

3.5 Discussion of findings in relation to this thesis

Both the social representations of STIs and stigma related to STIs encompass dirt as a main theme. Through my analysis, I have interpreted dirt as a common perception of STIs, using data from participants with STI-associated symptoms, but not necessarily caused by STIs. Dirt poses a threat and contamination risk to individuals' physical health (including STI status) as well as moral status and reputation. Dirt can be seen as an additional component of STI stigma which frames experiences of genito-urinary symptoms and associated help-seeking.

3.5.1 Empirical reflections

Although dirt has been linked to STIs in the literature already (Waldby, Kippax and Crawford, 1993; Lawless, Kippax and Crawford, 1996; Lewis *et al.*, 1999; Nack, 2000; Scoular, Duncan and Hart, 2001; Lee and Craft, 2002; Shefer *et al.*, 2002; Holt *et al.*, 2010; Cook, 2014), this has predominantly been in relation to STI diagnoses in clinical settings. Descriptions of dirt in relation to STIs have been descriptive, focussing mainly on how individuals have felt soon after their diagnosis. Dirt as a concept has not been unpacked further using interpretative analysis in a non-clinical sample to consider the different dimensions and implications. Both Shefer et al. (2002) and East et al. (2012) considered dirt as a stereotype of STIs involved in stigmatisation processes, but did not directly link dirt and stigma, as I do based on my findings. My findings about STI dirt being a component of STI stigma link the socio-cultural context of STIs to individual experiences of symptoms and help-seeking. This provides a framing for the subsequent results chapters.

Social understandings precede experiences and can exist independently of experiential understanding i.e. a person does not have to have had an STI in order to have perceptions of them or contribute to more general social representations of these infections. Having experience of an STI can in turn lead to evolution of an individuals' social representations of STIs, often reducing the negative connotations

and normalising the infection in line with other health experiences. For example, two men who were diagnosed with STIs (i13 and i22) did not consider that their own experience aligned with the negative social representations STIs.

Dirt and stigma have negative connotations and associations as I emphasised in the paper and are generally considered as problematic in public health terms – they should be managed, reduced and/or eliminated. However, Mulholland and Van Wersch (2007) points out the usefulness of stigma and participants' desire to get rid of the contamination of STIs by seeking care at a sexual health service. Therefore stigma may have facilitated attendance and helped fulfil the public health aim to reduce untreated STIs. On this basis, Mulholland questions whether STIs should be destigmatised. My findings partially support this notion in that my participants also talked about "*getting rid*" of STI dirt, however I found a broader range of approaches to dealing with the dirt, including silencing and concealing, which tends to deter care-seeking behaviour, potentially contributing to undiagnosed and untreated infections. This does then pose interesting questions for public health practitioners about using a one-size fits all approach and the unanticipated and unwanted outcomes from de-stigmatisation efforts. Whilst I am not attempting to answer this question, it is important to reflect on the wider implications of my research even if (or especially if) they result in ideas that challenge the norms.

3.5.2   Methodological reflections

Using a two-step analytic process enabled me to scope the breadth of my rich dataset to map diverse themes, creating a descriptive overview of participant accounts. This helped me identify dirt as an important theme in relation to perceptions of STIs, which I then took forward into the second stage of analysis to systematically index and chart data about dirt and make sense of the depth and complexity contained within individuals' narratives.

The study interview setting and participants' behaviour towards me provided methodologically oriented examples of STI stigma. Some participants were wary of being overheard by others present in the house talking explicitly about STIs and personal health issues – especially parents or housemates. This was a factor in the request by two participants to conduct the interview outside of their home – one in my car, parked round the corner from their house (i20) and one at LSHTM (i9). Others closed the door to the room where the interview was taking place, lowered their voices or paused when they heard someone else moving around or occasionally interrupting the interview by entering the space we were in. This exemplified empirical themes around concealment and silencing and alerted me to the efforts that participants went to hide their talk about STIs let alone hiding symptoms or diagnoses.

Most participants presented themselves during the interview as non-judgemental individuals with liberal views, distancing themselves from those who stigmatise STIs. However, there was often contradictions within their accounts highlighted the contested position they occupied. Another technique participants used in the interviews was conveying a viewpoint from the perspective of another group or individual such as people who were a different age to them, religious groups or individuals who had different sexual behaviour to them. This dissociation allowed them to access and present different perspectives but remain distant and therefore avoid judgement for sharing these views.

3.6 Chapter Summary

In this chapter I have argued that dirt is a common social representation of STIs and a key component of STI stigma, acting as a mark, imbued with symbolic meaning that goes beyond the physiological status. Dirt provides a new way of understanding STI stigma as my findings suggest individuals seek to avoid dirt to manage the risk of moral and physical contagion. Elision between different

dimensions of dirt may help explain the persistence of STI stigma but needs to be investigated further. Dirt frames interpretations of sensations and help-seeking responses both of which will be explored in more details in chapters 4 and 5 respectively. Although only one aspect in a complex constellation of socio-cultural factors, dirt has emerged as a potential new target for de-stigmatisation efforts.

CHAPTER 4   RESULTS: MAKING SENSE OF GENITO-URINARY SENSATIONS AND SYMPTOMS

4.1   Chapter Overview

In the previous chapter I presented social representations of STIs and the stigma results paper which explored sense-making about STI stigma. Findings showed that dirt was a key attribute of STI stigma; STIs and people, places and behaviours associated with STIs were stigmatised to reduce the risk of contamination, which extended to genito-urinary symptom experiences. Symptoms are manifestations of physical dirt, some of which are associated with additional moral dirt and were also linked to hygiene dirt. This led me to explore how STI stigma influences lived experiences and interpretations of manifest symptoms of these infections.

This chapter presents empirical findings from the survey and semi-structured interview data about genito-urinary symptoms in the first of my mixed methods results papers. I contextualise the paper in the pre-amble, focussing on methodological aspects. I then present the unpublished article "Prevalence, lived experiences and making sense of genito-urinary symptoms: mixed methods study using the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)", followed by a discussion of the paper in the context of the thesis examining and extending key findings from the paper.

4.2   Introduction to the research paper

This is a mixed methods results paper about genito-urinary symptoms. The aim of this paper is to examine the prevalence, lived experiences and sense-making processes that give meaning to genito-urinary symptoms to provide a comprehensive overview of this public health issue. The findings from this chapter relate to the third research question listed in the study protocol paper (chapter 2)

"How do people interpret genito-urinary symptoms?" and also provide insight into the second research question about how stigma influences experiences of genito-urinary symptoms.

From the Natsal-3 dataset, I used variables relating to individual symptoms, STI risk perception, STI positivity from urine testing and composite variables for experience of any symptom for women and men, as well as socio-demographic, health and sexual behaviour variables. I also draw on a subset of the semi-structured interview data in this chapter. Data pertaining to personal symptomatic experiences and accounts of how these were perceived and interpreted are presented and linked to the population pattern of genito-urinary symptoms. There are two meta-themes within the paper: the nature of symptoms and the meaning of symptoms. These encompassed seven key themes: 1) symptom pain and visibility, 2) boundaries between normal and abnormal, 3) re-gaining control over bodies, 4) determining cause through a lay explanatory framework, 5) concern about sensations, 6) information seeking shaping meaning and 7) interrupting sense-making.

Although Natsal-3 conceptualised these genito-urinary symptoms in the context of STIs, I approached this study with a broader perspective, focussing on participants' experiences and the meanings they attributed to the symptoms. I am not trying to determine 'truths' about the causes of symptoms as this is not an objective of this study. I am not medically trained and did not wish to use self-sampling/self-testing diagnostic tests within my qualitative interview even if it was ethically feasible to do so.

There is no national data about how common these symptoms are in the population outside and separate to health care services. It is important to determine the prevalence of symptoms to determine how best to manage them and examining the population pattern of symptoms in conjunction with individual experiences and meanings will help strengthen evidence of how best to support

individuals if and when they experience symptoms. By examining the relationship between infections, symptoms and perceived risk of STIs, I hope to consider how useful symptoms are in determining untreated STIs and unmet need for sexual health.

I have already mentioned my shift in focus from considering symptoms as an indicator of potential need for care and way to examine non-attendance behaviour, to becoming central to the range of care-seeking responses described (see chapter 2). During data collection, individuals' raw accounts of their lived experiences of these symptoms struck me as key determinants of their subsequent actions and the ways they interpreted what was happening to their bodies fascinated me. I realised the story of non-attendance would be incomplete without an in-depth examination of symptoms. I had originally planned to present data about symptoms and care-seeking responses together in the same paper to consider the process as a whole and enable each aspect to contextualise explanations of the other. However, as my analyses progressed, I realised how rich my data about symptoms were and in-depth examination of symptoms in their own right would give me a more detailed understanding of the lived experience of having symptoms. This in turn would enable a deeper understanding of participants' decisions about their care needs and engagement with services. This paper builds on, and extends the literature base described in section 1.5, chapter 1.

I used the survey data as a framework in which to gain an overview of symptom experiences in the population and then used individual lived experiences and interpretations to explain and extend these findings through the data from semi-structured interviews. Participant's accounts of symptoms were entangled with other stories relating to past and current sexual relationships, upbringing and knowledge about infections as well as other health issues they had experienced; this added valuable contextual insight but often made extracting data pertaining to specific genito-urinary symptom experiences more difficult. This paper, like the

other results papers in this thesis has not yet been submitted for publication but I have written it with the intention of submitting to BMC Public Health as I would like these findings to reach a broader public health audience rather than an STI-specific audience.

Note: I have included the full tables in the paper for ease of understanding. The convergence coding matrices and mixed methods matrices presented in this paper and the help-seeking results paper (chapter 5) are central to the mixed methods approach I have used and support later discussion of the value of integration in this way. They will be submitted as supplementary files to the journals.

4.3 Research Paper: Symptoms results paper

Status: To be submitted to BMC Public Health after thesis submission

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SECTION A – Student Details

Student	Fiona Mapp
Principal Supervisor	Ford Hickson
Thesis Title	Sexually Transmitted Infections: A Mixed Methods Study of Stigma, Symptoms and Help-seeking

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	BMC Public Health
Please list the paper's authors in the intended authorship order:	Fiona Mapp, Ford Hickson, Catherine H. Mercer, Kirstin Mitchell, Soazig Clifton, Anne M. Johnson, Jessica Datta, Nigel Field, Kaye Wellings
Stage of publication	**Not yet submitted**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	FM conceived the design of this study in conjunction with KW, CHM and FH. FM conducted and analysed all semi-structured interviews with support from FH and KW. FM wrote and edited all drafts with critical input from all authors. The final draft of the paper will be circulated to all authors for

	approval before submission.

Student Signature: ▮▮▮▮▮▮ **Date:** 01/08/17

Supervisor Signature: ▮▮▮▮▮▮ **Date:** 1/8/17

Prevalence, Lived experiences and making sense of genito-urinary symptoms: mixed methods study using Britain's Third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)

Fiona Mapp, Ford Hickson, Catherine H. Mercer, Kirstin Mitchell, Soazig Clifton, Anne M. Johnson, Jessica Datta, Nigel Field, Melissa J Palmer, Kaye Wellings

Abstract

Background

Genito-urinary symptoms can indicate an underlying infection, condition or disease requiring prompt access to treatment. However symptoms are non-specific and subjective perceptions may not be interpreted as a need for medical intervention by women and men who experience them. We explore the prevalence, lived experiences and sense-making processes of genito-urinary symptoms.

Methods

We used linked survey data and semi-structured interview data from Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3, undertaken 2010-12) focussing on reported genito-urinary symptoms. Prevalence estimates were calculated using complex survey analyses and qualitative data were analysed using thematic analysis. Key findings were integrated through use of a mixed methods matrix and a convergence coding matrix.

Results

From a total of 8,947 sexually experienced participants aged 16-44, 21.6% (95% CI 20.4-22.9) of women and 5.6% (95% CI 4.9-6.6) of men reported recent symptoms (past month). Pain urinating was the most commonly reported symptom by women and men. Semi-structured interviews with 16 women and 11 men suggested experiences of having symptoms were diverse, and key dimensions of genito-urinary symptoms were painfulness, their visible appearance and emotional responses. Participants expressed uncertainty about the boundaries between

normal and abnormal physiology and the normalising of sensations was common. We propose a 'Cause-Concern Cycle' to explain how participants made sense of sensations, highlighting the iterative nature of this process which stops when no new information is available, symptoms disappear or individuals accept an explanation. Integration of survey and semi-structured interview data highlighted differences in biomedical and lay explanations of symptoms and their links to STIs.

Conclusions

Genito-urinary symptoms are more commonly reported by women than men and the meaning(s) attributed to experiences mediate subsequent decisions and actions about whether to seek care. As very few participants considered STIs as a likely cause of their symptoms, these findings support the broad provision of STI testing and treatment services outside of specialist care including asymptomatic screening.

Key words: Genito-urinary symptoms; uro-genital symptoms; STIs; prevalence estimates; lived experience; sense-making; lay interpretation, meaning; mixed methods

Introduction

Genito-urinary symptoms are associated with a range of health conditions including cancers, (Centers for Disease Control and Prevention, 2014; NHS Choices, 2014b; Low *et al.*, 2015a), urinary tract infections (UTIs) (Huppert *et al.*, 2007; Tomas *et al.*, 2015) sexual function problems (Mitchell *et al.*, 2013, 2016) and, more commonly, sexually transmitted infections (STIs) (Low *et al.*, 2006; Mercer *et al.*, 2007). Overlapping symptomatology and poor predictive values of some symptoms such as vaginal discharge (George *et al.*, 2004; Mitchell, 2004; Low *et al.*, 2006) for STIs result in uncertainty, anxiety and often delayed care-seeking to appropriate services (Gott *et al.*, 1999; Mercer *et al.*, 2007) for those who experience symptoms. Misinterpretation of the cause of genito-urinary symptoms and delays in accessing appropriate care increases the risk of negative sequelae and may make

infections and their complications harder to treat (Eng, 1997), although not all genito-urinary symptoms require medical intervention. Therefore, there are both individual and public health benefits to responding to genito-urinary symptoms in a timely and appropriate way.

STI diagnoses have increased substantially since the 1990s (Public Health England, 2016; Nicoll et al., 2001). Having symptoms is the most common reason for attending sexual health clinics (Mercer *et al.*, 2012) and symptomatic individuals attending a sexual health clinic are more likely to be diagnosed with an STI than those without symptoms (Mercer *et al.*, 2007). 29% of women and men diagnosed with Chlamydia in the past year had tested because they had symptoms (Woodhall *et al.*, 2015). However, STI symptoms are often attributed to *"innocent explanations"* (Dixon-Woods *et al.*, 2001) such as natural bodily changes and may be expected to resolve without medical intervention (Hook *et al.*, 1997). Population-based estimates of STI prevalence show chlamydia, gonorrhoea, HIV and high-risk HPV are distributed heterogeneously within the population (Sonnenberg *et al.*, 2013) and give some insight into the association between STIs and symptoms. Women who had *Mycoplasma genitalium* detected in their urine were more likely to report STI symptoms (especially post-coital bleeding) than women who tested negative (Sonnenberg *et al.*, 2015a). Six out of seven women who tested positive for *Trichomonas vaginalis* also reported symptoms (abnormal or odorous vaginal discharge) (Field *et al.*, 2016). Not everyone with symptoms has an STI and not everyone with an STI has symptoms but nonetheless, symptoms are a clinical indicator of infection and a key part of STI experiences. Symptoms are used to triage patients within services and assess their care needs as part of a sexual history, but little is known about how symptoms are experienced and interpreted outside of medical settings. Symptoms in men are particularly under-researched. Some studies have looked at individuals' experiences of specific infections (for example genital warts (Hammarlund and Nystrom, 2004)) but few have looked at a range of symptom experiences in different population groups to

understand symptoms as a broader social phenomenon. Focusing on symptoms instead of STI diagnoses allows us to take a broader view of sexual health and examine how symptoms affect physical, emotional and social wellbeing (World Health Organization, 2006). A focus on symptoms also highlights social norms about the abnormalisation and medicalisation of normal physiology (particularly of women (Kirkham, 2007a). Individuals have different thresholds at which bodily sensations are interpreted as symptoms and varying resilience (immunologically and socially) to symptoms once established as such (Ahlzén, 2008). Recent attention to senses (particularly sight, smell and touch) and sensations (Howes, 2004; Hinton, Howes and Kirmayer, 2008) and how these are transformed into symptoms (Hay, 2008; Fainzang and Haxaire, 2011; Brandner *et al.*, 2014) has suggested a range of individual and socio-cultural factors governing the transition. Sense-making has been described as a contextualised process in which information is retrospectively simplified and interpreted to create meaning. This allows categorisation and communication of information and stimulates action (Woodside, 2001; Weick, Sutcliffe and Obstfeld, 2005). Sense-making is culturally constructed (Weick, Sutcliffe and Obstfeld, 2005) and is characterised by plausibility of the explanation rather than accuracy (Weick, Sutcliffe and Obstfeld, 2005) (in this case of clinical diagnosis) but the mechanism of individual sense-making is not well understood in relation to health issues.

Evidence about STI symptoms outside of medical settings is needed to understand experiences and care needs, and to improve individual and public health outcomes. We use data from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) to address this gap by exploring genito-urinary symptom prevalence, lived experiences and sense-making processes. We integrate findings from the survey analyses and interview data to provide a comprehensive overview of genito-urinary symptoms in Britain that may inform future healthcare provision.

Methods

The full study protocol has been published (Mapp *et al.*, 2016) and is described briefly here.

Study design

We analysed survey data from which we identified and sampled participants to follow-up with semi-structured interviews. Survey and semi-structured interview data were analysed separately and then key findings from each strand were integrated in a second stage of analysis to connect (Fetters, Curry and Creswell, 2013a) and extend findings (Sandelowski, Voils and Barroso, 2006) using convergent coding and mixed methods matrices (O'Cathain, Murphy and Nicholl, 2010).

Natsal-3 survey

Natsal-3 is a multi-stage, clustered, stratified probability sample survey examining sexual behaviour in the British resident population with data collected between September 2010 and August 2012 using computer-assisted personal interviewing (CAPI) with computer-assisted self-interview (CASI). Urine was collected from a sample of sexually-experienced participants (defined as those who reported at least one sexual partner in their lifetime) and was tested for *Chlamydia trachomatis*, *Neisseria gonorrhoeae, Mycoplasma genitalium,* human papillomavirus types and HIV antibody. The full methods are reported elsewhere (Erens et al., 2013). This study draws on a sub-sample of sexually experienced participants aged 16-44 years reflecting question routing within the CASI.

The primary outcome was reported symptom experience, analysing responses to the CASI question included in the section about STIs: *"In the last month, that is since (date one month ago), have you had any of the following symptoms?"* (Erens et al., 2013) (see table 1). Prevalence estimates of reported symptoms were calculated with 95% confidence intervals using the survey commands in Stata V.14.1 to account for stratification, clustering and weighting of the dataset. Logistic regression models were used to calculate odds ratios and adjusted for age (aAOR).

Analyses were stratified by age group and gender to reflect differences in emergent qualitative data. Semi-structured interview data prompted us to examine STI positivity and perceived STI risk perception (excluding HIV) which we measured using a four-point scale ranging from "greatly at risk" to "not at all at risk," in participants who reported symptoms.

Semi-structured interviews

Participants were drawn from Natsal-3 respondents. We purposively sampled women and men who had reported at least one genito-urinary symptom (see table 2), had reported no previous attendances at a sexual health clinic, and had agreed to be re-contacted (3.19% of total Natsal-3 sample were eligible). Our sampling procedure enabled us to follow-up with participants who reported a clinical indicator of STIs and explore how they understood and rationalised this. We selected participants to maximise diversity of symptomatic experiences outside of specialist healthcare. We wrote to potential participants inviting them to take part in an interview and followed the letter up with a telephone call. Interviews were conducted by FM, between May 2014 and March 2015 at the participant's home or other convenient location. The topic guide incorporated four domains: STI social representations; symptom experiences and meanings; care-seeking behaviour; STI stigma. Specifically participants were asked about their lived experiences of genito-urinary symptoms and the meanings they had imputed to make sense of them. Interviews lasted between 35 and 108 minutes, median length was 68 minutes and were digitally recorded and transcribed verbatim. We used thematic analysis (Braun and Clarke, 2006) to explore the lived experiences of genito-urinary symptoms, sense-making processes and meanings constructed around the experience. One third of transcripts were double coded. Through inductive analysis, we developed emergent themes and looked for relationships and connections between them. The two over-arching themes relating to sense-making were explored in more detail through the data to develop the Cause-Concern Cycle. We used NVivo V.11 for data organisation.

Results

Survey findings

Participants

Key characteristics of the full Natsal-3 sample are reported elsewhere (Mercer *et al.*, 2013). Of the 15,162 participants in Natsal-3, 8947 were aged 16-44 years and sexually experienced and 1403 people reported one or more symptoms in the past month. Data for this question were missing for 1.4% of eligible participants.

Prevalence of genito-urinary symptoms

The prevalence of reporting the symptoms listed in Natsal-3 in the past month was 21.6% (95% CI 20.4-22.9) n=1182 for women and 5.6% (95% CI 4.9-6.6) n=221 for men (table 1). Experiencing pain when urinating was the symptom most commonly reported by women (7.1% (95% CI 6.3-8.0) n=384) and men (2.5% (95% CI 2.0-3.2) n=101) and genital ulcer/sore the least commonly reported (women 0.5% (95% CI 0.3-0.7) n=25), men 0.2% (95% CI 0.1-0.3) n=7) (table 1). Women aged 16-29 were more likely to have experienced (any) symptoms than those aged 30-44 (12.0% (95% CI 11.1-13.0) n=793 vs 9.6% (95% CI 8.6-10.7) n=389). Experience of the following specific symptoms declined with increased age for women: pain urinating, abnormal vaginal discharge, unpleasant odour associated with discharge, vaginal pain during sex and to a lesser extent, abnormal bleeding between periods. There was no significant relationship between age and symptoms for men. Multiple symptoms were reported by 7.5% (95% CI 6.7-8.4) n=420 of women and 0.8% (95% CI 0.5-1.2) n=25 of men. The most frequently co-reported symptoms were vaginal pain during sex and lower abdominal/pelvic pain experienced by 22.1% (n=92) of women who reported multiple symptoms. Pain urinating and painful testicles were the most common co-reported symptoms for men experienced by 47.7% of men who reported multiple symptoms (n=12), however, as a small number of men reported more than one symptom, estimates may be unreliable.

Table 1: Prevalence of genito-urinary symptoms reported in the past month by participants aged 16-44 years, by age group and sex

Symptoms reported in the last month	16-19 years % (95% CI)	20-24 years % (95% CI)	25-29 years % (95% CI)	30-34 years % (95% CI)	35-39 years % (95% CI)	40-44 years % (95% CI)	All ages % (95% CI)	p value**
Women								
Any symptom	**27.1** **(23.7, 30.9)**	**28.3** **(25.2, 31.6)**	**26.1** **(23.4, 28.9)**	**20.3** **(17.8, 23.2)**	**16.0** **(13.0, 19.6)**	**15.6** **(12.8, 19.0)**	**21.6** **(20.4, 22.9)**	<0.0001
Pain, burning or stinging when passing urine	11.9 (9.6, 14.6)	8.5 (6.7, 10.6)	9.4 (7.6, 11.5)	6.1 (4.7, 7.9)	4.9 (3.3, 7.2)	4.7 (3.2, 6.9)	7.1 (6.3, 8.0)	<0.0001
Genital wart / lump	1.0 (0.4, 2.6)	1.4 (0.8, 2.4)	0.5 (0.2, 1.2)	0.6 (0.2, 1.3)	0.2 (0.0, 1.3)	0.6 (0.2, 1.9)	0.7 (0.5, 1.0)	0.1364
Genital ulcer / sore	0.3 (0.1, 1.5)	0.1 (0.0, 0.8)	0.9 (0.5, 1.7)	0.4 (0.1, 1.1)	0.6 (0.2, 2.0)	0.4 (0.1, 1.3)	0.5 (0.3, 0.7)	0.3147
Abnormal vaginal discharge	7.0 (5.2, 9.3)	5.6 (4.2, 7.3)	5.1 (3.7, 6.8)	3.6 (2.5,5.1)	2.6 (1.6, 4.3)	1.9 (1.1, 3.3)	4.0 (3.4, 4.6)	<0.0001
Unpleasant odour associated with vaginal discharge	6.8 (4.9, 9.3)	5.3 (3.9, 7.2)	4.4 (3.2, 5.9)	3.2 (2.2, 4.7)	2.2 (1.3, 3.7)	3.0 (1.8, 5.0)	3.9 (3.3, 4.6)	0.0018
Vaginal pain during sex	6.9 (5.1, 9.2)	9.0 (7.1, 11.2)	7.2 (5.7, 9.1)	5.5 (3.9, 7.6)	2.8 (1.7, 4.5)	3.2 (1.9, 5.1)	5.6 (4.9, 6.3)	<0.0001
Abnormal bleeding between periods	4.4 (3.1, 6.3)	5.8 (4.3, 7.9)	5.9 (4.4,7.9)	4.1 (3.0, 5.6)	2.8 (1.7, 4.5)	3.6 (2.4, 5.5)	4.4 (3.8, 5.1)	0.0259
Bleeding after sex (not during a period)	3.3 (2.1, 5.0)	3.9 (2.9, 5.4)	3.4 (2.3, 4.9)	2.9 (1.9, 4.4)	1.2 (0.5, 2.7)	2.7 (1.6, 4.6)	2.8 (2.4, 3.4)	0.0790
Lower abdominal or pelvic pain (not	5.1	6.5	7.1	5.1	4.4	4.6	5.5	0.1683

related to periods)	(3.7, 7.0)	(5.1, 8.3)	(5.6, 9.1)	(3.7, 7.0)	(2.9, 6.7)	(3.1, 6.9)	(4.8, 6.3)	
Unweighted denominator*	675	1065	1364	1033	591	598	5326	
Weighted denominator*	344	624	670	653	673	751	3716	
Men								
Any symptom	**8.0**	**6.3**	**6.0**	**5.9**	**3.7**	**5.0**	**5.7**	0.1763
	(5.9, 10.7)	**(4.7, 8.5)**	**(4.4, 8.2)**	**(4.2, 8.3)**	**(2.3, 5.9)**	**(3.1, 8.0)**	**(4.9, 6.6)**	
Pain, burning or stinging when passing urine	2.8	2.6	3.0	2.8	2.8	1.5	2.5	0.5829
	(1.69, 4.5)	(1.7, 4.2)	(1.9, 4.8)	(1.7, 4.7)	(1.6, 4.7)	(0.6, 3.3)	(2.0, 3.2)	
Genital wart / lump	0.8	1.0	0.9	1.0	0.2	1.1	0.8	0.7293
	(0.3, 2.0)	(0.5, 2.1)	(0.3, 2.4)	(0.3, 2.6)	(0.0, 1.6)	(0.3, 3.7)	(0.5, 1.3)	
Genital ulcer /sore	0.6	0.0	0.0	0.4	0.0	0.1	0.2	0.0849
	(0.2, 2.1)	–	–	(0.1, 1.3)	–	(0.0, 0.8)	(0.1, 0.3)	
Discharge from the end of the penis	0.5	0.6	1.3	0.3	0.5	0.0	0.5	0.0753
	(0.2, 1.7)	(0.2, 1.5)	(0.5, 3.0)	(0.1, 1.2)	(0.1, 1.9)	–	(0.3, 0.9)	
Painful testicles	3.9	2.9	2.2	2.6	0.7	2.6	2.4	0.0744
	(2.6, 6.0)	(1.8, 4.6)	(1.4, 3.6)	(1.5, 4.4)	(0.2, 2.2)	(1.4, 4.8)	(1.9, 3.0)	
Unweighted denominator*	582	793	826	630	382	408	3621	
Weighted denominator*	374	629	651	654	671	724	3702	

* Denominator is all sexually experienced women and men aged 16-44 years

** χ² p value for association with age-group

One or more STIs were detected in the urine of 30.4% (95% CI 27.1-34.0, n = 302) women and 8.5% (95% CI 5.8-12.3, n = 34) of men who also reported symptoms, although the STI detected may not have caused the symptoms reported. Participants who reported symptoms were more likely than those who did not report symptoms to perceive themselves to be 'greatly' or 'quite a lot' at risk of getting an STI (women: 6.6% (95% CI 5.2-8.4) vs 2.7% (95% CI 2.2-3.4), aAOR 2.2 (95% CI 1.6-3.0); men: 14.2% (95% CI 9.5-20.8) vs 4.8% (9% CI 4.1-5.6), aAOR 3.0 (95% CI 1.8-5.1)).

Semi-structured interview findings

Participants

We interviewed 27 participants (16 women and 11 men) aged 19-47 years including one gay man and one bisexual woman; three were Asian/Asian British, one was black British and the other participants were white British/white other. We did not recruit any women who reported abnormal vaginal discharge in their initial Natsal-3 interview, but this was frequently mentioned by participants during the semi-structured interview when asked about lifetime symptomatic episodes. None of the men in our sample had experienced genital ulcers/sores. Some men did not report any symptoms suggesting they may have mis-reported their experience in the survey, forgotten about their symptomatic experience(s) or were unwilling to disclose their experience in a face-to-face qualitative interview setting (table 2).

Table 2: Mixed method matrix of quantitative and qualitative findings for individual participants

Particip-ant no.	Age	Symptoms experienced past month*	Symptoms experienced ever¤	Previous STI diagnoses or conditions*¤	Suspected cause of symptoms¤	Emotional response¤
Women						
i2	35-39	Abdominal/pelvic pain	Pain urinating; vaginal pain during sex; bleeding after sex; abdominal/pelvic pain	None	Medically unknown cause of abdominal pain; other symptoms linked to existing health conditions and side effects of medication	*"Nervous," "scared," "got me down,"* uncertain, relief at negative chlamydia test
i3	20-24	Abdominal/pelvic pain	Abnormal vaginal discharge; vaginal pain during sex; abdominal/pelvic pain	None	Vaginal discharge – linked to periods; painful sex – small vagina; abdominal pain – bad posture	Worried about worst case scenario (cervical cancer)
i4	25-29	Abnormal bleeding between periods; abdominal/pelvic pain	Pain urinating; abnormal vaginal discharge; vaginal pain during sex; abnormal bleeding between periods; bleeding after sex; abdominal/pelvic pain	Thrush,* cystitis¤	Pain urinating – cystitis Vaginal discharge – unknown, normal; bleeding between periods and after sex – normal, linked to contraception and effects of childbirth	*"Not really fussed by it" "just kind of take it in my stride"*
i6	35-39	Abnormal bleeding between periods	Pain urinating; abnormal vaginal discharge	Thrush*	Vaginal discharge - thrush	*"worried," "ashamed"* and uncertain what are normal bodily changes
i7	40-44	Genital ulcer/sore	Pain urinating; genital ulcer/sore; abnormal vaginal discharge; abnormal bleeding between periods	Diagnosed but can't remember which one*	Pain urinating – pregnancy; genital sore – unknown but possibly related to periods, irritation from washing too much; vaginal discharge –	Indifferent

					normal; bleeding between periods – not discussed	
i8	16-19	Abnormal bleeding between periods	Pain urinating; vaginal pain during sex; abnormal bleeding between periods; bleeding after sex; abdominal/pelvic pain	None	Pain urinating – during labour; unknown causes for other symptoms - possibly linked to contraception or periods; abdominal pain disappeared and retrospectively justified as "obviously nothing"	Contradictory accounts of how worried she was – all symptoms were worrying but then rationalised in relation to the experience of others
i9	20-24	Pain urinating; vaginal pain during sex; abnormal bleeding between periods	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge; vaginal pain during sex; abnormal bleeding between periods	Cystitis¤	Pain urinating – cystitis (due to dehydration); vaginal discharge and odour occur together – unknown; painful sex – normalised "not being ready for sex;" bleeding between periods – normalised "I've got crazy periods"	Self-conscious about discharge, confused
i12	25-29	Unpleasant odour associated with vaginal discharge	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge; abdominal/pelvic pain	Cystitis¤	Pain urinating – cystitis (due to low iron levels; vaginal discharge and odour – ongoing and medically unexplained; abdominal pain – symphysis pubis dysfunction (SPD) during pregnancy	*"Just get on with it;"* worried about risk of miscarriage from abdominal pain during pregnancy; confusing during uncertainty before diagnosis
i16	25-29	Abdominal/pelvic pain	Pain urinating; abnormal vaginal discharge; abnormal	Thrush*	Pain urinating – kidney infection (due to excessive alcohol consumption);	Scary; worried about uncertainty of cause, nerve-wracking

			bleeding between periods; abdominal/pelvic pain		bleeding between periods and abdominal pain – linked to having polycystic ovaries but uncertain of exact cause Thrush – antibiotic use	
i18	30-34	Pain urinating	Pain urinating; unpleasant odour associated with vaginal discharge	Thrush[¤]	Unknown	Worry
i19	30-34	Bleeding after sex; abdominal/pelvic pain	Pain urinating; abnormal vaginal discharge; vaginal pain during sex; abnormal bleeding between periods; abdominal/pelvic pain	UTI[¤]	Pain urinating – UTI; bleeding between periods – complications from a miscarriage	Distressing, frightening, panic, but no stigma or embarrassment
i25	45-49	Unpleasant odour associated with vaginal discharge	Pain urinating; abnormal vaginal discharge	Chlamydia;* genital/ gynaecological surgery;*cystitis,[¤] HPV[¤]	Pain urinating - unknown cause the first time she experienced symptoms; now recognises them and keeps antibiotics in case Vaginal discharge – some sort of bacteria (linked to sexual partner at the time)	Scared, embarrassed, worried
i26	16-19	Genital ulcer/sore	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge; vaginal pain during sex	Kidney infection, thrush[¤]	Pain urinating – kidney infection; vaginal discharge and odour – thrush as a side effect of antibiotics for kidney infection; painful sex – normal part of sex	Not worried
i27	25-29	Genital ulcer/sore; genital wart / lump	Pain urinating; abnormal vaginal discharge; vaginal pain during sex; abdominal/pelvic pain	Kidney infection[¤]	Pain urinating – urine infection, dehydration; vaginal discharge – normal; pain during sex –	Not worried about pain urinating or discharge; worried about painful sex as it happened after pregnancy;

					normal; abdominal pain – pregnancy;	worried about abdominal pain during pregnancy
i28	30-34	Unpleasant odour associated with vaginal discharge	Abnormal vaginal discharge	None	Not sure if it is normal or abnormal discharge	Worried and uncertain about what is normal
i29	40-44	Unpleasant odour associated with vaginal discharge	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge odour; abdominal/pelvic pain	Thrush;* bacterial vaginosis;* genital/ gynaecological surgery;* HPV¤	Pain urinating – urine infection; vaginal discharge and odour – thrush; abdominal pain – dietary intolerances	Worried about abdominal pain due to some uncertainty about cause; ongoing worries about HPV
Men						
i10	20-24	Painful testicles	Painful testicles	None	Unknown	Worry (about testicular cancer as cause)
i11	16-19	Painful testicles	None	None	N/A	N/A
i13	20-24	Genital wart/lump	Genital wart/lump	Genital warts¤	Unknown then googled and recognised symptoms as genital warts	Conflicted – embarrassment, irritating, implications for sexual relationships, not ashamed, distressed, warts are *"harmless"* so lucky not to have other symptoms; unpleasant in every way; warts are nasty
i14	45-49	Pain urinating	Pain urinating; genital lump (not a wart); painful testicles	Urine infection;¤ epididymal cyst¤	Pain urinating – urine infection; genital lump – suspected testicular cancer but diagnosed with epididymal cyst; painful testicles – kicked by someone	Extreme fear, worry, relief at diagnosis
i15	30-34	Pain urinating	Pain urinating; painful testicles	None	Pain urinating – *"too much drinking, too much smoking, not enough*	Worry, panicked

					eating, not enough exercise, not enough water;" painful testicles – injury eg. mountain biking	
i17	30-34	Penile discharge	Pain urinating; penile discharge; painful testicles	None	Unknown – possibly linked to cycling, new pants, changing washing powder	*"Freaked out,"* fear, concern persists as no resolution
i20	30-34	Pain urinating; painful testicles	Pain urinating; penile discharge; painful testicles	Urine infection, kidney stones, haematospermia, epididymal cysts¤	Pain urinating – urine infection or excessive alcohol consumption; penile discharge – googled and found haematospermia	Worried about health generally
i21	20-24	Painful testicles	None	None	N/A	N/A
i22	30-34	Painful testicles	Pain urinating; painful testicles	Diagnosed with something causing painful testicles but can't remember what; chlamydia¤	Unknown	Really worried about pain in testicles, relieved to have diagnosis; worried about pain urinating because of unknown cause.
i23	20-24	Painful testicles	Pain urinating; painful testicles	Bladder infection	Unknown	Worried about pain urinating and general confusion about causes of symptoms
i24	16-19	Painful testicles	Pain urinating; painful testicles	Not disclosed	Pain urinating – excessive alcohol consumption and dehydration; painful testicles – sports injury but fear about testicular cancer	*"Plays on your mind;"* worried; *"down about it;"* unhappy

* Natsal-3 survey data; ¤ Qualitative interview data

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Sensations and symptoms varied between participants. Some had experienced repeated episodes of the same symptoms, allowing for diverse lived experiences. Despite the variability, participants' accounts encompassed two main themes: symptom physicality and the boundaries of (ab)normality.

Dimensions of symptom experiences

There were three dimensions to the lived experience of genito-urinary symptoms: pain, visible appearance (to the self and others) and emotional responses. The majority of participants described having had painful genito-urinary symptoms at least once in their lives. The level of discomfort and individual thresholds for pain experiences varied from *"a little bit of pain" (i3, i10)* to being *"very painful and extremely uncomfortable" (i29).* Painful symptoms were unpleasant and often described as physically draining but hidden from other people as pain could be described, but not directly shown, meaning interpretation of pain occurred at the individual level. Sharing and comparing experiences of painful symptoms with their social network and/or healthcare professionals led to increased reassurance and the experience became less isolating. This contrasted with experiences of visible symptoms such as bleeding, discharge, warts and ulcers, which often elicited negative feelings as one woman explained: *"I suppose it's because what makes you feel repulsed yourself… so yeah, warty, ulcery discharge stuff really makes me feel sick" (i19, woman, aged 30-34).*

The visible appearance of symptoms as well as associated smells and physical sensations provided key sensory information which was used to interpret and monitor the experience. Both pain and visible symptoms also had substantial affective capacity eliciting a range of negative emotions including anxiety, embarrassment and disgust. Worry was the most common emotional response and centred on concern for an individual's future health, particularly their fertility, rather than their current physical experiences. Fertility worries were expressed by

women and men. One, young woman explained her specific worries in relation to the symptoms she had experienced:

> *I worry it's [her symptoms] going to stop me having more kids… I*
> *just worry it's going to lead to something more later on in life.*
> *Whereas I don't worry about what it's doing to my body now, 'cos*
> *I think if I'm not bleeding every day that's fine. (i8, woman, aged*
> *16-19)*

Uncertainty about the possible cause was an important influence on the emotional meanings sensations had. Emotions could exacerbate physical experiences and sensations took on additional, negative meaning if linked to more serious outcomes.

> *[I had] a lump which happened over Easter and I couldn't see a*
> *doctor and I thought, I was convinced I was dying… and it was*
> *nothing…it was just an epididymal cyst, it was fine… I just*
> *convinced myself that I hadn't long left like a bloody idiot. (i14,*
> *man, aged 45-49)*

Without prompt access to healthcare, this participant created an extreme situation in his mind and although there were no physical changes to his symptoms, emotionally his condition deteriorated making the whole experience more difficult to manage.

Boundaries of normal and abnormal

Experiencing symptoms such as pain or visible abnormalities indicated possible bodily changes, although participants were uncertain at what point sensations they were feeling became symptoms of disease and about the parameters of normal physiological fluctuations and pathological deviations.

Although the survey explicitly asked about symptoms, during the semi-structured interviews, participants did not often describe their experience in this way. Instead they talked about bodily changes as isolated, recurring or ongoing events and experiences focussing on the sensations involved – how their bodies felt, looked and/or smelt.

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> *I had three very, very small lumps erm on my penis… no pain, no itching, no irritation, so it's only visibly unpleasant. (i13, man, aged 20-24)*

When sensations were associated with increased levels of concern and a suspected underlying medical cause such as an infection or disease they were transformed by participants into symptoms. In this way, sensations related to having sex in particular were seen as distinct from medical explanations requiring diagnosis. Vaginal pain during sex and bleeding afterwards were experienced by women and perceived as personal characteristics and sexual practices – *"I'm not a very big girl"* (i3) [having a small vagina], *"do[ing] different positions,"* (i3) and *"not being ready for sex"* (i9) or sex being *"too rough"* (i16).

The most intense period of sense-making occurred at the onset of sensations when physical feelings, smells and appearances were or were not attributed to being 'symptoms.' Whether these sensations continued to be construed as symptoms depended on their natural course. Subsequent changes to, or gradual disappearance of, the sensations commonly prompted revision of perceptions of bodily experiences transforming the meaning of the overall experience.

> *The pain in my stomach, I don't have that much anymore, so that was obviously nothing really. (i8, woman, aged 16-19)*

In other instances, sensations which had been viewed as symptoms were retrospectively re-conceptualised as sensations when the experience was over and there had been no perceived adverse outcomes. The term 'symptom' therefore had varying relevance to individuals' accounts of their experiences.

Several participants normalised sensations, interpreting them in the context of healthy bodily change. Puberty was often used as an example of normal, healthy changes that occur within and to the body, particularly menarche, and these experiences *"de-sensitised"* (i7) some women to changes in genito-urinary health. Getting older offered an additional account for natural body changes. This

normalising process increased acceptance of sensations and reduced concern about the experience.

> *I think it is probably normal to bleed between periods. (i8, woman, aged 16-19)*

> *They're normal things that every woman would go through really, like the bleeding or the pains and stuff…being sore or having a lump (i27, woman, aged 25-29)*

The view was also expressed that 'normal' differs between individuals so comparison of experiences is not helpful and can exacerbate uncertainty about the significance of bodily sensations and symptoms. Recurrent symptoms or ongoing health issues were initially considered abnormal but became normal for the individual over time and as they adapted to living with symptoms.

> *It's been so long, I just have to kind of accept how it is, I'm not saying it's [abnormal vaginal discharge] great but, just have to get on with it. (i12, woman, 25-29 years)*

Sensations were also frequently interpreted as a side effect or consequence of taking hormonal contraception, or of sexual activity. Although influenced by external factors, these experiences were still 'normal' to individuals as the cause was situated in their day-to-day experiences. Normalising responses were particularly gendered as women had far more opportunities to consider their sensations in the context of other potential causes – menstruation, contraception, receptive sex – than men did.

Both women and men described the influence of their social network and cultural narratives on whether or not they normalised their sensations. If they knew other people who had had similar symptoms, or they perceived the issue to be a common problem, their own experience was less of a concern. Women in particular perceived common sensations and symptoms to be less problematic than those experienced by fewer people.

I wasn't necessarily worried because I think it's [pain urinating]
quite a common thing, like urine infections I don't know, quite a
common thing or problem. (i26, woman, aged 16-19)

Urine infections and thrush in women were perceived to be particularly common causes. Women's tendency to normalise their experience of bodily sensations contrasted with men's as they were much more likely to be perceived as exceptional events in their life that were vividly recalled.

Sense-making processes

Participants endeavoured to make sense of their experiences and create meanings to re-gain control over their bodies. The dimensions of cause and concern were important in participants lived experiences of genito-urinary symptoms. We propose the Cause-Concern Cycle to help explain sense-making processes.

The Cause-Concern Cycle

The themes of 'searching for possible causes' and 'fluctuating concern about symptoms' emerged from analysis of the data and appeared to be central to how participants made sense of their experiences. We identified the relationship between these and closely related themes and developed the Cause-Concern Cycle as a conceptual model for making sense of genito-urinary sensations (see figure 1).
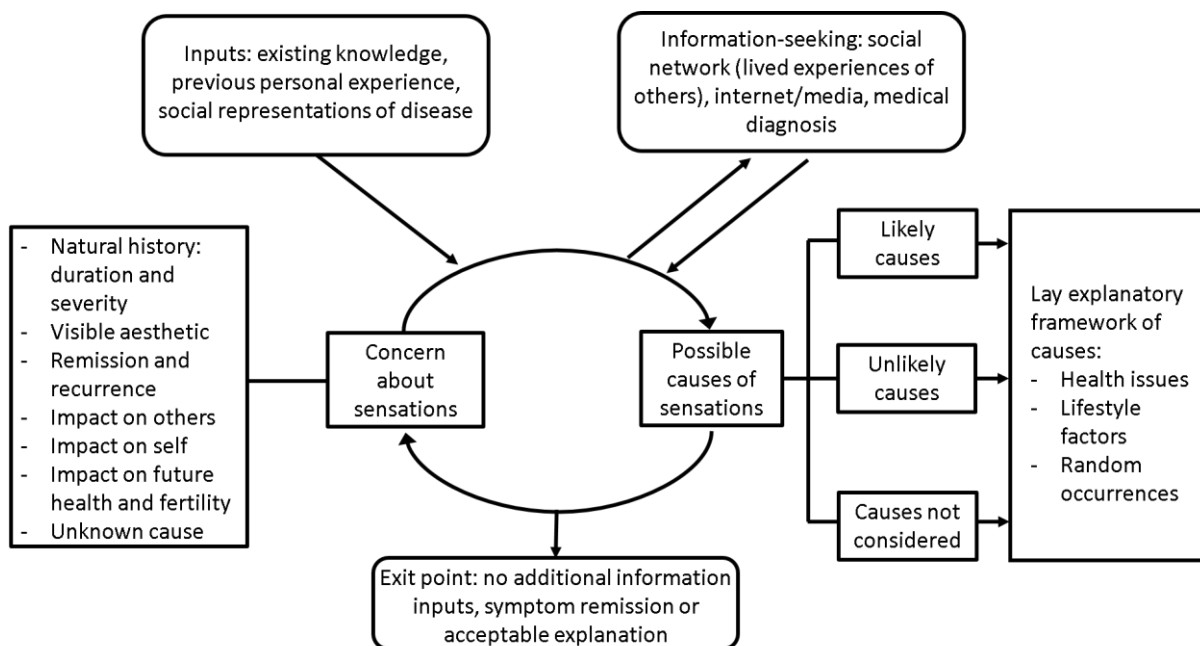
Figure 1: Diagram representing the Cause-Concern Cycle of sense-making about genito-urinary sensations

Participants made sense of their sensations through the iterative process depicted in the Cause-Concern Cycle. The level of concern determined the importance of finding an explanation for the sensation which led to a range of possible causes being considered. The most likely causes in turn fed back into the level of concern expressed about symptoms.

> *This actually happened the other day, I had a bit of pain, and I got really wound up like "oh my god I'm gonna have testicular cancer" but I just decided to myself I'd just leave it for a day and if it stopped hurting, then I could stop worrying about it, which it did. (i10, man, aged 20-24)*

Concerns encompassed what the sensations were, if they would get worse or disappear naturally, if or when they would recur, the impact they had on immediate social networks and individuals' sex lives, how painful the sensations would be, duration and the possible impact on future health, particularly fertility. Lay explanatory frameworks of likely causes of symptoms encompassed three main

themes: health issues, lifestyle factors and random occurrences (see table 2) and were dependent on the timing and context when they developed.

> *I got freaked out because there was no reason why it [pain urinating and penile discharge] should happen, nothing, I'd not changed anything apart from like I say, I might have put a new pair of pants on or changed my wash powder or something like that but other than that there was no reason why it should happen. (i17, man, aged 30-34)*

Health issues were the most likely explanations and included suspected and diagnosed UTIs or STIs, physiological changes during pregnancy and childbirth, bleeding related to menstruation or contraception, dietary intolerances, insect bites, side effects of medication and underlying diagnosed health conditions including polycystic ovarian syndrome, haematospermia and previous miscarriages or abortions. Poor hygiene was considered by participants as a potential cause of infection in general but dismissed as unlikely to explain their own symptoms as they did not perceive their own cleanliness to be problematic. Fears about cervical and testicular cancer were commonly expressed and were viewed as "*a horrible thing to have to think about*" (i17) and "*an awful disease*" *(i11).* Finding a lump imported ready-made negative social meanings about cancer, often bypassing the search for other possible explanations. Men were more likely to suspect that sensations/symptoms were caused by lifestyle factors such as drinking alcohol, dehydration, injuries from sport, wearing tight underwear or changing washing powder. However sensations arising from sexual activity, such as genital pain and bleeding after sex affected women more than men. One younger woman thought that bad posture was the likely cause of her abdominal pain. If the experience could not be linked to a likely cause, sensations were viewed as random occurrences.

Participants considered the timing of symptoms and the context in which symptoms had developed, as well as their ideas about 'likely causes' to develop their own lay explanatory framework to make sense of their experience of symptoms. Unlikely causes were frequently mentioned in accounts of sense-making, suggesting there

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was some awareness of the potential range of causes but these were disregarded because they did not fit with individuals' perception of themselves, the symptoms or the context of the experience. STIs were considered dirty in the context of both hygiene and morality and so very few participants considered them as a possible cause of symptoms.

> *I suppose because I know they're symptoms of other things as well and not necessarily STIs so I'd put in my head it wasn't anything to do with an STI 'cos I wouldn't get one of them. (i19, woman, aged 30-34)*

Being in a long-term relationship, especially a marriage, was used by participants as evidence that their symptoms were not caused by STIs. This implies there are common values and assumptions to these types of sexual partnerships especially around monogamy. Very few participants were diagnosed with STIs after seeking care for the symptoms they reported, and lived experiences of having these infections influenced their perception of STIs, considering them less dirty than other participants. Individuals drew on various sources of information in their search for the most likely explanation for their symptoms, which acted as inputs to the Cause-Concern Cycle (see figure 1). Previous personal experience of the symptoms increased familiarity of the sensation and for some, increased certainty about the underlying cause. Existing knowledge and social representations of diseases set the parameters of the explanatory framework and if these did not result in a satisfactory explanation, additional information was actively sought, informed by the sense-making and meaning derived from the experience so far.

The lived experiences or knowledge of others – close friends, siblings and mothers (but rarely fathers) - in an individual's social network were also used in understanding symptoms if experiences were similar. However the benefit of this type of knowledge was dependent on existing levels of trust, the nature of symptoms and the extent to which the individuals were prepared to share or conceal their experience from others. This resulted in highly selective disclosure.

Participants commonly used cultural reference points including the media, news and TV programmes including soap operas and health and medical programmes to inform their sense-making and knowledge about symptoms.

The internet was often mentioned spontaneously in relation to information-seeking. It represented a contested source of knowledge as online material was viewed both as a valuable, anonymous source of information about health issues and as a source of misinformation and extreme visual images (particularly from Google image searches) causing or exacerbating stress.

> *It's more convenient to just Google it and self-diagnose, even if you've been [self] diagnosed for the wrong thing. (i16, woman, aged 25-29)*

> *I do [Google symptoms] but then I always wish I hadn't... you can go off on all crazy scary tangents can't you on the internet, so yeah a little bit cautious when it comes to Googling health information. (i19, woman, aged 30-34)*

Participants described multi-layered patterns of information-seeking behaviour to fit the type of information they were looking for – generally reassurance that symptoms were relatively harmless but sometimes seeking out worst case scenarios. Google, NHS accredited websites and forums with discussion threads describing the lived experiences of having similar symptoms by anonymous users were the main internet destinations for participants in this study. The internet was highly influential in the sense-making process and the immediacy and accessibility of a range of information was occasionally prioritised over accuracy; tensions that constrained sense-making.

Several of those interviewed did seek healthcare and regarded a medical diagnosis as the best source of information and support, but if healthcare professionals did not provide an explanation, sense-making was suspended. One woman (i12, cited above) had medically unexplained abnormal vaginal discharge explained the impact of not knowing the cause on her experience.

Well I can't really explain it because I don't know what it is…even
on the doctors notes it's like, question mark…I'd rather know what
it is so at least I knew so I could just forget about [it]…I could just
live with it, but what if it was something that was really wrong?
(i12, woman, aged 25-29)

This interruption to the process of sense-making occurred because all information sources had been exhausted but left the participant with an unsatisfactory, incomplete explanation and prolonged the search for likely explanations; the period of time over which sense-making occurred varied between participants and sensations. However not everyone sought information to help explain their symptoms which restricted their sense-making process and the meanings attached to the experience and interrupted the Cause-Concern Cycle when all possible explanations had been exhausted.

Interviewer: Did you do anything else, like go and get
information from somewhere?

Participant: I didn't, no…I didn't go to the doctors, I didn't even
Google it to be fair, I just hoped it would go away, probably
because I didn't know what Google would say! [Laughs] The fear
stopped me from doing it so yeah, I just left it till it went away
(i17, man, aged 30-34).

Sense-making was a continual, fluid process, characterised by uncertainty. New information or a change in sensations led to new interpretations and a shift in what the sensations were thought to mean. The process was ongoing throughout the period of uncertainty until bodily changes were explained by a likely story accounting for cause, context and outcome, taking into account existing beliefs and values. Alternatively, sensations resolved themselves or were normalised and so no longer needed to be understood. Participants attempted to make sense of the symptoms they were experiencing to generate a logical explanation which in turn formed the basis of meanings about symptoms.

Should it happen again [pain urinating] I know how to take
antibiotics and I know it can happen whether I wash or not,
whether I've got a boyfriend or not and that was sorted for me…I

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felt comfortable, of course it was horrendous and all that but I felt
I was in control…I felt that I know what it is, I don't need to be
scared. (i25, woman, aged 45-49)

After acquiring meaning, symptoms were perceived to become more manageable as meanings inferred associated actions and decisions. Individuals felt they were able to regain control after a period of uncertainty, and devise strategies on how to cope with their symptoms.

Exceptions to the Cause-Concern Cycle

The only participants whose accounts do not fit the Cause-Concern Cycle of sense-making were the participants who did not report any symptoms during the semi-structured interviews. This suggests there is internal validity for the Cause-Concern Cycle as a mechanism for explaining how people make sense of genito-urinary symptoms.

Integrated findings

Data from both the survey and semi-structured interviews showed divergence in how common symptoms were between women and men, with women reporting more recent and lifetime experiences (table 3). This is partly due to female anatomy which increases symptom possibilities and reflected in the survey as women were asked about more symptoms than men. However our findings suggested symptom prevalence estimates may in fact be higher than those calculated from Natsal-3 data, particularly for women, due to the uncertainty about what constitutes a symptom and the gendered tendency to normalise experiences which may have resulted in under-reporting of symptoms. Ideas about what constituted a symptom differed between data sources. Natsal-3 asked about the list of abnormalities (table 1) in the context of STIs and specifically used the word 'symptoms'. However, our interview data problematised this classification by highlighting participants' own perceptions of symptoms as sensations with an underlying medical cause that gave them concern, but not commonly linked to STIs. Most participants in our interview

sample did not consider STIs as a likely cause of their bodily changes which is at odds with the survey data that suggested people reporting symptoms perceived themselves to be at risk of STIs, although this could be a characteristic of the sample and not transferable to other contexts.

As the survey and semi-structured interview data were collected sequentially with a minimum of 22 months between data collection phases (Mapp *et al.*, 2016), it was difficult to triangulate individual-level data from each strand. Participants reported on different symptomatic experiences and many considered their lives to have changed (especially relationship status, sexual behaviour, knowledge) between the survey and interview data collection, particularly younger people. The qualitative research revealed some instances in which the survey findings were not confirmed in semi-structured interviews. For example, more women reported a genital ulcer / sore in Natsal-3 than during the semi-structured interview. Some men did not describe recent symptoms in the semi-structured interview, suggesting that they may have mis-reported their symptoms in the survey, forgotten about their symptomatic experience(s) or been unwilling to disclose their experience in a semi-structured interview.

Table 3: Convergence coding matrix - integration of findings from quantitative and qualitative strands according to theme

Theme	Quantitative findings	Qualitative findings	Integration
Commonality of genito-urinary symptoms	• 21.6% of women and 5.6% of men reported recent symptoms • Pain urinating was common, genital ulcers and warts were rare • Women were more likely to experience multiple symptoms than men	• Multiple symptom episodes were commonly described; some symptoms were persistent and/or recurred, especially for women • Differentiation between symptom of disease and bodily sensations; bodily sensations were more commonly experienced than symptoms	• Survey and interview data examined different aspects of commonality-difficult to meaningfully integrate • Survey and interviews interpreted the concept of 'symptom' differently and produced different types of knowledge about what symptoms were. • Data divergence – sociological qualitative findings problematised biomedical survey data
Lived experiences of genito-urinary symptoms	Silence	• Differentiation between pain and visible symptoms • Focus on sensations not symptoms • Sensations were often normalised depending on context and information from others' experiences; not often associated with STIs	N/A – qualitative data provided exploratory data about these experiences
Meaning of genito-urinary symptoms	Silence	• Suspected cause and level of concern determined meaning, informed by information-seeking behaviour (previous experience, internet, TV, social network, medical diagnosis) • Suspected causes: health issues (not often STI-related), lifestyle factors or random occurrences	N/A – qualitative data provided exploratory insight into how this process occurs

Discussion

Main findings

This mixed methods study examined genito-urinary symptom prevalence, lived experiences and sense-making processes as reported by participants in a national probability sample survey. Symptoms were more commonly reported by women than men, and were highly heterogeneous experiences, conceptualised in terms of painfulness, visible appearance and emotional responses. There was uncertainty about the boundaries of normal and abnormal sensations and when participants perceived an underlying medical cause to be likely and they were concerned about the experience, sensations were re-cast as symptoms. Participants reporting symptoms in the survey were also more likely to perceive themselves at risk of STIs but few participants who took part in subsequent interviews believed their symptoms to be caused by an STI. Individuals created meaning about sensations to regain control over their experiences through a fluid sense-making process we have depicted in the Cause-Concern Cycle. Sense-making processes were disrupted or ceased when no new information was available, symptoms improved or disappeared when an acceptable explanation was reached.

Strengths and weaknesses of this study

This is the first known study to report estimates of the prevalence of genito-urinary symptoms in the British population based on a sample that is broadly representative and therefore generalizable to the general population enabling symptoms to be studied independently of medical contexts. The Cause-Concern Cycle is a novel conceptual model to help explain sense-making processes for genito-urinary symptoms but is likely to have wider relevance. Using a mixed methods approach enabled us to combine population trends with individual conceptualisations to offer comprehensive insights into genito-urinary health issues. The sequential study design enabled us to draw linked samples and generate very detailed information about participants, increasing the explanatory potential of this study. Findings from the mixed methods approach emphasise gender

differences in genito-urinary sensation experiences and meanings and also suggests that there may be under-reporting of symptoms in Natsal-3 if sensations were not perceived as symptoms.

Natsal-3 is a cross-sectional survey so cannot determine causality of genito-urinary symptoms and we are unable to determine if reported symptoms were linked to underlying STIs or other causes. The symptoms question was asked to those aged 16-44 years so it was not possible to look at symptoms in older people. Urine was tested for five STIs and only a sub-sample of sexually experienced Natsal-3 participants provided a sample. As this study conducts secondary analysis of Natsal-3 data, variables related to symptom experience were limited but using mixed methods enabled us to offset this limitation, to some extent, with additional, tailored, semi-structured interview data. There was a delay between data collection periods for the survey and semi-structured interviews of between 22 and 44 months. This resulted in high numbers of participants becoming uncontactable through change of address and/or phone number and it was difficult to triangulate findings about specific symptom experiences.

Findings in relation to other studies

Genito-urinary symptoms have not previously been studied at a population level in Britain and we are not aware of comparable data from other countries. We considered genito-urinary symptoms broadly allowing us to make comparisons across symptomatic experiences, gender and age. Our findings re-iterate the non-specificity of STI symptoms and suggest lay and biomedical interpretations of genito-urinary issues differ considerably. Natsal-3 linked population prevalence of STIs to specific risk factors (high partner numbers and condomless sex) and showed that those at highest risk reported attending sexual health clinics (Sonnenberg *et al.*, 2013) but did not consider how experience of symptoms was associated with this decision. Although we do not consider symptom experiences in relation to care-seeking here, these data are reported elsewhere (help-seeking results paper, chapter 5). Most of our participants did not consider STIs as a likely cause of their

sensations which is also common in patient populations (Dixon-Woods *et al.*, 2001) and our study highlights the range of alternative explanations participants used as well as the types of information they were reliant on to help them make sense of their sensations. Normalising is a common response to genito-urinary symptoms as shown in other studies (Dixon-Woods *et al.*, 2001; Low *et al.*, 2015a). We found the highest prevalence of symptoms in 20-24 year old women and 16-19 year old men which mirrors the higher prevalence of STIs in young people (Public Health England, 2016). However overall, our findings suggest using reported genito-urinary symptoms is unlikely to be a good proxy for estimating STI prevalence in Britain as has been done in Iran (Nasirian *et al.*, 2016) in the absence of generalisable STI estimates. Nasirian et al. (Ibid) found 30% of men and 82% of women had experienced at least one STI-associated symptom in the previous year although these findings cannot be easily compared to this study as the timeframe, list of symptoms and cultural context are very different.

The Cause-Concern Cycle generated from our data provides a new conceptual model that can be used to understand sense-making about genito-urinary symptoms and how this influences help-seeking behaviour. It aligns with sense-making theory which prioritises the plausibility of meanings over accuracy of information (Weick, Sutcliffe and Obstfeld, 2005). This study builds on these existing frameworks (Ibid) by explicating the sense-making process through which sensations are transformed into symptoms and highlights the fluidity of sense-making and the iterative nature of this process. Our findings suggest both individual and socio-cultural factors are important in sense-making, which supports other research about sensations and symptoms (Hay, 2008; Fainzang and Haxaire, 2011; Brandner *et al.*, 2014) highlighting that the transformation process from sensation to symptom is a social process, interpreted in context and shaped through verbal communication about the experience (Hay, 2008).

Meaning of the study and implications for clinicians and policy makers

Cis-women disproportionately experience the burden of symptoms due to female anatomy which is more susceptible to UTIs and thrush (Minardi *et al.*, 2011) and increases risk from STIs as the moist environment and thinner vaginal lining make it easier for bacteria and viruses to replicate (Centers for Disease Control and Prevention, 2011). However many STIs are asymptomatic and some symptoms may have other causes. Although symptoms may not be caused by infectious agents where there is public health value in prompt treatment, managing the underlying cause will help maintain good sexual health as symptoms disrupt physical, emotional and social wellbeing (World Health Organization, 2006). Improving the quality of experiences is important in its own right as positive sexual experiences improve health more generally (Wellings and Johnson, 2013) and managing symptoms is part of this approach.

Our findings support the provision of services through fully integrated sexual health clinics to enable a range of treatment to be offered to completely resolve symptoms even if STI tests are negative. Links to sexual function services in particular may help improve overall sexual health and wellbeing as there is an inverse association between sexual function and risk behaviour (Mitchell *et al.*, 2013). These results allude to the paradox of healthcare provision, particularly when free at the point of access, as the healthcare system cannot afford every sensation experienced to be presented to a service but public health values caution and preventing missed opportunities to diagnose and prevent onward transmission of infections. Going forwards, healthcare professionals and health literature should avoid using the word symptom and focus on sensations to understand the experience from the individuals' perspective and the context in which the changes developed. Given the wide use of the internet as an information source, better signposting to accurate information would help improve sense-making about symptoms and decisions about care needs. Symptoms may be useful as clinical indicators for STIs but should be combined with risk factors for infection to assess care needs and practitioners should be aware that biomedical interpretations of

symptoms may not align with patient views. This is particularly pertinent given the shift to managing self-reported asymptomatic patients through online pathways (personal communication with Dr. Gary Brook, London North West Healthcare 20.06.2017).

Unanswered questions and future research

The precise relationship between symptoms and STIs in the population remains unclear. Linking reported population survey data with healthcare records will help elucidate medical causes of genito-urinary symptoms. Exploring the existential meanings of genito-urinary sensations in more detail, particularly in relation to healthcare-seeking behaviours, is likely to provide insight into how sensations are acted upon. Our findings show that using the term 'symptom' may not be sufficient to capture the range of issues that occur on and around the genitals and future studies should take this into account when designing data collection instruments.

4.4 Discussion of findings in relation to this thesis

Having presented the mixed methods paper about genito-urinary symptoms, I now discuss how understanding different aspects of symptoms (particularly prevalence, lived experiences and sense-making) helps address the overall aim of this thesis: exploring how STIs influence experiences of symptoms and care-seeking. I have organised this into empirical and methodological reflections on the paper. In doing so I continue the conceptual linking of stigma, symptoms and help-seeking in order to understand unmet healthcare needs and untreated STIs.

4.4.1 Empirical reflections

Throughout this thesis, there has been tension within the research about the genito-urinary symptoms I am studying and if they are associated with STIs and/or other (often unknown) underlying causes. The survey analyses showed gender differences between the number of women and men reporting symptoms which are not reflected to the same extent in STI diagnoses (Sonnenberg *et al.*, 2013; Public Health England, 2017b). Survey data also showed there was an association between reporting symptoms and a perceived risk of STIs but the semi-structured data revealed attempts by participants to distance themselves from STIs. The lens through which symptoms were accounted for framed participants' experiences of their symptoms – these interpretive lenses encompassed a multitude of individual and social beliefs, norms, attitudes and values and stigma relating to STIs, illness and physiology. They made sense of the sensations and symptoms in a way that frequently positioned STIs as an unlikely cause and emphasised protective effects of their own behaviour, particularly being in a long-term sexual partnership and having good personal hygiene practices. This discrepancy may in part have been related to methodology (see methodological reflections section 4.4.2), however from the previous chapter I found that STI stigma frames experiences in the context of dirt and this is likely to influence interpretations of symptoms and subsequent help-seeking.

Although genito-urinary symptoms may not be related to STIs, they are indicators of, and have implications, for other health needs, as I discussed in the introduction to this paper. Symptoms affect sexual health more generally than STIs as my findings show, and are disruptive to everyday lived realities because of their painfulness, visibility and/or the emotional responses they provoke. Through the course of conducting, analysing and writing up my data, I have shifted from an STI framing to a broader sexual health framing in order to understand the impact of genito-urinary sensations and symptoms in other ways. The World Health Organization's defines sexual health as *"a state of physical, mental and social well-being in relation to sexuality. It requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence"* (World Health Organization, 2006). Even if there is not a public health imperative to address all genito-urinary issues on the basis of detecting infection and disease at an early stage, treating and preventing transmission and harmful sequelae, improving well-being and sexual pleasure may improve health more generally and prevent future illness (Wellings and Johnson, 2013). The Caerphilly cohort study demonstrated a protective effect of sexual activity on health with improved general fitness, cardiovascular health and lower rates of depressive symptoms in participants who reported high orgasm frequency than those reporting low orgasm frequency (Davey Smith, Frankel and Yarnell, 1997). Symptoms can impede sexual activity, leading to poorer health overall. As Wellings and Johnson (2013) point out in their editorial in the Lancet, the WHO definition (2006) is widely cited but poorly incorporated into public health practice. Little consideration is given to the quality of sexual experiences and relationships, in favour of a focus on preventing adverse outcomes.

Understanding genito-urinary symptoms and the distinction between them and sensations is also important to understand the process of help-seeking and attending healthcare services; neither can be fully understood in isolation.

Interpretation of bodily changes is important in determining help-seeking decisions. The meanings given to experiencing bodily sensations mediate subsequent responses to them and these findings will be built upon in the next chapter.

4.4.2 Methodological reflections

There were tensions between different types of knowledge about what a symptom was. Using a mixed methods approach challenged knowledge production from both the survey and semi-structured interview data, allowing each to problematise findings from the other method. The question about symptoms in Natsal-3 was asked during the CASI in the section about STIs to those aged 16-44 years who were sexually experienced. This reflects the biomedical perspective of Natsal-3 which viewed the symptoms as those of STIs and therefore focussed on those most likely to be at risk of an STI. It followed questions about attendance at health care services (hypothetical preference and actual attendance at sexual health clinics) and previous STI diagnoses. This may have led participants to think about them as symptoms of STIs and most of the participants who took part in the semi-structured interviews were quick to point out the list of symptoms included in this study (see appendix B, p.318) could also be linked to many other health-related and other causes. The semi-structured interviews were also framed in terms of STIs and discussion of participants' symptom experiences followed questions about perceptions of STIs. Discrepancies about how symptoms were linked to STIs observed between the survey and semi-structured interviews may also have arisen as an artefact of each method. Symptoms were reported via the CASI in Natsal-3 data collection which did not require disclosure or justification to anyone whereas the semi-structured interview necessitated face-to-face discussion of the whole experience and participants were more likely to consider how they were presenting themselves to me.

The one month time frame helped reduce recall bias and provided a snapshot of symptom prevalence at the time of Natsal-3 interview. The meaning participants' had given to the symptom episode based on the level of concern influenced if this was recalled and described during the semi-structured interview (symptoms that had caused greater concern were more likely to be remembered and discussed). The question specifically mentioned the word symptom and as our semi-structured interview data showed, most people perceived symptoms to have an underlying medical cause, therefore this may have led to under-reporting if the experience was perceived to be a normal sensation. The Natsal-3 question about perceived risk of STIs to the self was separated from the other STI questions and asked during the second face-to-face CAPI in the attitudinal section. This gave some distance between answering questions about symptoms (whether they were perceived to be STIs or not).

Several participants reported additional symptoms during the semi-structured interviews that did not form part of the Natsal-3 set of response options. These included rashes and itching around the genitals, blood in the urine, and some women disclosed miscarriages and abortions when I asked if they had had any other similar experiences (to the list of symptoms used as a prompt). These other sensations, symptoms and healthcare issues shared meaning with the list of STI-associated symptoms used in this study suggesting they are interpreted in similar ways. This further emphasises the discrepancy between lay and clinical understandings of sexual and genital health issues. There are possible implications for help-seeking behaviour and how individuals triage their health needs according to service set-up.

4.5 Chapter Summary

In this chapter, I revealed the different constructions of what a symptom is according to survey and interview data. I have suggested that symptoms are

sensations that cause concern and where an underlying medical cause is suspected and highlighted the significant difference in the prevalence of reported symptoms in women compared to men. I examined the process of sensations transforming into symptoms but my exploration ended at this point as I was interested in linking symptoms and help-seeking. However, some symptoms are transformed back into sensations if assurance about the insignificance of the experience is gained from a credible source (Ahlzén, 2008). This often relies on a medical diagnosis which is not examined in any detail here given the focus on non-attendance.

Although I have framed this work in the context of STIs and sexual health to understand untreated infection, not all symptom experiences relate to STIs. I do not have access to clinical outcome data to examine underlying causes and discovering clinical 'truths' was not part of the scope of my investigation and examination of genito-urinary symptoms. The meanings given to the sensations experienced, directly relate to what happens next. Help-seeking in response to symptoms is explored fully in the next chapter, although in the data the relationship between symptoms and help-seeking is not linear and as easy to separate as my thesis chapters suggest.

CHAPTER 5   RESULTS: HELP-SEEKING RESPONSES TO GENITO-URINARY SYMPTOMS

5.1   Chapter Overview

Chapter 4 included the first of my mixed methods results papers which highlighted that genito-urinary symptoms are common experiences for women but not all such bodily sensations are interpreted as STI symptoms or as care needs. This suggested the meanings attributed to symptoms and bodily sensations determined the response to them – seeking help signifies the symptom(s) as a health issue causing concern. Findings from chapter 3 suggested that dirt frames individual experiences and carries through to this final empirical results chapter of the thesis, where I continue the story of symptom experiences by examining help-seeking responses. I focus on non-attendance at specialist sexual healthcare services in particular, using Natsal-3 survey data and findings from the follow-up semi-structured interviews.

To address the main aim of this thesis (understanding how STIs influence lived experiences of symptoms and help-seeking to help explain unmet need), this chapter follows the same format as the other results chapters (chapters 3 and 4). I elucidate different care-seeking pathways in response to experiencing symptoms and suggest individuals act to seek control over their bodily experiences. The mixed methods paper about care-seeking responses titled "Experiencing genito-urinary symptoms and (not) attending sexual health care: mixed methods research from Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)" is the focus. The introduction to the paper (section 5.2) provides the background to the research, while the discussion of the paper (section 5.4) contextualises these findings about responses to symptoms to situate the paper within the story of the thesis.

5.2 Introduction to the research paper

This paper links closely to the previous paper about symptoms (chapter 4) as the story about symptoms and help-seeking responses are entwined when considered as an individual's lived experience. There were also some boundary issues in the content of this paper. A core Natsal-3 output about service use shaped my thinking and ideas. Originally I wanted to present a profile of non-attenders here to explore associations between personal characteristics and healthcare non-use, however this analysis was too similar to the Natsal-3 paper. Instead I joined the Natsal-3 working group for the service use paper (which does not constitute part of this thesis) titled: "Sexual health clinic attendance and non-attendance in Britain: Findings from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)." This work was led by Dr. Clare Tanton and Dr. Rebecca Geary (joint first authors) and has now been published in BMJ Sexually Transmitted Infections (Tanton *et al.*, 2017).

The paper I present here addresses research question 4, *"why do some people with genito-urinary symptoms not seek care at sexual health clinics?"* To answer this question, I also examine non-attendance and service preference through two additional research questions within the paper. The paper builds on literature presented in the background section about help-seeking (section 1.5.2). I problematised the narrow scope of current definitions of care-seeking behaviour, the service attendance framing and the focus on patients instead of encompassing the range of behaviours and care pathways that do not result in a visit to a medical setting. In taking this approach, both the paper and surrounding chapter also provide answers to the fifth methodologically oriented question: "*to what extent can survey and semi-structured interview data be integrated to explain, contextualise and extend findings about genito-urinary symptoms and care-seeking responses?"*

My focus was on non-attendance at sexual health clinics as this has not been well covered in the literature to date, is an important aspect of unmet need and untreated STIs and was a sampling frame and data sub-set available by using Natsal-3. From the previous paper, it was apparent that not all symptoms were caused by STIs and so may not be appropriate to present to specialist care, however sexual health clinics also manage other issues such as candidosis, vaginosis, urinary tract infections (UTIs) and cervical cytology which are important in maintaining good sexual health and wellbeing (World Health Organization, 2006). Because of my initial assumptions about my population of non-attenders, I sought to explore the absence of care-seeking. However due to the multi-faceted nature of sexual health service provision and the increasing role of GPs and primary care (Department of Health, 2001; Independent Advisory Group on Sexual Health and HIV by Medical Foundation for AIDS and Sexual Health, 2008), as well as the transience of some symptoms and time elapsed between data collection phases, I soon realised that a broader exploration of the different types of response and the reasoning for them would be more useful to understand unmet need.

I adopted a mixed methods approach to consider individual accounts about the experiences of non-attendance at sexual health services and other help-seeking responses after experiencing symptoms in the context of population patterns. The format is similar to the symptoms paper (chapter 4).

I used survey data to gain an overview of the population pattern of non-attendance at sexual health clinics and then explore individual accounts and reasoning about perceived care needs. The paper addresses four main themes within the meta-theme of seeking control. The four themes (not seeking medical care; seeking information; seeking care at non-specialist services; seeking care at sexual health clinics) relate to different responses to experiencing symptoms and collectively encompass the diversity of information and support available to participants. These themes were developed inductively from analysis of participants' accounts, as

described in the methods, and closely relate to the meaning of symptoms discussed in the previous paper (chapter 4).

5.3 Research Paper: Help-seeking results paper

Status: To be submitted to BMJ Open after thesis submission

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RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	Fiona Mapp
Principal Supervisor	Ford Hickson
Thesis Title	Sexually Transmitted Infections: A Mixed Methods Study of Stigma, Symptoms and Help-seeking

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?			
When was the work published?			
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion			
Have you retained the copyright for the work?*	Choose an item.	Was the work subject to academic peer review?	Choose an item.

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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	BMJ Open
Please list the paper's authors in the intended authorship order:	Fiona Mapp, Kaye Wellings, Catherine H. Mercer, Kirstin Mitchell, Clare Tanton, Soazig Clifton, Jessica Datta, Nigel Field, Ford Hickson
Stage of publication	**Not yet submitted**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	FM conceived the design of this study in conjunction with KW, CHM and FH. FM conducted and analysed all semi-structured interviews with support from FH and KW. FM wrote and edited all drafts with critical input from all authors. The final draft of the paper will be circulated to all authors for

	approval before submission.

Student Signature: ████████ **Date:** _04/08/17_

Supervisor Signature: ████████ **Date:** _4/8/17_

Experiencing genito-urinary symptoms and not attending sexual health care: mixed methods research from Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)

Fiona Mapp, Kaye Wellings, Catherine H. Mercer, Kirstin Mitchell, Clare Tanton, Soazig Clifton, Jessica Datta, Nigel Field, Melissa J Palmer, Ford Hickson

Abstract

Objectives: To explore help-seeking strategies for genito-urinary symptoms, focussing on non-attenders at sexual health clinics.

Design: Sequential mixed methods design using semi-structured interviews to explain and expand survey data.

Setting: British general population

Participants: 1403 participants aged 16-44 (1182 women) reporting recent experience of genito-urinary symptoms who participated in Britain's third National Survey of Sexual Attitudes & Lifestyles (Natsal-3) undertaken 2010-2012; semi-structured interviews with 27 of these participants (16 women) who also reported in Natsal-3 to have never attended a sexual health clinic, conducted May 2014 - March 2015.

Primary and secondary outcome measures: Non-attendance at sexual health clinic (past year) and preferred service for STI care; semi-structured interview domains were social representations of STIs, symptom experiences, care-seeking responses, STI stigma.

Results: In the past year 85.9% of women (95% CI 83.7 - 87.9) and 87.6% of men (95% CI 82.3 - 91.5) with genito-urinary symptoms reported not attending a sexual health clinic. For over half of participants, the GP was cited as their preferred hypothetical service for STI care amongst those reporting symptoms (women 58.5% (95% CI 55.2 - 61.6); men 54.3% (95% CI 47.1 - 61.3)). Semi-structured interviews

elucidated four main help-seeking responses to experiencing symptoms: not seeking healthcare, seeking information to self-diagnose and self-treat, seeking care at non-specialist services, seeking care at sexual health clinics. Collectively, responses suggested individuals sought control over their bodies and prioritised emotional reassurance over accessing medical expertise. Integrating survey and interview data highlighted some discrepancies between datasets due to delayed attendance and mis-reporting attendance in Natsal-3, confirmed preference for GP care and extended explanations of help-seeking.

Conclusions: GPs are preferred to SHCs for treating genito-urinary symptoms but when individuals do attend specialist care, they have good experiences. Non-attendance at sexual health services did not equate to participants doing nothing about their symptoms. Maintaining service choice is important to accommodate individual preferences and perceived care needs. Normalising attendance at sexual health clinics and supporting STI testing outside of traditional healthcare settings will facilitate appropriate symptom management.

Key words: genito-urinary symptoms; sexually transmitted infections; sexual health clinics; GUM clinics; care-seeking; help-seeking; non-attendance; mixed methods

Introduction

In Britain sexual health clinics (SHCs) are specialised services for managing genito-urinary health including sexually transmitted infection (STI) testing, diagnosis and treatment, and providing sexual health advice (NHS Choices, 2011). Services were first set-up as specialist, accessible and confidential alternatives to family doctors (*The Report of the Royal Commission on Venereal Diseases*, 1916) and although these remain key tenets of service provision, they are also stigmatised (Kinghorn, 2001; Scoular, Duncan and Hart, 2001). SHC attendance has nonetheless increased over the last three decades (Sonnenberg *et al.*, 2013) with symptoms being the most commonly reported reason for attendance at SHCs in England as shown using

semi-structured interviews (Dixon-Woods *et al.*, 2001) and surveys with patients (Mercer *et al.*, 2012). However, while approximately one-fifth of women and 6% of men are estimated to have experienced genito-urinary symptoms in the past month (see symptoms paper, chapter 4) (which equates to almost 3.3 million adults), national surveillance data recorded 2 million attendances (excluding follow-up attendances) at SHCs in England in 2016 (Public Health England, 2017c). This suggests that a proportion of people with symptoms do not attend SHCs. So why do people not seek specialist care when they experience genito-urinary symptoms?

Genito-urinary symptoms such as painful urination and abnormal vaginal or penile discharge can indicate underlying infections or disease such as those which are sexually transmitted (Low *et al.*, 2006). If left undiagnosed and untreated, they can cause serious harm to individuals and in the case of STIs, their sexual partners (Ibid). This contributes to the burden of poor sexual and reproductive health in the population and reduces individual quality of life and wellbeing. Effective and timely treatment is important in mitigating deleterious effects of STIs and other causes of genito-urinary symptoms for individual and population health, but there is little evidence about help-seeking among people with symptoms. Non-attendance is irrational from a medical perspective but may be rational for individuals depending on their subjective values and beliefs about health and healthcare (Buetow, 2007).

In this paper, we use genito-urinary symptoms as an indicator of potential need for care and draw on survey and semi-structured interview data from Natsal-3 to explore help-seeking strategies in response to symptoms, focussing on non-attendance at SHCs.

Methods

Full details of methods are described in the study protocol (Mapp *et al.*, 2016).

Study design

We combined survey data and data from follow-up semi-structured interviews to connect and extend findings about help-seeking for genito-urinary symptoms. Following preliminary analysis of data from the Natsal-3 survey, we used survey participants' responses relating to experience of symptoms and non-attendance at SHCs to draw a sub-sample invited to participate in follow-up semi-structured interviews. Data from the entire Natsal-3 survey were used to contextualise interview data and we integrated findings from the two datasets to provide combined insights into help-seeking strategies for symptoms.

Natsal-3 survey

Natsal-3 is a probability sample survey (n=15,162) of sexual behaviour among women and men aged 16-74 years, resident in Britain (Erens *et al.*, 2013) with 58% response rate. Questions are asked via computer-assisted personal interview (CAPI) and computer-assisted self-interview (CASI) for sensitive topics. In the CASI sexually experienced participants (defined as having reported at least one lifetime sexual partner) aged 16-44 (determined by survey skip patterns based on STI risk (Sonnenberg *et al.*, 2013)) were asked "In the last month, that is since (date one month ago), have you had any of the following symptoms?" Response options were as follows (we excluded symptom number 2 for women and men to improve association with STIs):

Women:

1. Pain, burning or stinging when passing urine
2. Passing urine more often than usual
3. Genital wart / lump
4. Genital ulcer / sore
5. Abnormal vaginal discharge
6. Unpleasant odour associated with vaginal discharge
7. Vaginal pain during sex
8. Abnormal bleeding between periods
9. Bleeding after sex (not during a period)
10. Lower abdominal or pelvic pain (not related to periods)

11. None of these

Men:

1. Pain, burning or stinging when passing urine
2. Passing urine more often than usual
3. Genital wart / lump
4. Genital ulcer /sore
5. Discharge from the end of the penis
6. Painful testicles
7. None of these

We calculated the prevalence of non-attendance at SHCs in the past year amongst those who reported symptoms, as an indicator of potential unmet need for healthcare. We then examined hypothetical service preference asked in the survey as: "**If** you thought that you might have an infection that is transmitted by sex, where would you **first** go to seek diagnosis and/or treatment?"

Response options:
1. General practice (GP) surgery
2. Sexual health clinic (GUM clinic)
3. NHS Family planning clinic / contraceptive clinic / reproductive health clinic
4. NHS Antenatal clinic / midwife
5. Private non-NHS clinic or doctor
6. Pharmacy / chemist
7. Internet site offering treatment
8. Youth advisory clinic (e.g. Brook clinic)
9. Hospital accident and emergency (A&E) department
10. Somewhere else

We used logistic regression to produce odds ratios for stating SHC, adjusting for previous SHC attendance and age (aAOR). Analyses were carried out using survey commands in Stata V.14.1 to account for stratification, clustering and weighting of survey data and were stratified by gender to reflect differences in care-seeking behaviour (Mansfield, Addis and Mahalik, 2003), reported symptom prevalence (see symptoms paper) and emergent semi-structured interview findings.

Semi-structured interviews

We wanted to explain non-attendance at SHCs reported in the survey so explored care-seeking responses to experiencing genito-urinary symptoms. Participants who had agreed to be re-contacted, had reported symptom(s) and had never attended a SHC were recruited for a face-to-face semi-structured interview, conducted by FM at their home or other convenient location. We used purposive sampling from eligible survey participants to reflect diversity of personal characteristics, experiences and geographical location among participants. Interviews took place between 22 and 44 months (median = 30 months) after the fieldwork for Natsal-3 was conducted, and lasted between 35 and 108 minutes.

Interviews were digitally recorded and transcribed verbatim and we used thematic analysis (Braun and Clarke, 2006) to explore lived experiences and meanings of help-seeking strategies in response to symptoms. Data were coded by hand and emergent themes were grouped using an excel spreadsheet to identify connections within and between transcripts. We organised the data into different care pathways as the explanations for non-attendance at sexual health clinics and explored themes within and across each pathway to understand how individuals had made sense of their care needs. We used NVivo V.11 to organise data and one third of transcripts were double coded by KW and FH.

Results

Survey data

Participants

Detailed descriptions of the Natsal-3 sample have already been reported (Mercer *et al.*, 2013). Of sexually experienced participants aged 16-44 years (n=8878[1]

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[1] Excludes participants with missing data for symptom variables

(unweighted) n= 7353 (weighted)), 21.6% (95% CI 20.4-22.9) of women and 5.6% (95% CI 4.9-6.6) of men reported recent genito-urinary symptoms. Missing data were 1.4% for reported symptoms and 3.4% for reported SHC attendance.

Non-attendance at SHCs

Table 1: Prevalence of reported non-attendance at a SHC in the past year among sexually experienced participants aged 16-44 years who reported symptoms - by age group and sex

Age group	Women		Men	
	Non-attendance in past year % (95% CI)	Denominator*: unweighted, weighted	Non-attendance in past year % (95% CI)	Denominator*: unweighted, weighted
16-24 years	73.6 (69.0 – 77.8)	474, 268	78.2 (67.7 – 86.0)	98, 70
25-34 years	89.4 (86.2 - 92.0)	518, 305	88.9 (79.5 - 94.3)	84, 77
35-44 years	95.9 (91.8 - 97.9)	190, 222	97.0 (88.5 - 99.3)	39**, 61
All ages	**85.9 (83.7 - 87.9)**	**1182, 795**	**87.6 (82.3 - 91.5)**	**221, 208**
p value***	<0.0001		0.0014	

*Denominator is all sexually experienced women and men aged 16-44 years who reported symptoms
** Small number of participants so estimates may be unreliable
*** χ2 p value for association with age-group

The prevalence of non-attendance at a SHC in the past year for all women and men reporting symptoms was high (women: 85.9% (95% CI 83.7 - 87.9); men: 87.6% (95% CI 82.3 - 91.5)); there were no significant gender differences in attendance behaviour (see table 1). We found higher levels of recent non-attendance with increasing age for both women and men. We examined non-attendance ever at

SHCs amongst those reporting symptoms and found that 55.8% (95% CI 52.5 – 59.1) of women and 53.8% (95% CI 46.2 – 61.2) of men had never attended.

Service preference

General practice was the preferred provider for hypothetical STI care for both women (58.5% (95% CI (55.2 - 61.6)) and men (54.3% (95% CI 47.1 - 61.3)) who reported symptoms (table 2). Participants with symptoms who had previously attended a SHC were more likely to choose a SHC as their preferred hypothetical service than those who had not previously attended a SHC (women 57.7% (95% CI 53.0-62.3) vs 14.8% (95%CI 11.7-18.5), aAOR 7.3 (95% CI 5.3-10.0); men 63.8% (95% CI 53.0-73.4) vs. 19.7% (95% CI 13.1-28.5), aAOR 7.2 (95% CI 3.6–14.2), data not shown.

Table 2: Hypothetical service choice of sexually experienced participants aged 16-44 years who reported symptoms stratified by sex and age group

Age group	Women % (95% CI)			Men % (95% CI)		
	16-24	25-34	35-44	16-24	25-34	35-44
GP	44.5	58.4	75.4	53.7	38.29	75.96
	(39.5-49.6)	(53.5-63.2)	(68.1-81.5)	(42.8-64.3)	(27.7-50.2)	(56.6-88.4)
SHC	43.6	35.7	19.3	38.91	52.9	24.04
	(38.6-48.7)	(31.0-40.6)	(14.0-26.2)	(28.9-50.0)	(41.0-64.4)	(11.6-43.4)
Other*	12.0	5.9	5.3	7.4	8.8	0
	(9.1-15.6)	(4.0-8.6)	(2.7-10.0)	(3.3-15.7)	(3.4-21.1)	
Denominator**: weighted, unweighted	268, 474	305, 518	222, 190	70, 98	77, 84	59, 38***

* Other healthcare services: NHS Family planning clinic / contraceptive clinic / reproductive health clinic; NHS Antenatal clinic / midwife; Private non-NHS clinic or doctor; Pharmacy / chemist; Internet site offering treatment; Youth advisory clinic (e.g. Brook clinic); Hospital accident and emergency (A&E) department; Somewhere else
** Denominator is all sexually experienced women and men aged 16-44 years who reported symptoms
*** Small numbers, therefore estimates may be unreliable

Semi-structured interview data

Participants

Semi-structured interviews were completed with 16 women and 11 men aged 19-47. The majority were white British/other, four were Asian/Asian British or Black/Black British; five did not have English as their first language. Participants' lifetime experiences of genito-urinary symptoms and help-seeking are described in table 3. Help-seeking varied by symptom(s) reported and between participants.

Table 3: Overview of qualitative participants' reported genito-urinary symptoms, hypothetical service preference and care-seeking behaviour

Inter-view no.	Sex	Age*	Symptoms reported in Natsal-3 (past month)	Symptoms reported in semi-structured interview (ever)	Hypothetical service preference	Care-seeking for symptoms reported in semi-structured interview (ever)
Data source	CAPI	CAPI, SSI	CASI	SSI	CASI	SSI
i2	Female	35-39	Abdominal/pelvic pain	Pain urinating; vaginal pain during sex; bleeding after sex; abdominal/pelvic pain	GP	GP for abdominal pain, referred on to NHS gynaecologist
i3	Female	20-24	Abdominal/pelvic pain	Abnormal vaginal discharge; vaginal pain during sex; abdominal/pelvic pain	SHC	GP and private gynaecologist for different symptoms
i4	Female	25-29	Abnormal bleeding between periods; abdominal/pelvic pain	Pain urinating; abnormal vaginal discharge; vaginal pain during sex; abnormal bleeding between periods; bleeding after sex; abdominal/pelvic pain	SHC	None
i6	Female	35-39	Abnormal bleeding between periods	Pain urinating; abnormal vaginal discharge	SHC	Can't remember
i7	Female	40-44	Genital ulcer/sore	Pain urinating; genital ulcer/sore; abnormal vaginal discharge; abnormal bleeding between periods	GP	None
i8	Female	16-19	Abnormal bleeding between periods	Pain urinating; vaginal pain during sex; abnormal bleeding between periods; bleeding after sex; abdominal/pelvic pain	FPC	GP for abnormal bleeding between periods and abdominal pain
i9	Female	20-24	Pain urinating; vaginal pain during sex; abnormal bleeding between periods	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge; vaginal pain during sex; abnormal bleeding between periods	FPC	SHC for abnormal vaginal discharge and abnormal bleeding between periods
i10	Male	20-24	Painful testicles	Painful testicles	GP	None
i11	Male	16-19	Painful testicles	None	GP	None
i12	Female	25-29	Unpleasant odour associated with vaginal discharge	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge; abdominal/pelvic pain	GP	GP for abnormal discharge and odour, referred to hospital for further investigations; midwife for abdominal pain during pregnancy

i13	Male	20-24	Genital wart / lump	Genital wart/lump	SHC	SHC (different town) after third episode of warts
i14	Male	45-49	Pain urinating	Pain urinating; genital lump (not a wart); painful testicles	GP	GP for lump in testicles
i15	Male	30-34	Pain urinating	Pain urinating; painful testicles	GP	Pharmacist for pain urinating
i16	Female	25-29	Abdominal/pelvic pain	Pain urinating; abnormal vaginal discharge; abnormal bleeding between periods; abdominal/pelvic pain	FPC	GP for all symptoms except discharge; pharmacist for thrush (self-diagnosed)
i17	Male	30-34	Penile discharge	Pain urinating; penile discharge; painful testicles	SHC	None
i18	Female	30-34	Pain urinating	Pain urinating; unpleasant odour associated with vaginal discharge	GP	GP for all symptoms
i19	Female	30-34	Bleeding after sex; abdominal/pelvic pain	Pain urinating; abnormal vaginal discharge; vaginal pain during sex; abnormal bleeding between periods; abdominal/pelvic pain	SHC	Mentioned abnormal bleeding at contraception clinic visit but no care-seeking specifically for symptoms
i20	Male	30-34	Pain urinating; painful testicles	Pain urinating; penile discharge; painful testicles	GP	GP for all symptoms
i21	Male	20-24	Painful testicles	None	FPC	None
i22	Male	30-34	Painful testicles	Pain urinating; painful testicles	GP	GP for both symptoms
i23	Male	20-24	Painful testicles	Pain urinating; painful testicles	GP	GP for both symptoms
i24	Male	16-19	Painful testicles	Pain urinating; painful testicles	GP	SHC for pain urinating; GP for painful testicles
i25	Female	45-49	Unpleasant odour associated with vaginal discharge	Pain urinating; abnormal vaginal discharge	GP	GP for both symptoms
i26	Female	16-19	Genital ulcer/sore	Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge; vaginal pain during sex	SHC	Went to hospital for pain urinating
i27	Female	25-29	Genital ulcer/sore; genital wart / lump	Pain urinating; abnormal vaginal discharge; vaginal pain during sex; abdominal/pelvic pain	GP	GP for pain urinating; midwife for abdominal pain (during pregnancy)
i28	Female	30-34	Unpleasant odour associated with vaginal discharge	Abnormal vaginal discharge	GP	None

| i29 | Female | 40-44 | Unpleasant odour associated with vaginal discharge | Pain urinating; abnormal vaginal discharge; unpleasant odour associated with vaginal discharge odour; abdominal/pelvic pain | Internet | GP and private gynaecologist |

* Age at time of qualitative interview is calculated using the participant's date of birth and date of follow-up interview; GP = General practitioner (primary care); SSI = semi-structured interview; SHC = sexual health / GUM clinic; FPC = family planning clinic / contraceptive clinic / reproductive health clinic; shaded columns contain data from Natsal-3 survey

Survey data suggested that it was common for symptomatic participants to have not recently, or ever, attended a SHC. It also showed the GP was the preferred hypothetical care provider. Our semi-structured interview findings generated four themes which offer explanations for non-attendance at clinics and preference for non-specialist care: not seeking healthcare, seeking information to self-diagnose and/or self-treat, seeking care at a non-specialist sexual health service, and those who reported seeking care at a SHC. These are discussed separately and then interpreted collectively as seeking control over symptom experiences.

Not seeking healthcare

Individuals were highly selective about which symptoms they responded to, resulting in many symptoms not being presented to a healthcare professional. Several participants reported not seeking care from any health service in response to experiencing symptoms. Not seeking healthcare did not mean 'doing nothing' about symptoms; participants concealed symptoms, normalised them as physiological fluctuations or dismissed care needs. Real or perceived structural barriers around accessing services were cited as reasons for not seeking help or not attending care and STI stigma underpinned much of the non-help-seeking behaviour.

Concealment of symptoms

Symptoms were concealed through non-disclosure or partial disclosure (to chosen individuals and/or for specific symptoms). Women explained that, for example, vaginal discharge was rarely discussed with others as it was seen as too personal and not acceptable to talk about with friends or family members. Concern over what others would think discouraged many from disclosing their experiences. These decisions were presented as rational and considerate about not *"want[ing] to put that burden on anybody" (i14).* Participants also articulated uncertainty about how people would react and so non-disclosure helped to minimise or prevent potential

social judgement directed at individuals with symptoms. Multiple examples of non-disclosure and fear of judgement from friends, family and health professionals suggest that stigma is an implicit factor influencing non-healthcare-seeking behaviour. As genitals are generally covered up, it was easy for most participants to conceal their physical symptoms from others day-to-day. Some symptoms resulted in socially discernible clues, such as *"going to the toilet all the time,"* (i6) *"touch[ing] your genitals when you sit down to find a comfortable position"* (i22) or "*not going out"* (i24) as much, which made concealment more difficult. Concealing symptoms from sexual partners often involved abstaining from sex. Some participants mentioned washing more frequently to try and "get rid" of symptoms, particularly vaginal and penile discharge.

There were individuals who had not told anyone about their symptoms, until they reported them in Natsal-3, although the symptoms question was asked in the CASI. The semi-structured interview was the first opportunity the participant had to describe their experiences to the researcher.

> *Interviewer: And did you tell anyone about it?*
>
> *Participant: No, I didn't. No, I must admit I didn't even tell my wife, just kept it [penile discharge] private, kept it to myself, just kept looking every day and hoping it would [disappear]…I didn't go to the doctors, I didn't even Google it to be fair, I just hoped it would go away (i17, man, 30-34 years)*

Concealing symptoms from others eliminated social expectations about appropriate care-seeking behaviours, perpetuating non-attendance. Concealment suggests that individuals would prefer to deal with the personal and health consequences of their symptoms than the social consequences of disclosing to others.

Normalising symptoms and care-seeking behaviours
Normalising symptoms as natural bodily changes, especially by women, eliminated perceived need for any type of care, resulting in non-attendance at services.

Participants' resisted medicalising their experience and did not consider symptoms to be related to STIs. Increased familiarity with experiencing symptoms due to recurrent episodes or ongoing sensations reduced the likelihood that individuals would seek care for the problem, if the experience was not perceived to be having detrimental effects. Instead, symptoms became incorporated into their lived reality and sense of self, reducing the impetus to act. Social norms about certain symptom experiences, such as painful testicles for men and bleeding problems for women, normalised these issues as common occurrences not associated with help-seeking.

Dismissal of healthcare needs

Many participants' accounts reflected dismissal of a need to seek care. Some experiences were seen as *"not something you sort of go to your doctors with"* (i4) suggesting the relationship between experiencing symptoms and seeking care was not a simple causal sequence. In such cases, symptoms were perceived as mild and participants dismissed care-seeking as *"wasting their [doctor's] time (i12)."* Beliefs about the responsible use of healthcare came out particularly strongly in accounts of those who did not seek care for their symptoms, behaviour which affirmed a self-perceived identity as a responsible healthcare user. Participants made care-seeking decisions that were appropriate and rational to them, based on their previous experiences of symptoms and perceived severity, which often resulted in non-attendance at SHCs.

Women in particular did not see the need for healthcare if symptoms related to their sexual activity. There were clear distinctions made between "*medical issues*" which **occurred within** the female body that could be addressed through biomedical intervention, and sexual problems which were **endured by** the female body and considered to be personal and private matters. Symptoms related to sex, such as pain during and bleeding afterwards, were rarely reported to healthcare professionals for diagnosis.

> *Anything with my relationship and everything with sex and stuff*
> *like that…I wouldn't go to the doctors because I think that*
> *everybody's different in that sense and I don't find it as a medical*
> *thing where there might be something medically wrong or I might*
> *be ill or there might be a fault (i27, woman, 25-29 years)*

Participants did not seek medical solutions for symptoms related to sex and managed them within their sexual partnerships. The majority of participants did not link their symptoms with STIs. Participants were keen to avoid being diagnosed with an STI as that would *"make me feel a bit dirty, it would make me feel a bit stupid… and I'd panic because I don't know anything about it" (i9, woman, 23 years).* Avoiding interactions with healthcare minimised this risk.

Seeking information to self-diagnose and/or self-treat

For participants who did interpret symptoms as a health problem but did not actually seek medical care, self-diagnosis and self-treatment were common responses. We found several examples of participants attributing their symptoms to other conditions (particularly pain urinating as a UTI and vaginal discharge as thrush). Individuals were reliant on the internet, their social networks and previous experience of the same or similar symptoms to diagnose themselves. Immediacy and convenience of information were frequently prioritised over accuracy.

> *Trying to get into the doctors is hell sometimes, being told you've*
> *got three weeks to wait for an appointment when you've got all*
> *these symptoms busting out…so it's more convenient to just*
> *Google it and self-diagnose, even if you've been diagnosed for the*
> *wrong thing. (i16, woman, 25-29 years)*

Self-diagnosis gave individuals an explanation which they could then act upon to manage their symptoms. Accounts of self-treatment were also common and took two forms: buying over-the-counter medication (general analgesics or treatment developed specifically for an infection such as thrush or cystitis) and dietary changes such as drinking cranberry juice, reducing alcohol intake and increasing water consumption. Information from Google and advice from friends and family

helped guide subsequent decisions about seeking care from healthcare services if self-care options did not resolve the issue. Care-seeking was often based on the experiences and care pathways of their social network and was often influenced by structural factors particularly related to service accessibility: location, appointment availability and perceived ease of access were all important factors in not seeking care. Seeking emotional reassurance from others' lived experiences (online and in real life) rather than using biomedical information was important for many participants.

Seeking care at a non-specialised sexual health service

A large proportion of participants sought care at a service other than a SHC (table 3) for their symptoms with their GP being a popular choice, supporting service preferences observed in survey data. Presenting symptoms to the GP removed the necessity to navigate unfamiliar parts of the healthcare system, once the need for care had been established; one participant stated that *"if you don't know you've got the symptoms for that particular disease, you don't know to go to a sexual health clinic" (i11, man, 19 years).* Some participants relied on their GP to legitimise their need for specialist care, another manifestation of wanting to be a responsible patient, although this often added in an additional care-seeking process and potential delay to receiving treatment.

Women were better linked in to a local network of healthcare services than men, through accessing contraception, smear tests, pregnancy care and other gynaecological healthcare. Engagement with familiar healthcare services provided opportunities to mention genito-urinary symptoms and gain access to treatment and reassurance even if they had not specifically sought care for their symptoms. The general nature of non-SHC services offered individuals anonymity regarding their healthcare needs (but not their attendance behaviour). The waiting room had particular symbolic significance as the space where social identity and medical needs collided. SHCs differed from other services as participants felt they were

labelled as having *"caught something"* as soon as they entered the vicinity of the clinic, making them more vulnerable to social judgement and therefore less likely to seek care at specialised services.

> *A lot of people including myself still haven't gone to the clinic*
> *because if you're seen outside they go, "dirty little bitch!"... I had*
> *people staring, in the end I went to me doctors (i16, woman, 25-*
> *29 years)*

Clinic waiting rooms were perceived to be difficult social environments to negotiate due to stigma associated with STIs, clinics and being seen by others they knew (as one participant experienced). There was a lot of anxiety about being judged by other attendees. Clinics were generally unfamiliar environments and represented too many psychological barriers to overcome to be the preferred choice for care, although after attending once, some of these barriers were removed.

Seeking care at a SHC

A few younger participants, all aged under 25, attended a SHC in response to their symptoms. They were all very positive about their experiences, valuing the ease of access and specialism. Other younger women also mentioned attending a SHC for STI testing but not in response to having symptoms. These attendance patterns highlight disparities between survey and interview data. Natsal-3 didn't capture intention to seek care and their attendances at SHCs may have occurred after Natsal-3 data collection. There is also concordance with increased likelihood of choosing a SHC having previously attended. There was confusion about the different names and designation of service provision at a SHC and so some mis-reporting of experience may have occurred in the survey data.

Delays in care-seeking were commonly described, ranging from a few days to several months between the onset of symptoms and attending a healthcare service.

Yeah, there was a delay…it wasn't straight to the clinic, it was straight to the clinic on the third occasion…initially there was a two month delay…I was single at the time, the first time it happened, so I wasn't in a rush and I wasn't sexually promiscuous either so I wasn't in a rush to get rid of it (i13, man, 20-24 years)

In this case, Natsal-3 survey data were collected during or soon after the participant had experienced genital warts but before he had sought care. The semi-structured interview enabled exploration of the participant's story of delayed attendance. Most people wanted to legitimise symptoms and care needs before seeking help but their relationship status and sexual behaviour also influenced their impetus to treat symptoms.

Seeking control

These accounts provide insights into why symptoms reported in a research context might not be presented in a healthcare setting, especially a SHC. From their survey responses, most participants from our qualitative sample reported preferring the GP for hypothetical STI care, some would prefer SHCs, a few opted for a contraception clinic and choosing an internet site offering treatment was not a commonly preferred option. Perceiving a non-STI cause of symptoms directed participants away from clinics. Therefore, help-seeking to services other than SHCs was a rational decision by individuals as SHCs did not suit everyone's needs.

Four main responses to experiences of symptoms emerged and individuals shifted between different help-seeking strategies, for example, escalating their response from normalising symptoms, to attempting self-treatment before actively deciding to seek care and attending a specific service depending on the suspected cause and level of concern about the symptoms experienced (see symptoms paper, chapter 4) The severity of symptoms (for example how painful or how quickly they developed) also influenced help-seeking responses. Overall, responses focused on seeking control over symptom experiences, enacted in different ways and with differing thresholds for accommodating symptoms and living with uncertainty. As

information was readily available from a variety of sources, emotional reassurance was prioritised by most symptomatic individuals unless symptoms were severe.

Integrated findings

Findings from the qualitative semi-structured interviews help explain survey data about attendance patterns at SHCs and service preferences for STI care and genito-urinary symptoms. By explaining the quantitative findings using data from the same participants, we extend understanding of help-seeking behaviour for symptoms, enable more detailed interpretation of these data and strengthen conclusions about use of SHCs and offering service choice. Table 4 highlights the silence in the survey data in relation to using services other than SHCs and this may be useful to explore quantitatively in the future.

Table 4: Convergence coding matrix - integration of findings from quantitative and qualitative strands by theme

Theme	Quantitative findings	Qualitative findings	Integration
Engagement with SHCs	• High levels of non-attendance at SHCs for symptomatic women and men in the past year although approximately half had been to a SHC before. • Younger people more likely to have attended than older people • No significant gender differences in attendance	• Some younger participants had attended SHCs for symptoms and STI testing (delays in help-seeking and mis-reporting in survey) • Most participants did not think their symptoms were caused by STIs so did not seek specialist care at SHCs • Younger participants were more aware of SHCs	• Use of SHCs can vary depending on type of symptoms experienced and perceived cause of symptoms • SHCs perceived as a service for younger people • Qualitative findings help explain quantitative data
Service preference	• GP preferred unless individuals had previously attended a SHC	• GPs were a more familiar, less stigmatised type of healthcare service because of their generalist approach • Some participants preferred the specialism of SHCs once they were familiar with the service	• Choice of different services valued but decision-making about care needs and care-seeking is often complex • Need to better understand links between hypothetical service preferences and actual care-seeking behaviour for genito-urinary symptoms • Qualitative findings help explain quantitative data
Use of alternative services	Silence	• Did not seek any healthcare – concealment, normalisation, dismissal • Sought information (internet and social	N/A – qualitative data provided exploratory insight into this area

		network) to self-diagnose/self-treat • Sought care at another service – mainly GP	

SHC = SHC; GP = general practice/practitioner; STI = sexually transmitted infection

Discussion

Summary of findings

We used survey and semi-structured interview data from a national probability sample to explore help-seeking strategies for genito-urinary symptoms, focussing on non-attendance at SHCs. Our findings suggest that generally people did not seek care at SHCs in response to experiencing symptoms. GPs' were found to be the preferred provider in both survey and semi-structured interview data, although younger people and those reporting symptoms were more likely to have attended a clinic recently. Help-seeking focussed on gaining control over symptoms through four main types of responses – not seeking care, seeking information, seeking non-specialist care and attending a SHC – and participants often segued between different help-seeking pathways. The nature of symptoms and previous care-seeking influenced help-seeking. Surprisingly, we did not find quantifiable gender differences in non-attendance at SHCs despite other work reporting women being more likely to attend healthcare (Mulholland and Van Wersch, 2007).

Strengths and weaknesses of the study

A sequential mixed methods design enabled us to elicit additional detail about attendance and use findings from each dataset to inform interpretations of the other. For example, data about attendances at non-specialist services were not collected in Natsal-3, but interview data provided insight into decision-making and different care-seeking pathways. Sampling interview participants from Natsal-3's general population sample generated a non-patient sample, which is an under-used sampling approach in health services research, and enabled us to consider help-seeking independent of medical settings. The size and sampling strategy used in Natsal-3 resulted in the survey sample being broadly representative of the British population, therefore we can assume estimates of non-attendance at clinics and service preferences are generalisable at the national level.

The time frame of survey questions relating to symptoms and SHC attendance was not the same – symptoms were asked about in the past month and SHC attendance in the past year. We therefore knew which participants who reported symptoms had not sought care at a clinic when they were interviewed for Natsal-3 but had no quantitative data about their care-seeking intentions or outcomes. The cross-sectional design of Natsal-3 means that it is not possible to determine the causality of care-seeking behaviour. Semi-structured interviews provided data on care-seeking decisions and outcomes. The time between the survey and semi-structured interview data collection resulted in high levels of participant attrition due to non-contactability; participants who took part may not reflect help-seeking behaviours observed in the survey. We framed this study in terms of sexual health which may have primed participants to discuss their experience in the context of sex and STIs and silenced other explanations.

Strengths and weaknesses in relation to other studies

Our study was not dependent on service attendance to recruit participants which enabled a broader perspective on help-seeking behaviour compared to studies which sample from a healthcare setting, (for example (Dixon-Woods *et al.*, 2001; Scoular, Duncan and Hart, 2001; Mercer *et al.*, 2007)). We looked at individuals' behaviour and responses to experiencing symptoms, instead of relying exclusively on hypothetical constructs about intended behaviour. Many studies have found discrepancies between actual and intended behaviour and so our approach addresses some of these methodological issues. Our findings support those from similar studies using patient samples suggesting that previous attendance at a SHC makes subsequent visits more normal and acceptable (Dixon-Woods *et al.*, 2001; Scoular, Duncan and Hart, 2001) but stigma remains a significant barrier to initial attendance (Kinghorn, 2001; Balfe, Brugha, O' Donovan, *et al.*, 2010; Balfe, Brugha, O'Connell, *et al.*, 2010).

We used a sexual health framing for this study which oriented our perspective on symptoms and care-seeking to focus on non-attendance at specialist SHCs. Other studies, such as Low et al (2015) approached their research on gynaecological cancer symptoms from a more general perspective by not disclosing their specific disease focus to participants. Like this study, they found examples of self-management and seeking legitimation of symptoms. From a public health perspective, non-attendance at SHCs following genito-urinary symptom experience is a problem if, as a consequence, treatment of STIs is delayed. Considering help-seeking in the context of people's lives helps understand their priorities for health and healthcare and reasons for non-attendance. My findings about individuals' rationales for non-attendance are similar to those found in a study by Buetow (2007) and include the narrowing gap between patient and professional knowledge (due to alternate information sources) and reluctance to share misfortune with others (leading to concealment and not seeking care).

Meaning of this study

We found four main help-seeking responses for genito-urinary symptoms that help explain non-attendance, which have different implications for practice.

Firstly, not seeking care has implications for potential unmet need for STIs and other diseases. Maintaining broad provision of integrated sexual health services (Parmar 2013) ensures availability of healthcare without requiring specific care-seeking to specialist clinics. Developing interventions to normalise attendance and targeting specific issues around tendencies to normalise, conceal or dismiss symptoms may shift some individuals to pathways in to care. We suggest non-attendance be considered as part of the range of care-seeking responses and understood as rational according to individual's own reasoning, beliefs and priorities (Zola, 1973), which are often overlooked by the public health community. Interventions that align with individuals' priorities are more likely to achieve public health outcomes. Encouraging "bodily self-determination" (12 p595) whereby

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healthcare professionals respect the healthcare decisions of patients who are competent to do so even if they disagree, so as not to deter other forms of help-seeking is important to maintain relationships between individuals and healthcare services. Secondly, seeking information showed participants' willingness to improve their understanding of their symptoms. Although experiential knowledge was often prioritised, making accurate information easily accessible and signposting to healthcare services could help expedite attendance. Additionally, development of an online clinical care pathway has been shown to meet the needs for the fully automated management of chlamydia (Gibbs *et al.*, 2016) and appeals to young people (Aicken *et al.*, 2016) and may bridge the gap between searching for information using the internet and accessing healthcare. Thirdly, as genito-urinary symptoms are often presented to other services (such as primary care and contraception clinics), this suggests individuals are exercising their right to choose care that best suits their needs. There is good uptake and acceptability of non-SHC care for genito-urinary symptoms supporting policies to widen sexual health provision outside of specialist services (Independent Advisory Group on Sexual Health and HIV by Medical Foundation for AIDS and Sexual Health, 2008); this offers additional opportunities to test, treat and manage genito-urinary symptoms, providing health care professionals maintain sexual health skills. Effective signposting, communication and referrals between services will help timely management in the most appropriate service. Finally, delayed seeking to SHCs is associated with onward transmission of infection (Hook *et al.*, 1997). Although GPs are preferred initially and participants were reluctant to go to a SHC, those who did attend specialist care had good experiences and would choose to re-attend if needed. Therefore, there is a disjuncture between anticipated and actual experiences of SHCs and reducing barriers to access including normalising attendance is essential to ensure care-seekers do not experience further delays if they decide to seek specialist care.

Unanswered questions and future research

Future surveys should examine intentions to seek care and a wider range of actual care-seeking outcomes for genito-urinary symptoms to build on the exploratory findings of the qualitative strand of this study. Composite measures of unmet need combining risk behaviours, symptom experiences and STI testing and service use are needed to identify those with most need for healthcare and improve intervention targeting and service provision.

5.4 Discussion of findings in relation to this thesis

This mixed methods paper explored help-seeking responses to genito-urinary symptoms to understand why some people with genito-urinary symptoms do not attend sexual health clinics; this addresses care-seeking aspects of unmet need and untreated infections. By reporting and reflecting on prevalence estimates and lived experiences relating to this topic, I further problematised the issue of help-seeking behaviour which focusses only on attendance at services and also consider what constitutes non-attendance.

5.4.1 Empirical reflections

Non-attendance is not commonly explored. Many studies have investigated care-seeking behaviours to a range of different services and for different symptoms and conditions but 'care-seeking' has become synonymous with attendance at healthcare resulting in clinical resolution. Braunack-Mayer and Avery (2009) used Zola's (1973) refutation of three common assumptions as a starting point and concluded that deciding to seek help from a doctor involves a combination of social, psychological, cultural and biomedical factors. My findings fit with this broad conclusion but include those who did not seek care alongside those who did. The clash of lay and biomedical professional values was evident in my study as in others (Buetow, 2007). Originally I thought I was researching an 'absent behaviour' – i.e. not attending or not seeking help, but through my analysis, a range of other actions became apparent as presented in the paper (concealing and/or normalising symptoms and dismissing healthcare needs). Therefore non-attendance was studied in the context of what was done instead and found to not simply be the opposite of attendance at healthcare or an absence of seeking help. Leydon (2009) discusses the process through which women made decisions about seeking their GPs' care for urinary tract infection. The paper highlights multiple responses that formed an individuals' care-seeking approach; first trying self-care then only attending the GP

when symptoms became disruptive. I found examples of different types of help-seeking behaviour used and the gradual accumulation of care-seeking experiences but my findings give more weighting to personal strategies to self-manage symptoms such as concealment and dismissal of care needs. Participants also resisted medicalising their experiences. I was struck by how much onus is placed on individuals in the British health system to self-triage to an appropriate setting when there are multiple service options available. This is the tension of improving access and service choice, and has not received much research attention in terms of individuals who may not engage in healthcare.

Several of my participants implicitly valued the autonomy they had in seeking control over their symptoms, describing detailed decision-making and behaviours to access care. Two participants in particular did not access the seemingly obvious choice for sexual healthcare which reflected wider social and cultural influences. One man (i13) lived approximately 100m from his local sexual health clinic but structural barriers to access, including a text messaging appointment system prevented him from using this service and shaped his care-seeking behaviour. Similarly one woman (i18) lived very close to a pharmacy but as her partner worked in the pharmacy she chose to visit the GP for all health issues. I have not really discussed structural or logistical factors which influence help-seeking because of the research questions guiding this study and the focus on individual experiences. Further exploration of how structural barriers contribute to STI prevalence would be a necessary and logical next step. Literature on help-seeking for mental health conditions suggests that stigma concerns in combination with logistical barriers may account for under-utilization of healthcare among low-income women in the U.S. (Nadeem *et al.*, 2007). Similarly the stigmatisation of tuberculosis is an important determinant of health that increases delays to diagnosis and influences illness management (Courtwright and Turner, 2010; Craig *et al.*, 2017). Some of these findings are likely to be relevant for expanding understanding of how STI stigma influences help-seeking.

Some participants defaulted to their GP to shift the responsibility of further triage directly on to a medical professional. Seeking information from the internet or from family and friends achieved a similar goal of having additional input into their care-seeking response. I was surprised not to find significant gender differences in non-attendance from the survey data given that the literature suggests that women are more likely to seek care than men for physical problems (Thompson *et al.*, 2016). Mulholland and Van Wersch (2007) also observed gender differences in several aspects of STI care at GUM clinics in England including reluctance to attend. There was, however, a large difference in reported symptom prevalence between women and men (symptoms paper, chapter 4). I conducted additional analysis using an interaction term to understand whether the effect of previous attendance at a sexual health clinic (as the exposure) affected reported willingness to attend a clinic again (as the outcome) was significantly different for women and men. From this analysis, gender has no effect on people saying they would prefer going to a sexual health clinic for STI care if they had previously attended a clinic.

My findings that people who have been to a sexual health clinic would prefer to go again for STI care, suggests normalising and encouraging regular sexual health check-ups is an important aspect of sexual health care, in line with recommendations from Public Health England (Department of Health, 2013) and a useful strategy to help minimise unmet need. However, this research has made me aware of the fine balance between reducing unmet need and untreated STIs by encouraging attendance without over-whelming healthcare services. As Zola (1973) and Scambler (2008: 44) as well as others have pointed out, there are many more symptom experiences that occur in the population than are presented to healthcare services, a phenomenon coined the 'symptom iceberg' (Hannay, 1980). Scambler et al. (1981) used health diaries to calculate the ratio of consultations to symptom episodes; their findings show a ratio of 1:10 for "women's complaints like period pain" compared to 1:60 for headaches, highlighting the variability across different symptom types. They did not specifically include genito-urinary health issues. My

help-seeking paper, in combination with the previous paper about symptoms, challenges the assumption that all these experiences are interpreted as symptoms and that there are a range of responses to experiencing symptoms rather than a dichotomy of attending a healthcare service or not. Nonetheless, even if genito-urinary sensations and symptoms are not caused by STIs, medical intervention may still be appropriate to improve sexual well-being and maintain good quality sexual health (Wellings and Johnson, 2013). The implications of this work are discussed fully in section (7.4) in the final chapter.

5.4.2 Methodological reflections

A mixed methods approach enabled me to expand on patterns observed in the survey data and explain help-seeking behaviour for genito-urinary symptoms more fully. As the survey was cross-sectional and did not ask about intention to seek care, I used the semi-structured follow-up interviews to fill in the gaps and trace help-seeking behaviour from symptom to outcome.

Using Natsal-3 data to calculate population prevalence estimates of non-attendance at sexual health clinics and service preferences amongst those who had also reported symptoms gave me a good starting point for this analysis. Clearly sexual health clinics are only one part of sexual healthcare provision and so my intention was to use a mixed methods approach to extend understandings and initial insights gained from the survey. I was able to connect symptoms and help-seeking responses through participant accounts that were not restricted to one point in time or a specific set of questions and expand the range of different care pathways this study explored. Through doing the semi-structured interviews and initial analyses of the data I was able to problematise the category of non-attendance that I had somewhat artificially created from the Natsal-3 data. My sample included individuals who had sought care for their symptoms at other services, disrupting how I had been thinking about what non-attendance meant in this study. This

provided an opportunity to explore and explain service preferences and the decision-making behind care-seeking behaviour.

The question about previous sexual health clinic attendance was asked in the CASI directly after the question about hypothetical service preference and before questions about symptoms in the Natsal-3 module on sexually transmitted infections and HPV vaccinations. The question sequencing for the clinic attendance question is unlikely to have impacted on participant responses. The question asked about attendance at 'sexual health clinics' with 'GUM clinic' included in parentheses for clarification. These are common names for specialist sexual health services in the UK but it is possible some participants could not differentiate between different types of services offered in the NHS as I found some conflation of names used in the interviews. As Natsal-3 asked questions about service preferences, previous attendances, previous diagnoses and symptoms, it is possible that participating in the survey acted as an intervention of sorts for some participants, prompting them to seek care after taking part. This is purely speculative but may have foregrounded sexual health needs in participant's day-to-day life and triggered a visit to a healthcare service.

Given that the paper examines help-seeking responses (including not seeking care) in relation to experiencing genito-urinary symptoms, in hindsight, I might have included all participants who reported recent symptoms in Natsal-3 and not limited my sample to those who also reported never having attended a SHC. This would have increased the sampling frame and allowed better understanding of the breadth of help-seeking responses and outcomes.

5.5 Chapter Summary

This chapter explored why people with genito-urinary symptoms did not seek care at sexual health clinics and contributed to research on care-seeking by examining

non-attendance behaviour in participants not sampled from medical settings. I found a broad range of help-seeking behaviours which were collectively interpreted as efforts to re-gain control over bodily sensations and symptoms. Responses were categorised into four main care pathways, some of which did not include engagement with healthcare services but highlighted that non-attendance at a clinic does not constitute an absence of a care-seeking response or doing nothing about symptoms. Not seeking healthcare because of dismissal of needs and normalisation of symptoms links directly into findings from the previous chapter about how participants create meaning. These findings suggest that if sensations are not interpreted as symptoms (or not symptoms of STIs specifically), participants are unlikely to seek healthcare. Seeking information to self-diagnose and self-treat relates to when and how participants use information to make sense of their experience, key aspects of the Cause-Concern Cycle discussed in the symptoms results paper. Seeking care at another service ties into the social representations of STIs presented in chapter 3, as the stigma of STI dirt frames perceptions of sexual health services. However, those who had been to a clinic before used experiential knowledge instead of cultural narratives or other information sources to form perceptions of the service and were more likely to prefer specialist care. These findings show the importance of service choice and the complex decisions involved in self-triaging but acknowledge the fine balance of reducing unmet need without increasing unnecessary clinical attendance. Sexual health clinics may not be appropriate to test, treat and manage the full range of sexual health and wellbeing issues to which symptoms may be linked. The links between concepts, papers and chapters are explored in more detail in the next chapter (Integration of Findings) where gender as a cross-cutting themes is also examined to establish how influential a factor it is when considering how stigma frames experiences of symptoms and help-seeking.

CHAPTER 6 INTEGRATION OF FINDINGS

6.1 Chapter Overview

The previous chapter was the final empirical results chapter. In this penultimate chapter, I collate and integrate findings from the three empirical results chapters (about STI social representations and stigma, genito-urinary symptoms and help-seeking responses), as well as methodological and theoretical components of this study. By including a chapter which focusses on the integration of the different aspects of this work, I hope to comprehensively and systematically address the overall aim of this study and answer each of the research questions posed in the first chapter, to contribute to knowledge about unmet need and untreated STIs.

I start by reviewing the tools and approaches I have used to integrate data, then bring together findings from the three empirical results chapters to answer the four empirically-focussed research questions. I go on to reflect about how and why I have used a mixed methods approach in this study and what using mixed methods has enabled me to do, comparing the functions of mixing survey and interview data in chapters 4 and 5 to explore symptoms and help-seeking. This leads on to answering the fifth, methodologically-oriented research question posed in this thesis, before summarising the chapter, tying it back into the overall story of the thesis and linking this chapter into the discussion, implications and conclusions.

6.2 Tools for integrating survey and semi-structured interview data

I used my PhD study to explore different approaches to integrating data generated through different methods and from different epistemologies. Integration (or the linking, synthesising or meshing together) of data are a vital component of conducting mixed methods research to "*produce a whole through integration that is greater than the sum of the individual qualitative and quantitative parts*" (Fetters

and Freshwater, 2015, p. 116). I have addressed this in a separate stage of analysis in both mixed methods chapters (chapters 4 and 5). The integration of data are a key area of innovation in the mixed methods research community and there are already distinct factions forming, advocating different approaches to achieve this goal of a mixed methods research study (Sale, Lohfeld and Brazil, 2002; Mason, 2006; Fetters, Curry and Creswell, 2013a; Guest, 2013) (see section 2.2.3, chapter 2). My focus for the integration of survey and semi-structured interview data for this study has been on the interaction between different data sources and what this interaction tells me about my findings overall. Initially I used matrices similar to those summarised by Alicia O'Cathain in one of the first papers to explicitly address the issue of how to integrate results from qualitative and quantitative studies (O'Cathain, Murphy and Nicholl, 2010). I had seen a matrix used very effectively in a mixed methods study about preparedness for using rapid HIV self-tests by gay men and other men who have sex with men (Flowers *et al.*, 2017). I felt this was a useful approach for my study to enable me to generate more knowledge than independent analyses of each dataset alone could do (O'Cathain, Murphy and Nicholl, 2010). O'Cathain (Ibid) suggests different types of matrices should be used at different stages of the research process (differentiating between analysis stages and interpretation stages). However, I have applied them using an iterative approach to facilitate further analysis and interpretation of the data after initial independent analyses of the survey and semi-structured interviews. Integration was a major theme addressed in the workshops following the second conference of the Mixed Methods International Research Association and I was inspired by some of the visual data displays shown by Joke Bradt, Tim Guetterman and Susan Docherty (MMIRA, 2016). I applied the principles of visual data integration in my thesis to supplement data integration using matrices. Attending the conference coincided with my successful application for a small additional collaborative development grant from the Economic and Social Research Council (ESRC) to undertake some work with a graphic designer to help visualise my data and think about my findings

from a different perspective. This led me on to exploring the utility of joint displays to present and integrate my survey and semi-structured interview findings (see section 6.2.3).

6.2.1   Mixed methods matrices

Using Natsal-3 participants as my sampling frame (discussed in chapter 2) meant that I had different types of data (survey responses and the transcript from the semi-structured interview) about the same participants. The mixed methods matrix approach integrates data at the individual level i.e. for each participant who I conducted a follow-up interview with, having already completed Natsal-3. Clearly given the length of time between data collection for the survey and semi-structured interviews and the cross-sectional design of the survey, much of the data collected in Natsal-3 did not represent the participant's lifestyle at the time of interview. Indeed, several participants mentioned how much their lives had changed since the survey noting changes in relationship status and sexual behaviour in particular. I therefore chose 'stable' or retrospectively reported variables to integrate with elements of the semi-structured interviews. These included age, previous STI diagnoses and hypothetical service preference (although my findings in chapter 5 show that participants who had previously been to a sexual health clinic were more likely to choose this option in the future, and clinic attendance was more common amongst younger participants, so this element of behaviour may change over time). Using mixed methods matrices enabled me to collate different elements of participant's experiences in relation to my research questions about symptoms and care-seeking responses. I could place the symptoms they reported in Natsal-3 in the context of lifetime symptom experiences. This enabled comparison of the two datasets to identify if the same symptoms were reported (suggesting they were memorable or fairly common experiences as opposed to insignificant, one-off or transient sensations). I was also able to link symptoms to suspected causes and emotions (in the symptoms results paper – chapter 4) and hypothetical service

preferences and specific care-seeking responses for symptoms (help-seeking responses paper – chapter 5). By placing data from the survey and interview alongside each other for each participant, I was able to build up a more detailed picture of the individual, identify discrepancies or anomalies and consider their symptoms and care-seeking responses in a broader context. By collating data for each participant and placing together in a table, as I have done in the symptoms and help-seeking results papers (chapter 4 and 5), I was able to look for similarities and differences among the 27 participants in this study. I combined these with analysis of the broader patterns in the data (O'Cathain, Murphy and Nicholl, 2010), which facilitated my analysis of both datasets. Similar to O'Cathain et al.'s (Ibid) analyses, I found the mixed method matrix a quick and easy way of identifying negative cases or those who did not fit emerging patterns from other analyses. Having access to the full responses of each of the participants who took part in the follow-up semi-structured interviews was a particular strength of this study and negated the need for including a demographics questionnaire in the interviews. Using mixed methods matrices also contributed to the fifth methodological research question about integrating survey and semi-structured interview data to explain, contextualise and extend findings about symptoms and care-seeking. Looking at individual experiences of symptoms reported at each point of data collection and previously diagnosed STIs or other diagnosed conditions, coupled with perceived cause (Table 2, symptoms results paper) enabled a better understanding of participant sense-making processes. Using data about previous infections and conditions helped extend findings about how past personal health experiences inform current health issues. Similarly, in the help-seeking paper, table 3 links symptoms, hypothetical STI care preference and actual help-seeking responses. Displaying the data in a matrix helps map out individual help-seeking pathways and shows participants often did not seek care at their stated preferred service for STI care, which supports the finding that most did not perceive their symptoms to be STIs.

6.2.2 Convergence coding matrices

A convergence coding matrix is suggested by O'Cathain et al. (2010) as a method of integrating data adapted from the triangulation protocol (Farmer *et al.*, 2006). This approach helps move findings beyond the method through which they were generated to become more conceptual ideas about the phenomenon being studied (Farmer *et al.*, 2006; O'Cathain, Murphy and Nicholl, 2010). I have used convergence coding matrices in the same way in both of the mixed methods research papers (chapters 4 and 5) in this thesis. By organising the data by theme and presenting the survey and semi-structured interview findings in adjacent columns followed by a specific column for integrating results, I was able to identify areas of agreement, partial agreement, silence and dissonance (O'Cathain, Murphy and Nicholl, 2010) in the data. For example, there was dissonance about what constitutes a symptom and that the symptoms reported in Natsal-3 were those of STIs (table 3, symptoms paper). Table 4 (help-seeking paper) highlighted that both datasets supported findings that sexual health clinics were more commonly attended by younger participants and there did not appear to be gender differences in non-attendance at specialist services. There was also agreement that the GP was the preferred service for hypothetical STI care and care-seeking in response to genito-urinary symptoms. Although the application of this type of matrix in the symptoms and help-seeking results papers was the same, presenting findings in this way showed explicitly the different purpose of using a mixed methods approach to study each concept (discussed in 6.6 Reflections on using mixed methods). Including convergence coding matrices in the mixed methods results papers helped integrate data and aided interpretation of data by contextualising service preferences in lived experiences of symptoms and help-seeking and showing how themes such as common symptoms and normal experiences could be transferred across datasets.

6.2.3   Joint displays

A joint display is another data integration tool defined as a way to *"integrate the data by bringing the data together through a visual means to draw out new insights beyond the information gained from the separate quantitative and qualitative results"* (Fetters, Curry and Creswell, 2013b, p. 2143). Joint displays are a key area of innovation within mixed methods research (Guetterman, Fetters and Creswell, 2015) and, along with matrices, serve to provide an alternative (and in my opinion better) approach to written text to integrate different types of data. Guetterman's (Ibid) review of joint displays used in empirical health-related studies found that the most common types of joint displays were statistics-by-themes and side-by-side comparisons. For explanatory sequential study designs, path diagrams with clinical vignettes were also frequently used. Each of these types of joint displays demonstrates the potential to link and mix results from qualitative and quantitative components as well as combine theory.

I think there is potential to further innovate the uses of joint displays to visually link different types of data. This may help to show new trends, follow analytic lines across datasets, gain new insights from having multiple perspectives on the same data and translate findings into meaningful implications. Creative approaches are needed to progress understanding of data integration with a focus on visual elements of the displays rather than focussing exclusively on text. New ways of presenting and visualising qualitative data are also needed as most data visualisations are based on numerical data. I worked with a graphic designer in an iterative and highly collaborative way to visualise my findings. My brief to her was to be creative with my findings, to emphasise how the survey and semi-structured interview findings were linked and particularly how the latter contextualised, explained and extended the population patterns. We also had various discussions and ideas about novel approaches to presenting the semi-structured interview

findings data. Together we conceptualised the joint displays for the participant samples, symptoms and help-seeking results of this thesis shown in figures 3-5.

Figure 3: Joint display of participant flow in survey analyses and for semi-structured interview sampling
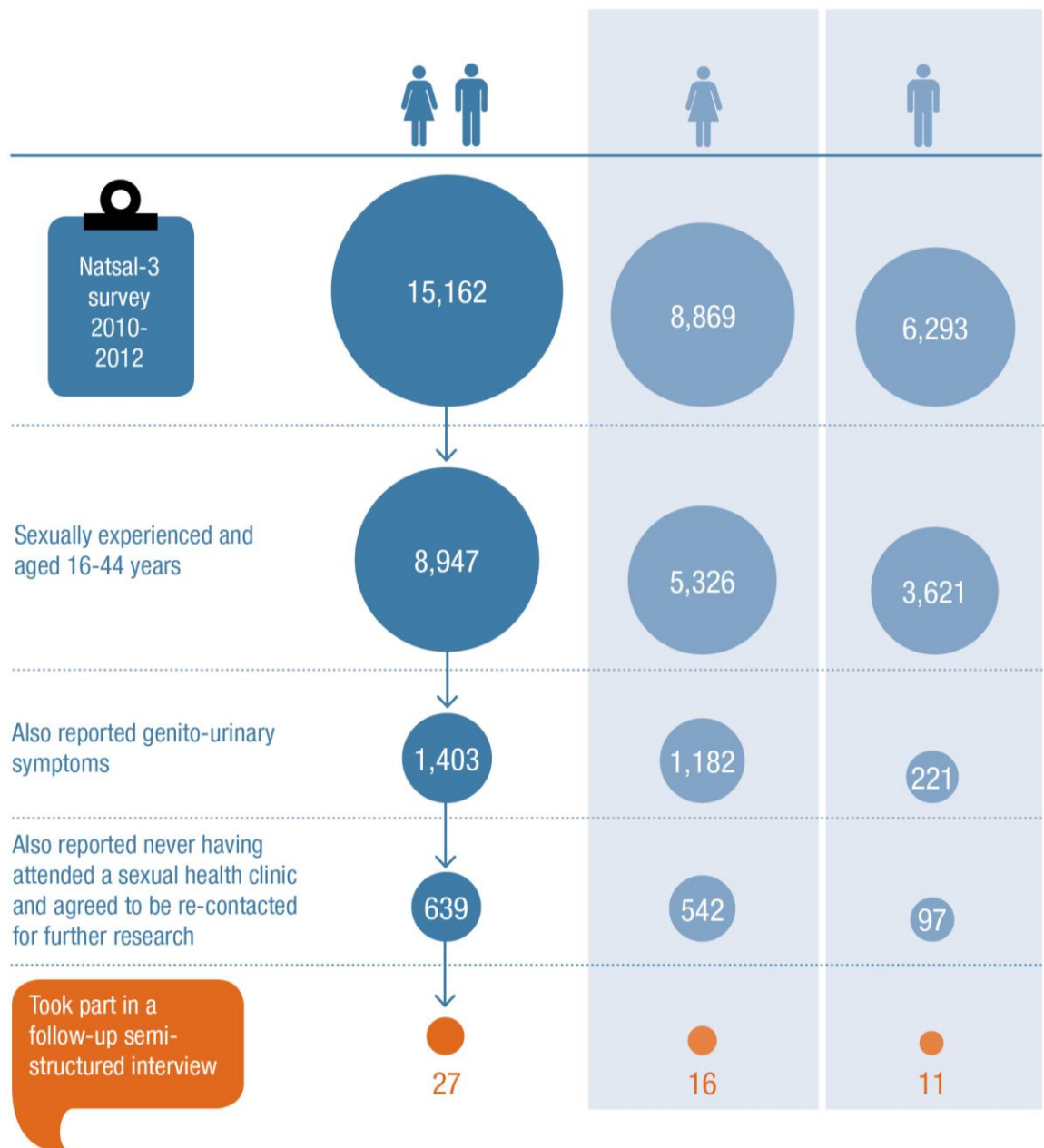
Figure 3 presents the survey and semi-structured interview sample sizes side-by-side and splits the two samples into women and men. Displaying the sample sizes in this way and using arrows to represent the flow of participants emphasises the linked nature of each component, highlighting that participants for the semi-structured interviews were recruited from a sub-population of Natsal-3 participants. This joint display does prioritise numerical data and may misrepresent the value of the semi-structured interviews as it does not represent the richness of the data produced, only the sample size. The use of colour (blue and orange) differentiates between different data sources and is consistent throughout the other joint displays so they can be used as a set as well as to represent different aspects within the body of results.

The second joint display (figure 4) also presents survey and semi-structured interview data side-by-side ensuring clear distinctions but easy comparison of findings from each data source. Showing the dimensions of symptoms (pain and particularly visibility and negative emotions) alongside the prevalence of symptoms in women and men gives some insight into the important aspects of the experiences that participants had reported and contextualises population patterns with experiential data. Similarly, displaying conflicting data about perceiving STIs to be causing the symptoms (in the survey but less so in the semi-structured interviews) enabled me to reflect on reasons why this might be, and consider the limitations of my sampling strategy (see section 7.3 of chapter 7) in conjunction with figure 4.

Figure 4: Joint display of survey and semi-structured interview findings about genito-urinary symptom experiences

Symptoms

Natsal-3 survey results

Reported genito-urinary symptoms in the past month by sexually experienced women and men aged 16-44

22%   **6%**

Most common symptoms ✓

Pain, burning or stinging when passing urine

Genital ulcers were the least common symptom

Younger women were more likely to report symptoms (past month) than older women

12% 16-29 year olds
10% 30-44 year olds

Women had increased reporting of more than one symptom than men

7.5%
0.8%

Reported genito-urinary symptoms and a positive STI urine test*

30%   **9%**

* Chlamydia, gonorrhoea, HIV, human papillomavirus and mycoplasma genitalium. The STI detected may not have caused the symptoms reported.

Participants who reported genito-urinary symptoms were 2-3 times more likely to perceive themselves to be 'greatly' or 'quite a lot' at risk of getting an STI than participants without symptoms.

Semi-structured interview results

Dimensions of genito-urinary symptoms

Pain: Participants had experienced painful symptoms

Visibility: Participants had experienced visible symptoms, eliciting greater disgust and repulsion

Emotions: Symptoms often resulted in negative emotions, including uncertainty about causes of symptoms

Words people used to describe symptoms

disgust ugly dirty unhygienic uncertainty horrendous contagious worry about future manky unpleasant embarrassment promiscuity anxiety scared freaked out unclean

I worry it's [her symptoms] going to stop me having more kids… I just worry it's going to lead to something more later on in life. Whereas I don't worry about what it's doing to my body now, 'cos I think if I'm not bleeding every day that's fine (i8) WOMAN, AGED 16-19 YEARS

[I had] a lump which happened over Easter and I couldn't see a doctor and I thought, I was convinced I was dying… and it was nothing…it was just an epididymal cyst, it was fine… I just convinced myself that I hadn't long left like a bloody idiot (i14) MAN, AGED 45-49 YEARS

Figure 5: Joint display of survey and semi-structured interview findings about help-seeking responses to genito-urinary symptoms

Help seeking

Natsal-3 survey results

Reported genito-urinary symptoms but had not been to a sexual health clinic in the past year

88%   86%

Preference for STI care

GP

59%   54%

16-24 year-olds were more likely to have been to a sexual health clinic recently than those aged 25 and older.

But, **those who had been to a sexual health clinic before** were 7-8 times more likely to prefer a specialist clinic compared to the GP.

SHC

Semi-structured interview results

Not seeking healthcare
- Several participants did not seek care from any health services
- Participants concealed, normalised and/or dismissed their symptoms and healthcare needs

… I must admit I didn't even tell my wife, just kept it [penile discharge] private, kept it to myself, just kept looking every day and hoping it would [disappear]…I didn't go to the doctors, I didn't even Google it to be fair, I just hoped it would go away **(i17) MAN, AGED 30-34 YEARS**

I do [Google symptoms] but then I always wish I hadn't... you can go off on all crazy scary tangents can't you on the internet, so yeah a little bit cautious when it comes to Googling health information **(I19) WOMAN, AGED 30-34 YEARS**

Seeking information to self-diagnose and/or self-treat

Participants used the internet, social networks and previous personal experience to manage their symptoms and guide decisions on healthcare

Seeking care at a non-specialised sexual health service
- Most participants used primary care or other non-specialist services – mainly their GP
- Women were better linked into sexual and reproductive healthcare services
- Stigma and fear of being judged prevented some participants accessing specialist sexual healthcare

Seeking care at a sexual health clinic

A few younger participants attended a sexual health clinic but delayed or mis-reported their experience

Yeah, there was a delay…it wasn't straight to the clinic, it was straight to the clinic on the third occasion…initially there was a two month delay…I was single at the time, the first time it [genital warts] happened, so I wasn't in a rush and I wasn't sexually promiscuous either so I wasn't in a rush to get rid of it **(I13) MAN, AGED 20-24 YEARS**

A lot of people including myself still haven't gone to the clinic because if you're seen outside they go, "dirty little bitch!"... I had people staring, in the end I went to me doctors **(i16) WOMAN, AGED 25-29 YEARS**

Figure 5 is the joint display of help-seeking data and highlights the sequential nature of the study. The survey findings about non-attendance at sexual health clinics and preferences for hypothetical STI care feed directly into the different types of help-seeking responses that participants reported in the semi-structured interviews. The semi-structured interview results connect and extend the survey findings and this visualisation also gives a sense of the dominance of the qualitative component of the study design. Displaying responses as a pathway suggests that seeking help is a process and contrasts with the static nature and presentation of the survey findings.

Creating joint displays about concepts that are hard to visualise such as genito-urinary symptoms constituted an additional challenge because of the sensitive nature of the topic and stigma associated with STIs. I have used similar approaches to those reviewed by Guetterman et al. (2015) for clarity and developing the joint displays gave me an additional perspective on my data, helping me think about the interface of datasets and the potential limitations of my sample. The neatness of reporting statistical summaries is juxtaposed with the messiness of semi-structured interview data. The process of creating a joint display highlighted the challenges of visualising text data effectively. Integrating the data in this way has exposed how different aspects of lived experiences are filtered through different lenses which are then represented in different ways. What I have tried to do by using mixed methods is bring together these different representations of symptoms and help-seeking in the context of stigma to understand each concept more fully.

6.3 Integration of empirical findings to answer the research questions

The empirical results of this study comprise a chapter presenting findings from the semi-structured interviews about the social representations of STIs including an exploration of STI dirt, and two mixed methods chapters presenting and integrating data from the survey and interviews about genito-urinary symptoms and help-

seeking responses. I organised my results chapters to map on to the four empirical research questions. There is some overlap between findings, which helps link questions together to achieve the overall aim of exploring how social representations of STIs influenced lived experiences of genito-urinary symptoms and care-seeking responses. Together, these findings add to understanding unmet need and untreated STIs as a public health issue. I will now summarise my findings in relation to the research questions, linking different elements of the study as necessary and reflecting on the extent to which each question has been answered. These research questions came from observations and gaps identified in the literature and reflect a specific stage in the research process, whilst many of my ideas about my data and analytical processes were still coming together. Publishing these questions in the study protocol paper (chapter 2) 'fixed' them at that point in time and acted as a useful guide for the latter stages of the project, but as is common in inductive analyses, research questions are revised and refined to accommodate pertinent findings (Green and Thorogood, 2009, pp. 36–37). This is the case for my study and so I am also using the following section to justify any revisions necessary to maximise the impact of my results.

6.3.1 Research questions 1 and 2

Can perceptions and social representations of STIs help explain genito-urinary symptom experiences and care-seeking behaviour?

What is the role of stigma in genito-urinary symptom perception and care-seeking?

The first two research questions in this study pertain to sociological and social psychological concepts and I examined them through the follow-up semi-structured interviews. As the research progressed and I learned more about the methods I was using, data I was producing and the process of writing, I realised the research questions needed amending to enable a better fit with the data and what I was

trying to achieve through this study. Therefore, I adapted the first research question from "c*an perceptions of STIs help explain genito-urinary symptom experiences and care-seeking behaviour*" to a more open question which better aligned with my data: "*How can understanding social representations of STIs help explain lived experiences of genito-urinary symptom and care-seeking responses?*" My findings presented in the first results paper and the rest of chapter 3 suggested links between representations of STIs and STI stigma. To prevent fragmentation and compartmentalisation of the story of how both influence individual symptom experiences and care-seeking, I am presenting the answers to research questions 1 and 2 here together.

These questions arose from examining the abundance of literature suggesting that STIs are stigmatised and viewed very negatively in society (for example (Cunningham *et al.*, 2002; Lichtenstein, Hook III and Sharma, 2005; Balfe, Brugha, O' Donovan, *et al.*, 2010; Balfe, Brugha, O'Connell, *et al.*, 2010; Hood and Friedman, 2011; Foster and Byers, 2013) and that stigma acts as a major barrier to accessing sexual healthcare (Dixon-Woods *et al.*, 2001; Kinghorn, 2001; Scoular, Duncan and Hart, 2001; Lichtenstein, 2004; Malta *et al.*, 2007; Balfe and Brugha, 2009; Balfe, Brugha, O' Donovan, *et al.*, 2010; Balfe, Brugha, O'Connell, *et al.*, 2010). I wanted to explore the socio-cultural factors that created the context for individuals' experiences. My findings showed that dirt is a key component of how STIs are perceived and understood and also suggested dirt to be a component of STI stigma. I now understand that there is conflation between moral and physical dimensions of dirt and the dirtiness of STIs is compounded by participants who see sex as dirty. From these findings, I can conclude that social representations of STIs and STI stigma operate together to frame symptom experiences and help-seeking responses in the context of dirt. Using dirt as a framing to understand symptoms and care-seeking enables me to situate these experiences in the socio-cultural context in which they occur and are made sense of by participants. This facilitates

the linking of individual experiences and population patterns of reporting symptoms and different help-seeking strategies.

The flash card activity revealed that STIs are perceived as different infections within this general category, but STI stigma is applied homogeneously to the group of infections. Participants stigmatised things associated with STIs because of the fear of contagion of moral and physical dirt. Applying STI dirt as a frame to the lived experience of genito-urinary symptoms helps me to interpret how participants interpreted sensations and symptoms. No-one thought of themselves as dirty when they had had symptoms, and issues of contagion and transmitting infection were not foregrounded in participants' minds, enabling them to distance themselves from STIs. They made sense of their sensations by looking for other 'non-dirty' explanations that were more likely, given how they perceived themselves. Sensations, particularly those that occurred internally with no visible signs were easy to conceal and/or normalise and so not considered to be related to STIs. Symptoms perceived as having a medical cause, or those that had visible signs could be interpreted in the same way as long as they did not encompass any aspects of dirt in their meaning. Normal physiology is not considered dirty but some abnormalities are, and so participants acted to minimise the amount of dirt associated with their experiences.

As shown in the results paper about help-seeking responses (chapter 5), STI stigma underpinned much of the non-seeking healthcare behaviour reported in both the survey and follow-up interviews. By considering these findings in relation to dirt, I can extend my understanding of these individual behaviours in a broader social context. Participants hiding symptoms (both visible and non-visible) through concealment and non-disclosure, and normalising sensations and symptoms can be understood as attempts to minimise dirt and feelings of dirtiness. Several participants mentioned washing more to try and get rid of the symptoms (dirt). Seeking information and emotional reassurance from others who had experienced

the same symptoms was important as it provided examples of others having successfully shed both visible and moral dirt, providing the participant did not consider them a dirty person. Care-seeking to services can be interpreted as taking action to get rid of the dirt but emotions associated with dirt and feelings of dirtiness might delay attendance. I summarised the different responses as participants' attempts to seek control over their bodies and the sensations and symptoms they experienced, but this behaviour can also be viewed as seeking control over the dirt.

To summarise, by exploring the social representations of STIs and STI stigma, I have found dirt to be a key component and developed dirt as a framing through which to understand lived experiences of genito-urinary symptoms and help-seeking responses. These findings about the role of dirt need to be synthesised with other established stigma theories to better explain underlying mechanisms through which STI stigma operates to stigmatise infections. Dirt appears to be an important factor but there may be others, not identified in this study that may influence symptom interpretation and decisions about care needs.

6.3.2   Research question 3

How do people interpret genito-urinary symptoms?

I asked this research question to access different aspects of the concept of 'symptom.' My findings incorporate reported symptom prevalence, lived experiences of a variety of different symptoms and a mechanism to explain how symptoms are interpreted. Using mixed methods also enabled me to problematise Natsal-3 assumptions about what a symptom is (discussed in section 6.4 – reflections on using mixed methods).

I discovered genito-urinary symptoms were far more commonly reported by women than men in Natsal-3 suggesting more women had experienced an abnormal

sensation recently and interpreted it in such a way as to align their experience with the types of experiences that Natsal-3 question asked about. This alignment of personal experience and Natsal-3 question interpretation resulted in estimates of population prevalence of genito-urinary symptoms of 22% for women and 6% for men. This constitutes one interpretation of what a symptom is.

During the interviews, I presented participants with the same list of symptoms that constituted the responses to the symptoms question in Natsal-3 and asked them about ever experiencing any of the things listed. This again required participants to recall past experiences and interpret what they had felt and compare that to the list of symptoms I gave them. An additional element of this approach to collecting data were asking about *ever* experiencing any of the symptoms (although as the interviews progressed I moved away from calling the listed items symptoms as I became sensitised to the different interpretations of what a symptom was). Lifetime experiences drew on ability to recall the experience, which in turn was determined by how significant the occurrence had been for the participant – a major emotive disruption or one that was transient and quickly forgotten. This related to the characteristics of the symptoms themselves and I presented findings about sensory (pain and visibility) and affective dimensions of symptoms in the symptoms results paper (chapter 4). Participants did not often use the word 'symptom' to describe and define their experiences and I concluded that symptoms were sensations that caused concern to individuals and had a suspected underlying medical cause. This is a second interpretation of what a symptom is.

Finally, not all sensations were interpreted as symptoms and very few symptoms were interpreted as being related to STIs, broadening my investigation to consider sexual health and wellbeing more generally. Participants made sense of sensations through the Cause-Concern Cycle, a model I proposed to explain the process of searching for possible explanations for bodily changes and feeding this back to inform the level of concern about the experience. The cycle depicts the range of

informational inputs and exit points which defined the parameters of the sense-making process. I suggested it was important for individuals to make sense and create meaning about their experiences to regain control over their bodies and make the experience more manageable.

Therefore, genito-urinary symptoms can be understood in terms of how common they are, what they feel like and how this relates to physiology and pathology as well as underlying causes and levels of concern which stimulates sense-making processes to attribute meaning to sensations and symptoms. These different aspects of the concept of 'symptom' are a product of the methods used to produce data about symptoms. There are likely to be other lived experiences of symptoms which could be elicited from different samples of participants, in different cultural contexts and/or by including different types of symptoms. Different reported experiences may lead to adjustment of explanations about how symptoms are interpreted through the Cause-Concern Cycle. My findings are located in the data produced from this study but I am not suggesting they are exhaustive in understanding the multi-dimensionality of genito-urinary symptoms.

6.3.3   Research question 4

Why do some people with genito-urinary symptoms not seek care at sexual health clinics?

This research question articulates my interest in non-attendance behaviour, which was my starting point for this study. By narrowing my focus to investigate those with a potential need for care (genito-urinary symptoms) not attending sexual health clinics, I set out to examine non-attendance as a category of behaviour by using a group of 'non-attenders' (participants who reported never having attended a sexual health clinic). My assumptions about this neat categorisation of participants and their care-seeking behaviour quickly became very messy but this

actually helped my analysis and I was able to use my data to explore different care-seeking pathways and the reasoning behind these choices. I found examples of four main responses to symptoms (and answers to the research question posed) – not seeking any healthcare, seeking information to self-diagnose and/or self-treat, seeking care at non-specialised health care services and seeking care at a sexual health clinic after delaying. I concluded that responses to having symptoms were not about seeking care specifically, it became about re-gaining control over their bodies and participants prioritised sources of knowledge, care and information that enabled them to do so. This often did not involve attending formal health care services but 'not attending' did not mean 'doing nothing' as there were many examples of concealing and normalising symptoms and dismissing healthcare needs. As my findings from chapter 3 showed, stigma operated in the background, but was foregrounded in silencing and concealment behaviours leading to not seeking any healthcare. Building on findings from chapter 4, if participants did not interpret symptoms as those of STIs, there was little reason for them to seek care at a sexual health clinic. As Zola suggested (1973), decisions about seeking care are rational if considered in the context of the individual's values and beliefs and my findings support his conclusion, but are drawn from a population sample instead of a patient sample.

I have suggested four main responses to having symptoms, although there are likely to be others. Considering why people don't attend specific services and what they do instead should become part of definitions of care-seeking. These definitions should move beyond viewing attendance at a health care service as the only end-point of a care-seeking pathway and consider alternative help-seeking responses as well.

6.4 Synthesis of other themes across concepts

In addition to the three main concepts of this thesis, I identified three other themes that ran through the thesis as a whole. These are gender, time and use of the internet, which have been implicit in much of the work presented so far but not directly addressed as themes until now. Reflexivity is also an essential theme to consider; it impacts on the whole study but is not an empirical theme in its own right. I have chosen to address the implications of reflexivity here to enable findings to be put in context and to consider my position in relation to the study findings.

6.4.1 Gender

All participants who took part in the semi-structured interviews identified themselves as cis-gendered. The Natsal-3 survey segued from the interviewer's perception of the participant's gender to the respondent's biological sex (as discussed in section 2.2.5). Precise discussion of sex differences is important for this study. Female and male bodies by definition are anatomically different and genitals are a major element of that definition. Females and males experience different types of symptoms and this was reflected in the Natsal-3 question gendered responses to symptoms (only three symptom responses were common to both – pain urinating, genital ulcer/sore, genital wart/lump). Not only were participants asked about different types of symptoms, but those presumed to be female were asked about more symptoms than men (nine different symptoms, compared to five for men – see appendix B, p.318).

Consequently, my findings about symptoms were associated with the most pronounced sex differences. Recent symptoms were more commonly reported by females than males in Natsal-3 and survey data also showed a higher prevalence of reporting symptoms and an STI detected in the urine sample in females (30% compared to 9% of males). Normalising symptoms and attributing them to biological causes such as menstruation, contraception and receptive vaginal sex

were common experiences and most women were quite accepting of symptoms as a periodic occurrence in their lives. UTIs and thrush were perceived as being especially common for women. Men blamed general lifestyle factors – external influences especially drinking alcohol, rather than emergent or underlying health issues. Interestingly, the gender gap on alcohol consumption is narrowing (White *et al.*, 2015) minimising the gendered effect of this behaviour.

Surprisingly, these differences in symptom experiences did not carry through into quantifiable variances by gender for care-seeking behaviour. Similarly high levels of non-attendance at sexual health clinics were seen for women and men and there were no significant gender differences observed for STI care preferences. Women tended to be better linked into a network of healthcare services such as their GP, contraception clinics, antenatal care and specialist gynaecology services because of ongoing needs in relation to female genital health (menstruation, smear tests, pregnancy and the disproportionate burden of contraception which falls on women). This gave women more opportunities to mention symptoms opportunistically during other engagement with services instead of proactively seeking care in response to symptoms as men had to.

Finally, gender differences have been discussed in other empirical studies, suggesting women felt more shame and internalised stigma more than men (Cunningham *et al.*, 2002; Mulholland and Van Wersch, 2007; Balfe, Brugha, O'Connell, *et al.*, 2010). Although I did not explore stigma in the same ways, I did observe some similar patterns in my data. Women portrayed themselves as the one with an STI or symptoms when talking hypothetically about how someone would be treated whereas men tended to talk about female partners as the person with the issue instead of themselves. This is a subtle difference but supports the idea that gender is a theme which intersects with experiences (of symptoms and help-seeking framed by STI dirt and the stigma of infections).

Sex and gender therefore manifested as a theme in the data in different ways, from physiology to behaviour and elements of self-presentation in the interview setting. I also recruited more women than men to participate in the follow-up semi-structured interviews but tried to give a space for both genders' accounts when presenting my findings to enable comparisons to be made. Undoubtedly, sex/gender was a strong influencer on many aspects of STI stigma, symptom experience and help-seeking but it is beyond the scope of this discussion to undertake a more granular analysis of gender as a theme in this study.

6.4.2 Time

Germain (1976 in Blinn & Harrist 1991) stated that time referred to the pacing, duration and rhythm of events and acted as an ecological variable i.e. at the group or population rather than individual level. In this study, time is a theme that, like gender cuts across concepts and the context of this thesis. My findings suggest time is relevant to the social context in which this research was conducted, individual symptoms and help-seeking experiences and the methods and feasibility of the design of this study. I discuss each of these dimensions of time as a cross-cutting theme in turn.

6.4.2.1 Time in relation to the social context of this study

I was very aware before I started this study, of the influence and impact time has on social research and how findings shape and are shaped by their place in social history. Stigma varies across cultures and over time, and there has been significant social progress and change since Goffman (1963) published "Stigma: Notes on the Management of Spoiled Identity". This study is precisely situated at a specific point in time, documented by the dates and duration of data collection (May 2014-March 2015) and analysis but also anchored in and framed by the cultural reference points participants used in their accounts. They drew on past events and often compared how STIs are represented now to common perceptions about earlier time periods.

The AIDS tombstones adverts (Central Office of Information for Deparment of Health, 1987) were particularly well noted as a stand-out memory for some (older) participants (i6, i14, i25) and there was more general awareness of the 1980s as the "AIDS era" (i6, i14, i10). Similarly, syphilis was often described as being an historical disease related specifically to the Victorian era (i10, i12). The cultural reference points mentioned by participants to illustrate their stories about STIs, stigma, symptoms and help-seeking, situated the data produced through the semi-structured interviews to a very precise time point. Two participants mentioned the ebola epidemic (i21 and i27), and two mentioned the ice bucket challenge (*The Guardian*, 2014). Several participants drew on things they had seen on the TV show Embarrassing Bodies and storylines in soaps (namely Emmerdale, EastEnders, Coronation Street and Hollyoaks) to illustrate and extend their accounts. If I carried out the same interviews again now, most of the main themes would probably emerge but some of these cultural reference points (particularly the transient examples) would be different and updated to the current context.

Time is also evidenced as a major factor in the shifting of the object or target of stigmatisation, from considering any sexual behaviour as deviant, to focussing on unprotected or unsafe sex as the activity that deserved most judgement. This shift has occurred gradually in line with changing social attitudes and norms around socially acceptable behaviours, measured by comparison of responses to attitudinal questions in Natsal (Mercer *et al.*, 2013). Some participants were able to comment on the changes in social attitudes, describing liberal views becoming more commonplace and the younger generations being more open-minded than older people, but others confined their accounts to their own experiences and did not explicitly position themselves in any particular social or cultural context.

6.4.2.2 Time in relation to symptoms and help-seeking

Time manifested in individual experiences of symptoms. Younger women reported more symptoms than older women (symptoms results paper – chapter 4)

suggesting age is an important factor in symptom experience and interpretation. It is possible that younger woman with less experience of having these types of symptoms are more likely to report them as they do not have the experiential knowledge to draw on to normalise them as non-symptoms and/or attribute them to other causes. Experience accumulates over the life course and older woman had had more time in which to experience sensations and symptoms as well as seek help and learn more about potential causes. Time was important in connecting the sequence of events that preceded sensations. Participants contextualised the sensations and symptoms they experienced in relation to the timing of other behaviours and occurrences such as recent sex or lifestyle factors such as drinking alcohol or changes to their daily lives. This enabled them to connect perceived cause and effect in time, helping individuals to understand and interpret their bodily changes. All participants described their symptoms over time, whether they were transient occurrences or long-term issues. The natural course of the sensation over time was monitored closely by participants and many described a "wait and see" approach to managing their experiences. Generally if symptoms got much worse or persisted for longer than expected, this prompted care-seeking but if they got better and disappeared, this constituted an end to that period of sense-making and I included remission of symptoms as an exit point of the Cause-Concern Cycle (symptoms results paper – chapter 4) to capture time as an influential factor. The "wait and see" response to symptoms was very variable with some participants waiting only a few days before seeking care and others waiting several months. The passage of time in between experiencing symptoms and seeking help acted as a delay to accessing care, which was exacerbated by other structural barriers to care impeding the pathway to receiving diagnosis and treatment as necessary.

6.4.2.3 Time in relation to methods

Time and timing of this study also had a big impact on the methods used and data produced. Natsal-3 was a cross-sectional survey and collected data about a snapshot at one point in time – the day of the Natsal-3 interview for each

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participant and the time period of each question (ever, past year, past month, first time, last time, how many times in a given time frame etc.). We know there is some seasonality to STI diagnoses (Cornelisse *et al.*, 2016). The design of this method eliminates the element of change over time as data about STI symptoms were not collected in previous iterations of the survey. The time elapsed between the Natsal-3 data collection and the follow-up semi-structured interview was a limitation of this study and product of the timing of my PhD, as I started September 2013, 13 months after survey data collection had finished. Despite prioritising gaining ethics approval and developing my field work tools, there was an inevitable delay between the two phases of data collection of between 22 and 44 months. This delay impacted on response rate and then what was recalled by participants in the semi-structured interviews but gave interesting insights into the durability of memories and feelings about specific symptom experiences and genito-urinary sensations. Both Natsal-3 and the semi-structured interviews required participants to reflect on past (and in some cases current) experiences of sensations and symptoms and help-seeking. The sequential design of the study enabled me to capture some of the outcomes of symptoms and understand processes over time that participants had experienced.

6.4.3   Use of the internet

This study did not seek to explore if and how the internet informed experiences and responses to symptoms but it emerged as a dominant theme in participant accounts. I found the number of participants who spontaneously incorporated the internet into accounts of their own and others' experiences surprising, which led to further examination of this observation and the emergence of "use of the internet" as a cross-cutting theme which intersects with findings about stigma, genito-urinary symptoms and help-seeking. There was no obvious similarities between the six participants who did not make reference to the internet within their interview.

The internet was a key cultural reference point for participants and was ubiquitous in their lives and health experiences. Google images was cited as a common source of disgust at the extreme visual images of STIs. These represented visible dirt for participants and elicited strong emotional responses, generating and reinforcing STI stigma because of the graphic nature of the images. Even those participants who had not specifically searched on Google images for STIs (or other related terms), had strong ideas about the nature of the likely images to be found and Google images appeared to represent the visual aspect of STIs, despite many acknowledging that most STIs were unlikely to look like that in real life.

The internet was also used to search for information about symptoms and STIs, as it was an easily accessible, anonymous and non-stigmatising way of obtaining information. Several participants described using forums to search for others' lived experiences of similar symptoms to gain emotional reassurance that may not have been accessible in real life. Forums provided a space and opportunity for participants to connect and share experiences with others, irrespective of their social or cultural networks, geographical distance or emotions relayed to bodily changes. There was general acknowledgement about potential misinformation on the internet highlighting the tensions about using it as a source of knowledge, but most participants described nuanced approaches to navigating and appraising knowledge about symptoms and STIs. Most considered first-hand accounts as valid forms of knowledge and looked for markers of legitimacy on more factual information – such as the NHS choices website, a trusted information source because it was linked to general trust of the NHS. The information received from the internet acted as inputs into the Cause-Concern Cycle to help form meaning about experiences, propagating the sense-making processes that occurred after sensations were initially felt.

Specific information was also sought using the internet to inform responses to symptoms as there were very few physical or socio-cultural barriers to Googling, or

searching for information in this way, compared with engaging in healthcare services offline. Information retrieved could both prompt or deter further care-seeking depending on the context and nature of symptoms and the type of information that was being sought - normally to confirm decisions rather than to consider the range of options available. The internet therefore acted as a signposting mechanism in many help-seeking processes. Use of the internet emerged from the semi-structured interviews as a common theme to contextualise and explain some of the other behaviours and actions participants described. However this theme can also be traced back to the Natsal-3 data in terms of help-seeking. Several questions were asked about finding information or seeking care, of which the internet was one of the response options in the survey. Natsal-3 showed men were more likely than women to cite the internet as their main source of information for sexual matters (Tanton *et al.*, 2015) and there was low reported use of the internet for STI testing (Aicken, Estcourt, *et al.*, 2016). These results suggest the internet is not as commonly used as face-to-face engagement with healthcare professionals, but Natsal-3 was developed in 2008 and there has been significant progress in testing technologies and management via online care pathways since them (Gibbs *et al.*, 2016; Estcourt *et al.*, 2017). In addition, the questions usually asked for the first choice, preferred option or only one response but my qualitative data suggested the internet is often used in conjunction with other sources of information or methods of accessing help rather than in isolation. I also discovered some of the varied uses of the internet in relation to sexual healthcare, which may act as exploratory data to examine online behaviour, attitudes and experiences in future studies.

The internet was used for self-diagnosis in place of medical professionals as this was considered easier and immediately accessible. This reflects a common trend in healthcare with other studies noting the increased role of the internet in people's health experiences, the emergence of "Dr. Google" as a social phenomenon and the increased health literacy of patients (Gray *et al.*, 2005). I observed a blurring of

online and offline worlds, with the internet seamlessly incorporated into many different aspects of participants' lives and therefore by extension, their health and health problems. This blurring of boundaries was exemplified during several of the interviews themselves. One of my participants (i11) googled syphilis on his phone during the flash card activity to gain immediate information about the infection. He then changed the positioning of the flash cards based on the information he found. This encroachment of the internet into data collection gave him additional information and shaped the subsequent data produced, but this in itself was a finding and was one of the first things that sensitised me to this overall theme. Subsequently two other participants (i17 and i29) who did not have English as their first language used Google translate during the internet to understand the terms 'thrush' and 'chlamydia' and ensure we had a shared language about the research topic.

6.5 Conceptual links between themes

Having answered the four empirical research questions, I explored the conceptual links between them to integrate the story of this thesis and think about my results collectively, thus extending the concepts of STI stigma and social representations of infections, genito-urinary symptom experiences and help-seeking responses. I developed a conceptual diagram for exploring these links, which evolved from a linear representation, to a Venn diagram approach, to what is shown in figure 6. This figure addresses the synthesis and intersections of the empirical findings about the three main concepts of this thesis, introduced theoretically in the background literature (section 1.5 – chapter 1). Although difficult in 2D representation, I have tried to show the socio-cultural context focussing on dirt as an attribute of STI stigma that frames multi-level experiences: population patterns and individual lived experiences of sensations transforming into symptoms linked to help-seeking responses. These experiences intersect with gender, time and internet use.

Figure 6: Diagram of links between empirical concepts and intersecting themes

Legend:
- Experience - symptoms
- Experience - help-seeking
- Socio-cultural context
- Intersecting themes – gender, time and internet use

Dirt (visible and metaphorical) is an attribute of STI stigma and frames individual experiences – stigmatize unprotected sex to minimise risk of pathological and moral contagion

Population level

Women experience more GU symptoms than men

YP more likely to have been to GUM; most participants prefer GP

Individual level

Sensations are transformed into symptoms when there is sufficient concern and perceived underlying medical cause

Most participants prefer GP; Use different help-seeking strategies to seek control over symptoms and emotional reassurance

Abbreviations: GU = genito-urinary; YP = young people; GUM = genito-urinary medicine clinic

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The predominantly negative social representations of STIs and the entrenched stigma linked to the pathological and moral dirt associated with the infections, form part of the social and cultural milieu in which genito-urinary symptoms are experienced and decisions made about care needs and how to respond. The stigma surrounding STIs acts to make individuals perceive visible symptoms as dirty and disgusting and the people and behaviours associated with them as morally dirty. Individuals may become stigmatised through labelling, distancing and avoiding processes but lay interpretations and experiences of these symptoms do not often consider STIs as a potential cause. STI stigma also influences care-seeking decision-making as participants may choose not to seek formal healthcare because of fear or embarrassment, or may choose a more general service, avoiding specialist care for fear of judgement, which also causes delays in seeking care. Symptoms are more commonly experienced by women than men and the lived experience of symptoms (i.e. how painful, visible and/or emotional symptoms are) is related to the care-seeking response. If an underlying medical cause is suspected or an individual is particularly concerned about the nature of the symptom and cannot access sufficient information by themselves, they are more likely to seek care. Previous care-seeking and symptom experiences impact decisions about where to triage themselves into the healthcare system and also feeds back into social representations of infections (particularly if an STI is diagnosed) and levels of associated stigma. By seeking help, participants were seeking control and reassurance over their experience. Gender and time intersect with STI stigma, symptom interpretation and help-seeking, contextualising overall experiences for participants and the internet is entangled in these experiences as a source of information informing each stage.

6.6 Reflexivity

Reflexivity has been an implicit consideration in all chapters so far and has been woven into the design, data collection and analysis of this study. I will now discuss

explicitly the influence on my results. Despite other literature and the voices of my participants being foregrounded up until this point, my position in relation to this research (particularly the qualitative components) and influence on all aspects of the research process cannot be separated or overlooked, and it is through the principle of reflexivity that this can be made explicit. Reflexivity has been described as "*the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome*" (Berger, 2015, p. 220). I am focussing predominantly on my positioning and situatedness in relation to the research and have chosen to extend my empirical themes about visibility and hiddenness to frame this discussion.

My position (and therefore influence on the data) relates to a number of personal characteristics, attitudes and beliefs. Berger (2015) highlights the main attributes to consider including gender, race, age, sexual orientation, personal experiences (in this case of genito-urinary symptoms and help-seeking), beliefs, biases, preferences, ideologies and emotional responses to participants. Although she states that reflexivity is a multi-dimensional process and must accommodate a variety of different characteristics, Berger's discussion of 'insider' (having similar or shared experiences with participants) and 'outsider' (an 'other' or different experience to those of participants) perspectives portrays these positions as rather static which does not sufficiently capture the intersections of identity and experience. I am considering my position as a range of intersecting personal characteristics and acknowledge the fluidity of positioning as well as the impact this has on the emic-etic (or insider-outsider) balance (Eppley, 2006). By considering these characteristics in terms of visibility and hiddenness, I have employed an additional analytic lens to considerations about reflexivity. Some aspects of my position were visible to the participants and I was not able to disguise or hide them – gender was particularly conspicuous from the initial contact letter and phone call, during the interview and in relation to discussions of female and male symptoms.

My approximate age was revealed when the participant first saw me as the interviews were face to face, as was my ethnic identity as white British. Other aspects of myself could be kept hidden and I chose not to disclose much about my personal experiences of symptoms and help-seeking (although some participants inferred or assumed that I had experienced some of the symptoms and had personal experience of attending different types of healthcare services). I was careful to remain neutral and focused on participant's own views and experiences during data collection and so my own beliefs, preferences and components of identity such as sexual orientation and ideologies were not visible to them.

I used multiple approaches and strategies to embed reflexivity into all aspects of this study to ensure continual self-appraisal to recognise and take responsibility for my positionality and influence on my research (Berger, 2015). Field notes including specific reference to my emotional response to participants and how easy I had found it to build rapport with them were a vital part of data collection and provided the necessary space and structure to allow me to reflect on my positionality in relation to each interview. I used a similar format for writing these notes after each interview and included details about my feelings before, during and after the interview, the interview setting, participant reactions to certain questions including the flash card activity and any additional information from conversations before or after the audio recording. Through writing about my own feelings about each participant, I was able to identify unconscious biases and judgements I had made on meeting them (and sometimes before I had met them) and use these to critically examine my analysis of the transcript. Double coding transcripts (conducted by two of my supervisors as well as colleagues in the Kritikos Study Group at LSHTM and a more informal PhD study group) also helped me to gain different perspectives on my data. Double coding ensured a more well-rounded approach to data analysis and reduced the impact of 'me' on interpreting my data. I returned to each transcript multiple times after the first round of coding to look for different elements of the data to write up the three results papers and each time I

discovered new meanings and interpretations, helped by reading related literature for new ideas. In the future, I would expand my approach to reflexivity by taking part in entry and exit interviews to formally record my own opinions, values, beliefs, experiences and ideas about the research topic before fieldwork commenced and after the last interview had been completed. This would enable me to better engage with and reflect on the assumptions I had made and explicate specific aspects of myself that were likely to have more influence on my findings than others.

I have already considered my position in terms of visible/non-visible attributes which are particularly pertinent to data collection, but the need for reflexivity precedes and extends beyond this phase. My personal characteristics assist and hinder all aspects of the research and a thorough examination of my own values, experiences and motivations for conducting this research are important to contextualise and critique my findings. When I set out the origin of this study in chapter 1, I highlighted my experience working in the field of sexual health as well as my own personal experiences of genito-urinary symptoms as important factors in defining this work. During the course of this study, my focus shifted away from prioritising exploration of non-attendance as a concept in itself and using symptoms as an indicator of potential need, to examining the lived experiences of symptoms (although help-seeking remained an important part of the story). This shift came about because of how participants talked about the importance of their own symptoms in making help-seeking decisions and my realisation that most did not view these symptoms as those of STIs. However this echoed my own experience of some of the symptoms included in the list of responses to the Natsal-3 question about symptoms. I realised my own experiences were becoming more important in understanding the lived experiences of others and I considered how I had made sense of bodily changes and what I had done about them. I have used experiences of symptoms that have occurred during this study as a sort of informal auto-ethnography (used as a reflexive tool not a systematic method of data collection) to

understand my own feelings and behaviours and then think about how that affected my research.

My own experiences of some of the genito-urinary symptoms I was studying (and manifestations of stigma that influenced how I thought about my experiences) afforded me 'insider' status (Padgett, 2008; Berger, 2015) which tends to confer three main advantages for the research (Kacen and Chaitin, 2006; Padgett, 2008; Berger, 2015). Firstly, it is generally easier to recruit participants if they identify you as being similar to them as Berger showed in her work documenting immigration processes in New York (Berger, 2015). However I did not disclose my experiences to participants and Natsal-3 provided me with a ready-made sampling frame to recruit from, so this benefit was not realised in this study. Secondly, being an 'insider' sensitised me to themes during the interviews and throughout the analysis process particularly around alternative non-STI explanations for symptoms and help-seeking that did not include visiting a health care professional. Finally, having shared experience gave me insight into the phenomena I was researching and made me aware of the sensitivities around talking about certain symptoms (such as abnormal vaginal discharge) and the normality of fluctuations relating to menstrual cycles in women. I also became conscious of my own stigmatisation of STIs – I did not want to be diagnosed with one and distanced my experience from explanations including STIs – and therefore I was able to pick up on similar occurrences in participant accounts and probe more deeply to elicit more data which may not have happened if I was an 'outsider.' However being an insider in terms of symptom, help-seeking and stigma experiences risked "*blurring boundaries*" (Berger, 2015, p. 224) between my own experiences and those of the participants in my sample. I took care to include analytical steps that would stop me from filtering participant accounts through my own experiences and miss vital cues in the data. Although I did not use my experiences to be an 'insider' from the participants' perspectives, I noted other similarities and differences between myself and the individual taking part in the interview. Gender and age were particularly relevant for shaping my relationship

with participants and several women assumed I had very similar experiences to them in terms of sensations, symptoms and care-seeking outcomes. I also interviewed several students who were interested in research and my methods and so I ended up disclosing that this was part of my PhD work to them which helped gain their trust from the start and opened up the interview (particularly with men) as they saw the value of research and had similar experiences of education themselves. Therefore, there was fluidity across many intersecting factors and I was never completely an 'insider' even with participants I felt most similar to.

Despite my 'insider' status being fluid depending on other characteristics of participants I interviewed, I felt more of an 'outsider' when interviewing men. Some of the men I interviewed brought up my lack of lived experience of the male-specific symptoms, particularly painful testicles. The advantage of being unfamiliar with these experiences was that the participant was positioned as the expert and I approached the topic, which I was becoming increasingly knowledgeable about and comfortable with, with a fresh perspective which was incredibly useful. I used themes that emerged from interviews with men and those with STIs to interrogate my analysis of the other interviews with participants I felt more similar to, to broaden my understanding of the topic as a whole. Including men and a range of different symptom experiences prompted me to focus on diligence in my analysis, producing more robust findings instead of being strongly led by my own beliefs and values. I felt my research questions were still relevant to men as they had been designed to focus on behaviours shared by both women and men despite the asymmetry of my own experiences and the composition of my sample for the semi-structured interviews.

My fluctuating insider-outsider position revealed tensions between my involvement and detachment with the participants and the data (Berger, 2015). The knowledge produced from the semi-structured interviews was dependent on me and a product of my interaction with each participant and differed fundamentally from the

objective nature of Natsal-3 survey data. It was only through reflexive practice throughout this study that I was able to effectively appraise how I had influenced the data and in what way and fully take responsibility for my own positioning in relation to this study.

To conclude this section about reflexivity, I will briefly summarise the explicit role my positioning had on the research process overall. My interest and experience of working in sexual health and wanting to understand the phenomenon of not seeking care inspired this study. This was augmented by my own personal experiences of some of the genito-urinary symptoms being studied and sensitised me particularly to non-STI explanations of symptoms and alternative help-seeking approaches that did not include sexual health clinics. This enabled me to problematise and extend survey findings.

I already had experience of both quantitative and qualitative research including using interviews as a method and was keen to pursue a mixed methods study which shaped the study design from the outset. I also wanted to explore the use of innovative methods as part of my data collection. The multiple aspects of my positioning as a young, white British cis-woman who was a student with experience of genito-urinary symptoms and help-seeking influenced my interaction with participants with some characteristics more visible to them which influenced how much of an insider or outsider I appeared to them. My research questions, devised in collaboration with my supervisors and incorporating observed phenomena and identified gaps in the literature, necessitated a phenomenological approach and I chose thematic analysis to accommodate this whilst remaining open to other themes within the data. The additional analysis of the STI perception data using the Framework approach helped deepen my understanding and strengthen my conclusions about STI dirt. My familiarity with some aspects of the data and unfamiliarity with others served as useful analytic tools to ensure robust and diligent analysis processes through interrogating transcripts with existing themes

derived from different participants from my sample. My own experiences of some of the symptoms and my care-seeking behaviour during the study inevitably influenced data production and analysis, and were instrumental for developing my findings about sense-making. This also helped develop my understanding of the importance and onus on the individual to self-triage and the resultant outcome of self-triaging to different types of healthcare services. This discussion of the role of reflexivity in this thesis is not intended to be used as additional data (as I have not used any formal method to capture these experiences, such as auto-ethnography (Muncey, 2010). Instead, including my own experiences serves as a useful reflective tool to put my findings in context and go on to thinking critically about the implications for policy and practice (section 7.4 – chapter 7).

6.7 Reflections on using mixed methods

The purpose of mixed methods research is to bring together different types of data (normally numerical and text) to expand understandings and gain comprehensive insight into complex phenomena (Sandelowski, 2000; Tariq and Woodman, 2013; Hesse-Biber, 2015) (as described in section 2.2.1 Mixing methodologies: research theory and approaches, chapter 2). I knew there would not be perfect alignment of survey and semi-structured interview data from the start of this work but synthesising and integrating different types of data and taking a multi-analytic perspective has helped me to better understand the sense-making processes and mechanisms surrounding interpretation of symptoms and help-seeking experiences. I looked for key patterns across the different data to draw out findings that were relevant to my broad intention of contributing to a better understanding of untreated STIs and unmet sexual health needs in Britain.

Using a mixed methods study design and presenting data by concept instead of by method allowed me to 'do' different things in the two mixed methods papers in chapters 4 and 5. The symptoms results paper exemplified sequential and iterative

use of the dataset to tell the story about genito-urinary symptoms. I was not aiming to discover definitive clinical truths about the cause of symptoms (and if I had been, this would not have been an appropriate study design), instead I wanted to understand individual experiences of symptoms. My semi-structured interview data about symptoms problematised the findings about STI symptoms from Natsal-3. There were a wide range of influences on participants' symptom experiences, which contrasted sharply with the biomedical lens used by the Natsal-3 team. The survey question: *"In the last month, that is since (date one month ago), have you had any of the following symptoms,"* (Natsal-3, 2013) was devised to understand symptoms of STIs and bacterial vaginosis in the population (personal communication with Dr. Nigel Field, UCL, 16.11.16). There was no real consideration for other causes of these symptoms, or an unpicking of what constitutes the concept of a symptom due to the post-positivist perspective of Natsal-3 and the need to generate robust population statistics about a range of sexual health issues. Whilst I cannot criticise Natsal-3 for this approach, using mixed methods allows for this unpicking to some extent using a different perspective and may help inform the design of Natsal-4.

Initially, the survey and semi-structured interview data appeared to show complementarity – both providing different types of data (reported recent prevalence and lived experiences) about symptoms, albeit at different time points. However as my analysis of the interview transcripts progressed, I realised most of my participants' interpretations of their experiences did not include STIs as a possible cause but Natsal-3 had assumed people were reporting STI symptoms. This prompted me to conduct additional analyses of the survey data to look at the presence of STIs in urine in participants who had reported symptoms, and consider individuals' perceived risk of STIs, which added an extra dimension to the exploration of symptoms which I may not have included otherwise. The dissonance revealed by comparing participant accounts to Natsal-3 responses highlighted problems in using that question to assess the prevalence of STI symptoms; symptoms may have been under-reported if individuals had not interpreted their

experience as being a symptom asked about in the survey. Investigating genito-urinary symptoms using mixed methods revealed the different ways a survey and a semi-structured interview made sense of the same concept because of the underlying difference in perspective, epistemology, assumptions and method of generating data.

In the help-seeking responses paper (chapter 5), using a mixed methods approach was designed to extend survey findings about care-seeking behaviour and connect (Fetters, Curry and Creswell, 2013a) them to participant accounts about decisions to seek care. Natsal-3 had only asked about attendance at sexual health clinics (ever and during various periods of time – in the past year, past five years etc.) and because it was a cross-sectional survey, could not capture the chronology of events or what individuals chose to do next. I was aware at the start of my PhD research that I would need to explore other possible care pathways (despite my early assumptions about non-attendance being a neat and well-defined category). For this paper, semi-structured interviews served to fill in the gaps about which healthcare services were accessed, when and why, as well as give contextualised accounts linking symptoms to care-seeking responses over time. Comparing the Natsal-3 full responses of the 27 participants who also took part in an interview revealed some discrepancies. These occurred because of changes in behaviour over time (for example, attending a sexual health clinic at a later stage) but there were also cases of mis-reporting (for example participants stating they had never attended a sexual health clinic in Natsal-3 but revealing they had previously been when their attendance history was explored in the follow-up interview). Integration exposed confusion and conflation of terminology, with some individuals viewing all interactions with a doctor or other health care professional as the same, regardless of the setting they took place in and others not being able to differentiate between contraception services and infection testing as they regarded it all as sexual health. Findings about service preferences showed agreement when comparing survey and interview data, strengthening conclusions about the GP being the preferred point of

access in the healthcare system (unless a person had already attended a specialist sexual health clinic).

Therefore, by using both survey and semi-structured interview data I have accessed the concepts of symptoms and care-seeking from different perspectives and generated different findings about each, but it was only through integration of these findings that the true value of my mixed methods study design was realised.

My reflections on the tools I have used for integration (section 6.2), and the functions and uses of a mixed methods approach discussed above to examine the concepts of symptoms and care-seeking responses, have alluded to an answer for the fifth, mixed methods research question of this thesis. In the first chapter, I posed the question: *to what extent can survey and semi-structured interview data be integrated to explain, contextualise and extend findings about genito-urinary symptoms and care-seeking responses?* To summarise, I have used matrices and joint displays to present, compare and identify patterns within the data about symptoms and care-seeking responses. Stigma and social representations were explored using data from the semi-structured interviews only, due to the absence of an appropriate quantitative stigma measure and my wish to use linked data (from the same participants) throughout this study. Integration of data enabled me to explain discrepancies in reported symptom patterns between women and men and the high prevalence of non-attendance at sexual health clinics. Explanations provided the context and individual lived experiences behind the survey responses which 'flattened' these experiences into numerical format for quantitative comparison. Contextualised findings about care-seeking decisions were essential to understand that not seeking care, or not seeking the most clinically appropriate care was a rational response for individuals based on the meanings they had attributed to their experiences and their requirements to regain control of their bodies. However, participant's reasoning was best understood within a broader pattern of behaviour (such as not attending a sexual health clinic), providing the

population context in which individual behaviours could be understood. Finally, integration served to extend findings about care-seeking behaviour not captured by Natsal-3, exploring alternative pathways into the health system, preferences about care providers and the chronology of responding to genito-urinary symptoms. Integration of findings also lead to identifying different variables to analyse in Natsal-3 from themes emerging from analysis of interview transcripts (for example, examining STI risk perception and the role of relationships in symptom reporting). Integrating data also sensitised me to potential thematic relationships and hierarchies in the interview data (such as alternative explanations for symptoms and sources of information to make sense of experiences) based on results from survey analyses. This iterative process of re-examination of each dataset lead to additional insights which may not have been achieved by other means. Therefore, integrating data about symptoms and care-seeking revealed areas of complementarity, agreement, dissonance and helped overcome silences in the survey data and served to deepen understanding and strengthen the implications and conclusions from this work. Additionally, by integrating survey and interview data, as far as the parameters of each data source allows, I have shown how different methods make sense of the same concepts in different ways. This lead to the problematisation of taken-for-granted assumptions about core concepts (e.g. what is a symptom?) Consequently, I was able to reflect on the nature of the data collected, which constitutes an additional function of integration for this thesis.

6.8 Chapter Summary

I have brought together the empirical findings from survey and semi-structured interview analyses, integrating them to answer my research questions and incorporating mixed methods tools including matrices and joint displays to facilitate data integration. Although this is an empirically oriented study, I was keen to learn and incorporate mixed methods research theory into my work and by doing so contribute to the progression of knowledge and ideas about integrating different

types of data. I presented gender, time and use of the internet as intersecting themes in this study and brought myself into discussion of this work by including discussion of reflexivity. These themes feature in the diagram I included to visually collate and explore connections between different concepts. This diagram summarises the main argument of my thesis: STI dirt frames lived experiences of symptoms and help-seeking responses. This argument is further refined and contextualised in the literature about STI stigma, symptoms and care-seeking in the following chapter where I also consider the main implications of this work.

CHAPTER 7 DISCUSSION, IMPLICATIONS AND CONCLUSIONS

7.1 Chapter Overview

This thesis aimed to understand how perceptions and social representations of STIs, particularly STI stigma influenced experiences of genito-urinary symptoms and help-seeking responses in a British context using a mixed methods approach. In this study, I asked specific research questions about social representations of STIs, the role of stigma, interpretations of symptoms and attendance patterns at sexual health clinics. So far I have presented and critically reflected on the background literature, the methodology and three empirical chapters comprising research papers using data generated from survey analyses and semi-structured interviews and subsequent discussion of each paper. I presented answers to the four research questions separately and then described the conceptual links between the core ideas and intersecting themes in the previous chapter to add empirical weight to the theoretical platform established in the background literature (section 1.5 and paper introductions). Here I focus on summarising the empirical, methodological and theoretical contributions of this study, the main limitations and implications in terms of public health practice, policy and future research before finishing with the overall conclusion.

7.2 Summary of findings

The study of STIs, stigma, symptoms and help-seeking behaviours are not new areas of research in themselves, as much progress has been made already in conceptualising these subjects and defining terms and parameters of each. Attendance at sexual health clinics has increased over the past decade and progress has been made in targeting services to those at highest risk of infection (Sonnenberg *et al.*, 2013) and reducing undiagnosed infection. Widening service provision to non-specialist settings (Department of Health, 2001; Medical

Foundation for Aids & Sexual Health, 2008) including online care pathways (SH:24, 2016; Estcourt *et al.*, 2017) and implementing national screening programmes (Public Health England, 2013) has further helped mitigate unmet sexual health needs. However not all STIs are presented to services, not all symptoms are caused by STIs but nonetheless may require intervention from healthcare professionals to maintain good sexual health and wellbeing. However, severe funding cuts to public health budgets and to sexual healthcare in particular (Robertson *et al.*, 2017a), combined with pervasive stigma related to STIs (Hood and Friedman, 2011), increases the challenge for individuals and healthcare professionals of attaining and maintaining good sexual health in 2017. This is the context in which the findings from this thesis are situated. In the following sub-sections, I summarise the original empirical, methodological and theoretical contributions that this study makes.

7.2.1   Empirical contributions

The core argument of this thesis is that STI dirt frames individual experiences and interpretations of genito-urinary symptoms and influences subsequent responses in relation to seeking help and healthcare. I characterised two dimensions of dirt – physical and moral, which were often conflated and described together in participant accounts. I determined the prevalence of genito-urinary symptoms in women and men in Britain from Natsal-3 data and then problematised conceptualisations and interpretations of genito-urinary symptoms. From analyses of my semi-structured interview data, I suggested a symptom is a sensation that causes concern and is perceived to have a medical cause. I also discovered a high prevalence of non-attendance at specialist sexual healthcare and preferences for STI care provided by the GP among symptomatic women and men. The four help-seeking pathways described by participants in response to symptoms were not novel findings in themselves, but my interpretation of these as seeking control and reassurance over their bodily experiences helps to extend understanding of healthcare-seeking behaviour in a sexual health context.

7.2.2 Methodological contributions

The main methodological contribution this study makes is the development of the flash card activity as a method to investigate perceptions of STIs. Whilst the inclusion of flash cards in social science research is not a new technique, the application of this approach to studying STIs is novel, as recognised by publishing the description of the activity as a methodological paper.

Conducting a mixed methods study with a quantitative component that allows for broadly generalisable results to the population and a qualitative component following up the same participants is not commonly undertaken. I took the opportunity of using Natsal-3 data in this way within the parameters of data governance and data usage agreements and so this study can be considered an example of adding value to large scale survey data through linked explanatory qualitative data.

7.2.3 Theoretical contributions

Although this thesis is empirically oriented, developing the Cause-Concern Cycle through inductive analysis of my semi-structured interview data constitutes a contribution to theory. I have used the model to help explain how my participants made sense of their bodily changes and attributed meaning to the experience and this general concept may be relevant for other sense-making processes about symptoms for other health conditions.

7.3 Limitations of this study

I have already discussed the strengths and limitations of the study design and methods in the discussion section of each of the three results papers (chapters 3-5)

but now bring together the limitations of the study to consider collectively. I also used the Mixed Methods Appraisal Tool (MMAT) (Pace *et al.*, 2012) to assess methodological quality and the assessment of each research component and the Good Reporting of A Mixed Methods Study (GRAMMS) (O'Cathain, Murphy and Nicholl, 2008) to consider how I have reported this study (see appendix M, p.356 for completed tables). From the MMAT appraisal, this study is limited by the response rate of 57% for Natsal-3. This is in line with declining response rates in other social surveys (de Leeuw and de Heer, 2002; Williams *et al.*, 2016).

Most of the other limitations of this study stem from using Natsal-3 for secondary data analysis so the questions were not designed specifically for this study and the timing of Natsal-3 in relation to the time period of this study was not optimal. The time frame of my two key variables – reported symptoms and reported previous attendance at a sexual health clinic did not match, as the Natsal-3 questions asked about the past month and the past year respectively. This made it more challenging to quantitatively assess the relationship between symptoms and help-seeking. The delay of 22 - 44 months between survey and semi-structured interview data collection had a big impact on the choice of participants I could recruit due to high levels of attrition and participants not being contactable by the means available to me (phone and writing a letter to their home address). Given that they had already agreed to take part in one round of data collection, be re-contacted and then participate in a second data collection phase, the participants I interviewed are likely to differ from those who refused to participate in either the survey or interview. Natsal-3 was cross-sectional offering a snap shot of one point in time and did not ask about care-seeking to other types of sexual health services (other than specialist clinics) which would have been advantageous for this study. The sampling strategy I chose to recruit participants for the semi-structured follow-up interviews was based on initial assumptions about the phenomena I was investigating. I chose people with symptoms as an indicator of potential STIs and possible need for care, and restricted my sample to those who had reported never attending a sexual

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health clinic to specifically examine non-attendance behaviour. This may have restricted the exploration of the breadth of help-seeking pathways in response to genito-urinary symptoms. Sampling may also account for some of the discrepancies in the survey and semi-structured interview data, for example, differences in perceived risk of STIs; those who thought they might have an STI or be at risk of STIs may also be more likely to have attended a sexual health clinic.

Finally the sexual health framing of this study and data collection and analysis in particular, may have primed participants to give a particular type of account (in both the survey and interviews) which might have affected the nature of their responses and the data produced.

I found terminology particularly problematic in this study and some of the terms I have used may be interpreted differently in different settings. I have used 'genito-urinary symptom' to encompass everything from a fleeting sensation, potential STIs and symptoms of other health problems; this enabled me to concisely convey the group of health issue of this thesis, although my findings about how individuals interpret what a symptom is (chapter 4) show that this is not accurate for all experiences. Before starting this work I knew (from my own experiences as well as the literature) that not all bodily sensations were symptoms, not all genito-urinary symptoms were caused by STIs and not all STIs produced symptoms. However, for ease of communication beyond the field of public health I have described the health issue I am studying as 'STI symptoms.' I have shifted from using the term care-seeking to help-seeking in response to my findings to encompass a wider range of responses to genito-urinary symptoms. I think these areas of tension give some insight into where the field of public health and addressing unmet need is going over the next few years. As Scott and Walter (2010) have already pointed out, consensus on definitions of help-seeking is essential to move forwards, refine models and improve understanding of attendance and delay behaviour and similar work needs to be done in relation to symptoms. Stigma is a well-established and

defined term so this has been less problematic to use but the distinction between STI-specific stigma and other more general forms of stigma is still blurred.

Based on the main weaknesses of this study, there are several things I would do differently in a similar future study. I would align the timing of survey and semi-structured data collection to reduce the time in between. This might help capture the same symptom experiences using different methods and minimise the issues in contacting participants and non-response rates that influenced this study. I would try to find data where the key time periods within questions matched (e.g. both symptoms and help-seeking reported in the past month). Investing more time conducting preliminary analyses of the survey data before starting follow-up semi-structured interviews would enable a better understanding of population patterns and allow for more precise sampling for the interviews to explore and explain specific survey data. For example, it would have been interesting to sample participants who perceived themselves to be at risk of STIs and who also reported symptoms (from survey data presented in the symptoms results paper, chapter 4) but time constraints prevented this approach for this study. Not including the additional inclusion criteria of never having attended a sexual health clinic would have increased my sampling frame and may have facilitated more exploration of both symptom and help-seeking experiences. Finally, with more experience of qualitative analysis, I would choose my analysis method in the design stage of the study to facilitate data analysis processes.

7.4 Implications of my findings

Having summarised this thesis and discussed the limitations of the study in this chapter so far, I move on to consider the bigger public health questions and how my results can inform public health practice, policy and future research. This study developed from an intention to improve understandings of, and approaches to address unmet sexual health needs, specifically thinking about reducing untreated

STIs by exploring STI stigma, symptom experiences and help-seeking responses. The following implications suggest relevant applications of my findings, whilst remaining grounded in my data and acknowledging the limitations of this study.

7.4.1 Implications for public health practice

There is no easy approach to reducing untreated STIs and a combination of evidence-based health promotion interventions and clinical service improvements are likely to have the greatest effect. As I noted in the debate paper in chapter 1, Britain has some of the best STI surveillance and open access healthcare provision already in place; the barriers to sexual healthcare are predominantly social and this study examines what happens to individuals and population patterns before they attend healthcare (if they do at all). Here I discuss four public health implications from my findings: dirt as a novel intervention target for sexual health promotion; maintenance of accurate information sources; support for existing service provision options; localised service and healthcare professional practice to align clinical and experiential priorities.

7.4.1.1 Dirt as a novel intervention target for sexual health promotion

It is overly simplistic to recommend a single public health campaign to increase awareness of potential causes of genito-urinary symptoms and encourage attendance at healthcare. As not all symptoms are caused by STIs (and many STIs are asymptomatic anyway) or require medical attention, this type of approach is likely to have deleterious effects on the health system with an increase of unnecessary attendances and very few undiagnosed STIs treated. This is not in line with current policy as potential service users who are not deemed to be complex, high-risk cases, are being diverted away from sexual health clinics into primary care or online care pathways. Encouraging help-seeking at a lower threshold (i.e. the emergence of non-specific symptoms with no other risk factors) will most likely result in healthcare professionals having to work harder to separate the 'signal' i.e.

clinically relevant signs from the 'noise' of personal experiences of normal physiology. For example, the "Don't Die of Ignorance campaign" to increase awareness of AIDS in 1987 increased attendances at GUM clinics of the worried well who did not require treatments (Nicoll *et al.*, 2001). There has already been a wealth of health promotion campaigns to encourage STI testing in the population (for example the "Chlamydia. Worth talking about" mass media campaign in 2010 aiming to increase the proportion of 15-24 year olds having a chlamydia test in NCSP). An interview-based evaluation of the campaign showed increased awareness of testing for chlamydia after the campaign compared to before (COI Research Management Summary on behalf of the Department of Health, 2011) and a time series analysis found no change in overall testing coverage but increased positivity rate suggesting normalising testing had helped target high-risk individuals (Gobin *et al.*, 2013). As not all symptoms examined in this study are caused by STIs, these do not relate well to this thesis.

Public health campaigns have been known to have paradoxical effects and negative unintended consequences on individuals and the public (Bonell *et al.*, 2014) and the seduction of recommending a 'magic bullet' as a solution could end up further stigmatising STIs, symptoms or help-seeking. However, whilst a general health campaign or educational intervention may not be suitable to address untreated STIs, developing an intervention based on my finding that dirt is a common social representation of STIs and related to STI stigma may provide additional leverage for this issue. Clearly more formative work and intervention development would be necessary to harness dirt as a useful target of interventions. This could be modelled on similar work by Biran et al. (2014) who developed interventions which used emotional motivators such as feelings of disgust and nurture rather than explicit health messaging to improve hand-washing and hygiene behaviour in rural India. This approach showed an increase of 31% of handwashing with soap six months after the campaign was rolled out (Ibid). Therefore an intervention based on my findings, focussing on getting rid of dirt instead of testing and treating STIs or

seeking healthcare may provide a new perspective to reduce STI stigma and untreated infections. In turn, a socially situated sexual health promotion intervention may contribute to broader de-stigmatisation efforts and reduced unmet need for sexual healthcare, by enabling individuals to manage and improve their health (World Health Organization, 2017).

My finding that STIs are considered dirty also has implications for classifying newly discovered pathogens as STIs. For example, there has been much debate in the past few years about *Mycoplasma genitalium* and whether it is a putative or confirmed STI. MG has been shown to be sexually transmissible (Hjorth *et al.*, 2006; Ma *et al.*, 2008), is associated with behavioural risk factors for other STIs in the British population and epidemiological evidence increasingly supports the view that it is a confirmed STI (Sonnenberg *et al.*, 2015b). However studies about MG have almost exclusively focused on the microbiology and epidemiology. Little thought has been given to the social implications of categorising it as an STI and the impact this may have on those diagnosed with the infection. The label of STI is likely to automatically transfer meaning and stigma (and may characterise MG as dirty). STI categorisation enables useful biomedical groupings of infections based on routes of transmission, enabling services to become specialised in managing the same types of health issues. However, social understandings of these infections and group characteristics are also important to understand to mitigate unintended consequences on individuals diagnosed with these infections. Categorising infections as STIs represents another example of biomedically informed decision making and service provision and lack of research about the social consequences.

7.4.1.2   Maintenance of accurate information sources

The second implication my findings have for public health practice relates to providing and signposting to and from accurate sources of information to improve opportunities for health education. I showed that accessing information from the internet was a key component of sense-making about symptoms and sensations

(through the Cause-Concern Cycle – described in the symptoms results paper), facilitating the interpretation of experiences. The internet was also a valued resource to self-diagnose, self-treat and find information about different types and location of services, helping improve access to healthcare and triaging to the most effective service. The NHS is a trusted brand and the NHS Choices website (NHS Choices, 2017) and or NHS symptom checker (NHS Choices, 2014) were mentioned explicitly by several participants. Maintaining relevant and accurate information about STIs as well as other genito-urinary infections, diseases and conditions through NHS web pages is essential to support the range of help-seeking behaviours observed within my data. Better general health education about STI symptoms and related health issues would be beneficial to improving health literacy about genito-urinary health and may reduce some of the negative emotional responses to symptoms found in this study. Specific, local information about what to expect when visiting a particular service is also useful to improve familiarity and allay anxiety about attending a specialist sexual health clinic. From my finding that the lived experience of others is important for participants to interpret and respond to symptoms, another implication relating to information provision is signposting directly from internet forums to NHS choices and/or local services. Strengthening links between other internet sites and NHS sites as well as offline healthcare services may help improve access to care and provide faster treatment. However this is still reliant on individuals' own interpretations of their experience.

7.4.1.3 Support for existing service provision options

My findings support the changes and improvements to sexual heath provision that have been implemented since 2001 (Department of Health, 2001) particularly around integrated services and more recent innovations such as self-sampling and self-testing. An integrated model of sexual health service provision is designed to *"improve sexual health by providing easy access to services through open access 'one stop shops', where the majority of sexual health and contraceptive needs can*

be met at one site, usually by one health professional, in services with extended opening hours and accessible locations" (Parmar and on behalf of the Department of health, 2013, p. 6). Knowing that women report more symptoms than men (symptoms paper, chapter 4) and report a greater number of opportunities to access healthcare for other things such as contraception, smear tests, menstruation issues (help-seeking paper, chapter 5), integrated services are well suited to address a range of women's care needs. This means that even if care is not being actively sought for symptoms, engagement with services who can provide STI testing and treatment will help reduce unmet sexual health needs based on the needs identified from the clinical consultation. Integrated services provide an alternative to the GP for men as well, and the more general healthcare remit helps keep the specific care need private until individuals see a healthcare professional. However partially integrated HIV services have been shown to increase felt stigma (Church *et al.*, 2013) and so service design and implementation is crucial to realising the benefits of integrating healthcare.

By taking a more holistic view of the patient, care needs are more likely to be met (Cook, 2017). The onus is on health care professionals to diagnose health issues rather than individuals having to create their own pathway to enable them to regain control over their bodies, triaging themselves into appropriate services until they feel this goal has been achieved. Physical examinations are important as individual interpretations of sensations and symptoms may be different to biomedically informed clinical signs. Sexual health clinics seeing self-reported asymptomatic patients, often find symptoms on examination highlighting the discrepancy in meanings and interpretations of bodily changes (personal communication with Ceri Evans, Chelsea and Westminster Hospital NHS Foundation Trust, 20.06.2017). Integrated care should enable more efficient transfer of patients within the healthcare system to resolve issues; if STI tests come back negative, there should be referral pathways in place to address other possible causes such as sexual function problems, UTIs, side effects of hormonal contraception or other

medication, and cancer. Given the breadth of help-seeking responses that did not involve accessing medical health care settings in this study, my findings support recent innovations in the provision of self-sampling (SH:24, 2016), self-testing (Napierala Mavedzenge, Baggaley and Corbett, 2013; Pant Pai *et al.*, 2013) and online care pathways (Estcourt *et al.*, 2017). Testing outside of formal clinical environments helps broaden the scope of help-seeking options and extends the boundaries of service provision beyond the physical clinical service environment. These methods may be used as a 'quick check' to eliminate or confirm STIs as a cause and lead on to other care-seeking using the information provided by test results (triaged to an appropriate clinical service for treatment or diverted to other care pathways). However, they do not provide comprehensive sexual healthcare and have yet to be fully evaluated. As symptoms are only part of the story of unmet need, screening approaches based on risk factors for STIs are still a central component of the range of options to address untreated STIs. In Britain STI screening targets high risk groups including people aged 25 and under, men who have sex with men and Black African ethnicities (Sonnenberg *et al.*, 2013). Screening reduces the need to self-triage to an appropriate care service and often takes place through outreach, removing the 'clinical-ness' of the testing experience by taking place in a range of social and community venues such as churches, bars, clubs and supermarket car parks. Combining evidence-based or theoretically informed approaches to respond effectively to symptoms alongside existing screening programmes and risk-based strategies is likely to result in the greatest impact on untreated STIs and improving unmet sexual health needs.

7.4.1.4 Localised service and healthcare professional practice to align clinical and experiential priorities

Finally my data suggest that specific, local improvements to key issues such as making the waiting room of sexual health clinics easier to negotiate may be beneficial and contribute to improved experiences at sexual health clinics, in turn making them more accessible for future attendances. For example, 56 Dean Street

considered patient experience when designing and commissioning their clinic services, providing Starbucks coffee and mini massages in their clinic waiting room. Burrell Street clinic has a buzzer system whereby patients receive a buzzer when they register which alerts them when it is time for their appointment, leaving them free to leave the clinic in the meantime. Healthcare professionals should consider re-framing their approach to a clinical consultation and focus on helping individuals achieve control (as defined by the individual) over their symptoms, prioritising the provision of emotional support and reassurance in conjunction with medical diagnosis and treatment. This approach would better align clinical and experiential priorities and reduce repeat attendances for the same issue that the patient feels has not been resolved. Healthcare professionals should also be aware of the link between symptoms, STIs and dirt and avoid language that reinforces physical, moral or hygiene dirt.

7.4.2 Implications for policy

Policies governing sexual health care provision shape sexual healthcare in practice. These findings have implications for two key policies related to sexual healthcare: they show support for the broadening of sexual healthcare provision beyond specialist services and highlight the misalignment of clinical and lay interpretations of symptoms which affects care pathways and the management of patients within services.

7.4.2.1 Support for broadening sexual healthcare provision

The national strategy for sexual health and HIV (Department of Health, 2001) recommended shifting uncomplicated sexual healthcare from specialist to primary care to help reduce undiagnosed STIs and HIV and reduce stigma associated with STIs and HIV. It aimed to integrate sexual health services to deliver more comprehensive care to patients and emphasise the importance of GUM clinics being open access.

Both the survey and interview findings showed general practice as the preferred choice for participants, and a range of approaches to help-seeking, which provides good evidence in support of broadening the delivery of sexual healthcare. Although this study examined individual views about their care needs and service options, high quality provision was important – participants emphasised they wanted healthcare professionals to be experienced, knowledgeable, take their concerns seriously and not treat genito-urinary symptoms differently to other health conditions. This suggests continued training and professional development is important for those working outside of specialist sexual health care services, as well as sufficient funding, links to local specialist services and other resources as necessary to ensure high quality care provision and prevent mismanagement of sexual health needs. However there is increasing pressure on GPs and primary care with an increasing workload that has not been matched by increased funding or work force (Baird *et al.*, 2016). Therefore, a key policy consideration is how to balance user preference for sexual healthcare in general practice with diminishing resources.

Despite the success of GP involvement in sexual healthcare provision, it is still vital to retain open access specialist services as one of the menu of service choices and a hub of specialised skills for complex care needs. Policies about sexual health should also focus on further normalising regular STI testing for everyone (although cost effectiveness should be taken in to consideration depending on the demographic profile of the local population). By encouraging sexual health check-ups from sexual debut in much the same way as going for sight tests or for dental check-ups, regular engagement with sexual health services is developed which should help identify potential issues earlier and test and treat for infections thereby reducing untreated STIs and unmet sexual health needs. However, I acknowledge that this is unlikely to be feasible or practical for services. My findings show that previous attendance at a sexual health clinic was associated with preference for the same specialist care again for future STI care needs suggesting familiarity is important for sexual

healthcare. However, as current policies (Department of Health, 2001; Independent Advisory Group on Sexual Health and HIV by Medical Foundation for AIDS and Sexual Health, 2008) are gradually pushing specialist sexual healthcare to prioritise complex, high-risk individuals and divert more simple care needs to primary care or online pathways, there is a risk that services will become less integrated and potentially more stigmatised. If specialist services become less integrated and more focussed on treating STIs, some service users may be deterred and service choice becomes restricted once again.

Long-term vision and strategy approaches are needed considering how changes in one part of the health system will affect service provision in other areas (not just in sexual health) to ensure high quality sexual healthcare is sustainable and continued progress can be made in all aspects of sexual health and wellbeing. I have shown that service choice is important and valued by patients for sexual and related health needs. Policies are needed to preserve and extend care provision beyond the boundaries of what has historically constituted a clinical service and prioritise integrated healthcare that advocates for patient needs alongside effective biomedical treatment.

7.4.2.2 Misalignment of clinical and lay interpretations of symptoms and associated care pathways

My findings highlighted differences in interpretations of symptoms and that lay individuals only made sense of sensations as being symptoms if they caused them concern and a medical cause was suspected. There may be some under-reporting of symptoms when individuals present to services and during sexual history taking because patients have made sense of sensations that would be considered symptoms in biomedical terms, using alternative explanatory frameworks. This misalignment of clinical and lay interpretations has implications for patient care and care pathways, especially as some services are shifting asymptomatic patients to online care pathways including self-sampling away from the clinic. This removes the

possibility of a physical examination to check for complicated infection and decide if there are any clinically indicated signs of infection or other causes of sexual ill health which may indicate other tests are needed (personal communication with Dr. Jo Gibbs, UCL, 18.07.17). Clarification within the BASHH standards for the management of STIs (British Association of Sexual Health and HIV, 2010) about what is meant by symptomatic and asymptomatic service users would help bring greater awareness of different interpretations of symptoms to healthcare professionals. A focus on physical sensations and clinically indicated signs may be more useful than asking patients about symptoms. Scope to easily move asymptomatic patients onto a care pathway to manage symptoms will ensure appropriate testing and treatment is carried out.

A mystery shopper study showed inequalities in accessing GUM clinics with a decline in the proportion of symptomatic patients who were offered an appointment within 48 hours in 2015 compared to 2014 (Foley *et al.*, 2017). The decline was greatest for women. However, the same study highlighted the increase in asymptomatic patients offered appointments within 48 hours from 50.7% in 2014 to 74.5% in 2015 (Ibid). These are promising results, however many services have since closed, amalgamated, reduced clinics and/or shifted asymptomatic patients to online care pathways due to funding cuts to public health budgets (Robertson *et al.*, 2017b), reducing opportunities for face-to-face consultations with a physical examination if required. A recent systematic review of return on investment for public health interventions (including anti-stigma campaigns and expanded HIV testing) concluded that cuts to public health budgets were a false economy as they would incur billions of pounds of additional costs to health services and the wider economy (Masters *et al.*, 2017). New policies for sexual healthcare provision are therefore needed to respond to reductions in available funding and ensure safe, effective and high quality service provision is maintained for patients who may not interpret their experiences as being symptoms related to sexual health needs.

7.4.2.3 Mapping my findings to other policies and recommendations

This thesis also maps on to three key areas within the Framework for Sexual Health Improvement in England (Department of Health, 2013), the latest national strategy document for sexual health provision. These are: tackling sexual illness related stigma; continuing to reduce STI prevalence through evidence-based preventative interventions and treatment initiatives; and promoting integration, quality, value for money and innovation in the development of sexual health interventions and services. Facilitating rapid access to high quality services is a key objective within the framework to improve individual and public health and mitigates unmet need. My thesis takes a step back from this end goal to consider other factors mediating interpretation of care needs and decisions about help-seeking, integrating population prevalence estimates with individual lived experiences.

Public Health England have also made recommendations about STI care based on their annual report detailing STI surveillance data (Public Health England, 2017a). These mostly focus on risk factors for STIs but promote screening as a tool to detect asymptomatic infections (or infections where symptoms have not been interpreted as such or not been sufficiently concerning to trigger care-seeking). They also recommend ensuring open access to sexual health services in line with previous policy (Department of Health, 2001). My findings support this recommendation to reduce additional barriers to attending services, although most people who had not used a specialist service did not perceive a personal care need that would warrant attendance. Additional work may be needed to raise awareness of the range of services on offer and information to help individuals triage themselves into the most appropriate place in the health system to further mitigate unmet sexual healthcare needs and untreated infections. Sexual health clinics were also more commonly used by younger participants in this study than by older participants. Whilst this is promising, as STI risk factors tend to cluster in younger age groups, this may be to the detriment of service provision to some population groups.

7.4.3 Implications for future research

This study achieved its aim of exploring how social understandings of STIs influenced lived experiences of genito-urinary symptoms and help-seeking responses, focussing on non-attendance to address untreated STIs as a public health issue. By conducting this study, I became aware of several empirical unanswered questions and potential areas for future research to expand understanding of stigma, symptoms and help-seeking as well as potential next steps for methodological advancements, and implications for Natsal-4 and similar population surveys of sexual health and wellbeing.

7.4.3.1 Future empirical research

Firstly, I explored lived experiences of stigma in response to calls to individualise stigma and health research (Link and Phelan, 2001; Liebenberg, 2009) to understand how STI stigma influenced symptom experiences and help-seeking responses. The next logical step would be to understand how dirt relates to conceptualisations of stigma as a social process operating in conjunction with power and culture structures (Parker and Aggleton, 2003; Link and Phelan, 2014). Secondly, a more comprehensive analysis linking experiential data about genito-urinary symptoms, underlying causes (from diagnostic tests and linking data within medical records) and health outcomes would facilitate exploration of the experience as a whole and how individuals manage and if and when they engage with healthcare. A cohort study recruiting and following up with people representative of the British population over the course of a year or longer would provide valuable insights into how genital health interacts with daily realities, healthcare and sexual health and wellbeing more generally than this study was able to determine. Finally, my findings about help-seeking responses indicate the need for a more inclusive definition of help-seeking for sexual health which is less patient-centric and encompasses behaviours and care pathways that do not result in attendance at a healthcare service. However consideration should be given to

whether improving definitions is a wider issue within health services research and instead of developing a sexual-health specific definition, work towards gaining consensus across different areas of health research as proposed by Scott and Walter (2010). This is the main reason I have not proposed a new definition for help-seeking as this would just add another way of describing a specific set of processes and actions to the literature rather than building on a broader synthesis of some of the key gaps in literature about help, health and care-seeking to create a bigger impact.

7.4.3.2 Natsal-4 development

This work also has methodological implications for Natsal-4, expanding the flash card activity as an image elicitation method and in terms of archiving and re-using my semi-structured interview data again in the future. My findings about symptoms have shown the variation in interpreting what this means in relation to sexual health. Labelling a group of sensations affecting genital health as a symptom may have influenced how Natsal participants answered this question. Including a similar question about symptoms in Natsal-4 should be given careful consideration. The response options given in Natsal-3 were non-specific, framed in terms of sexual health and therefore associated with STIs more than other potential causes, however the exact relationship between STIs and symptoms is unclear. The wording of some of the symptoms listed was misinterpreted by some of my interview participants. Several mentioned that 'lump' to them meant cancer implying this word had its own meaning independent of the context of genito-urinary symptoms. 'Sore' was interpreted as feeling a bit sore generally rather than the presence of a specific sore or ulcer on the genitals and abdominal pain was often understood as a symptom of stomach ache or indigestion. Whilst I did not set out to cognitively test Natsal-3 questions as part of my interviews, I gained useful insight into how participants may have interpreted different questions resulting in potential discrepancies in what Natsal-3 intended to measure and what participants reported. Themes relating to use of the internet that emerged from my findings

may be useful exploratory data to inform question wording or future studies about the relationship of the internet and sexual health issues. Natsal-3 did not include many questions about use of the internet as a result of the time period in which the survey was developed. However the subsequent proliferation of uses and ways of engaging with the internet needs to be understood, measured and addressed in Natsal-4 to ensure a true reflection of social and sexual attitudes and lifestyles. Another expansion of Natsal-4 questions (if there is sufficient space) would be to ask participants what the suspected cause of their symptoms was. A set of responses could be developed from my interview data in conjunction with other studies (Low *et al.*, 2015b; Tomas *et al.*, 2015). Examination of other care pathways and measuring the prevalence of attendance at different types of services outside of sexual health clinics is an important finding from this study that should be included in Natsal-4, especially given the current emphasis on sexual health provision in primary care. Additional formative research is likely to be needed to develop a comprehensive set of questions around symptom experience and care-seeking as well as cognitive testing and piloting of survey questions, but this work will act as a starting point. Asking about sex and gender must be improved for Natsal-4 and other similar surveys to ensure accuracy and precision in reporting findings. There are several examples of best practice for asking questions about sex and gender (for example (Carrotte *et al.*, 2016)) and it is important to include more than a binary categorisation of gender to understand sexual health and care needs for the whole of the British population. Findings in relation to symptom experiences in particular are likely to be very different for a trans population and for non-binary individuals.

7.4.3.3   Additional research avenues

There is potential to further develop the flash card activity as an image elicitation method to produce data about STIs and other sensitive topics, as I suggested in the conclusion of the flash card paper. Methodological investigations of different content and format of using the flash cards would generate an improved

understanding of the method and learning from visual methods theory could help expand approaches to analysis of the verbal and visual data.

7.5 Conclusion

This mixed methods study aimed to understand how social understandings of STIs and stigma influenced experiences of genito-urinary symptoms and help-seeking in the British population. In particular, I focused on examining non-attendance at healthcare services by women and men. Analysing and integrating survey and semi-structured interview data has provided multi-dimensional accounts of these phenomena suggesting that STIs are characterised by physical and moral dirt which is related to STI stigma and frames related experiences. Symptoms are perceived to be physical dirt, however sensations are only interpreted as symptoms if they cause concern and an underlying medical cause is suspected. This helps explain non-attendance at sexual health clinics as help-seeking occurs to regain control and access emotional reassurance from a source that is accessible and familiar; four main care pathways were observed in this study which drew on data from participants reporting genito-urinary symptoms and never having been to a sexual health clinic before.

As a study aligned with the broader public health issue of untreated STIs and unmet sexual health needs, this research provides insights into the links between population prevalence of symptom experience and non-attendance at sexual health clinics and the individual lived experiences and sense-making that occurs. It emphasises that the dirtiness of STIs could be a key aspect of the socio-cultural context of experiences which has not been recognised in public health campaigns or clinical practice sufficiently well to date. As well as contributing empirical knowledge about STI dirt, genito-urinary symptoms and attendance patterns at sexual health clinics, I demonstrated the applicability of the flash card activity and

developed the Cause-Concern Cycle as a way of explaining the transformation of sensations into symptoms.

The findings from this study are largely reassuring in that they suggest existing service provision across different types of healthcare settings provide sufficient choice and accessibility to high quality care regardless of perceived cause. Integrated services, screening programmes and the expansion of self-testing provide opportunities to address untreated STI and unmet sexual health needs even if face-to-face care is not actively sought or sensations are not interpreted as a need for care. However recent progress is threatened by public health funding cuts which are already affecting the delivery of sexual healthcare.

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APPENDICES

Appendix A: Scoping search for background literature section of introduction (chapter 1)

Concepts: stigma, symptoms, help-seeking

Type of data: peer-reviewed published journal articles, books and conference proceedings, grey literature as appropriate

Databases:

- Ovid SP MEDLINE
- Ovid SP EMBASE
- Web of Science
- Google and Google scholar

Search terms:

Stigma	Stigma, prejudice, discrimination, shame
Symptoms	Symptoms, signs, sensations, bodily changes, physical health issues
Help-seeking	Help-seeking, care-seeking, healthcare-seeking, information-seeking

The above search terms were combined with other concepts such as sexually transmitted infections, theory/framework and genito-urinary/sexual health to explore specific aspects of these concepts. Snowballing techniques were used to include other relevant studies and weekly email alerts for the Lancet, BMJ, Sexual Health, International Journal of STD & AIDS, STI and the sexual health research network further expanded the literature base.

I undertook a comprehensive search of literature for chapter 3 as follows:

Basic search strategy (adapted for each database):

1	exp HIV/
2	(human and immunodeficiency and virus).mp.
3	exp sexually transmitted disease/
4	1 or 2 or 3
5	("sexually transmitted infection" or STI or STD).mp.
6	("acquired immune deficiency syndrome" OR AIDS OR chancroid OR chlamydia trachomatis OR "lymphogranuloma venereum" OR LGV OR donovanosis OR "granuloma inguinale" OR "genital herpes" OR herpes simplex OR gonorrh#ea OR "genital warts" OR "human papillomavirus" OR HPV OR "hepatitis B" OR "mycoplasma genitalium" OR "pubic lice" OR "genital scabies" OR syphilis OR trichomon#as).mp.
7	4 OR 5 OR 6
8	(Dirt or dirty or dirtiness).mp
9	Moral OR clean OR hygien*
10	8 OR 9
11	7 AND 10

Databases used:

- PsychINFO
- International Bibliography of Social Sciences
- ASSIA
- Academic Search Complete
- Google Scholar
- MEDLINE
- EMBASE
- Web of Science

I also conducted mini reviews to scope literature about mixed methods integration (section 2.2.3, chapter 2), image elicitation methods (flash cards methods paper – chapter 2).

Appendix B: Natsal-3 survey questions and response options

Full details of survey questions, derived variables and questionnaire routing are available in the technical appendices (Erens, Phelps, Clifton, Hussey, *et al.*, 2013; Natsal-3, 2013)

Key questions and variables to collect data used in this study:

Participant sex: Rsex
INTERVIEWER: record whether respondent is male or female.

1 Male
2 Female

Participant age: ODoB OR Rage OR RAgeGr
ODoB
I would like to start by asking you a few questions about your health, but can I just check first:
What is your date of birth?
INTERVIEWER: enter in the format *dd/mm/yyyy*.

IF (RDoBY = NONRESPONSE) THEN
RAge
Can I just check, what was your age last birthday?

IF RAge=Nonresponse THEN
RAgeGr
Would you say roughly what age group you are in?
INTERVIEWER: If the respondent refuses to give you their age then please code what ***you*** *think the rough age group is.*

1 16 - 17
2 18 - 19
3 20 - 24
4 25 - 34
5 35 – 44
6 45 – 54
7 55 – 64
8 65 - 74
9 (Not established: don't use this code)

Participant symptoms: STISympM and STISympF

In the last month, that is since (date one month ago), have you had any of the following symptoms

Please type in the numbers for any that you have had.
If more than one, press the space bar between each number

Males (Rsex=Male AND respondent aged 16-44)
If none, type in '7'

1. Pain, burning or stinging when passing urine
2. Passing urine more often than usual
3. Genital wart / lump
4. Genital ulcer /sore
5. Discharge from the end of the penis
6. Painful testicles
7. None of these

Females (Rsex=Female AND (respondent aged 16-44)
If none, type in '11'

1. Pain, burning or stinging when passing urine
2. Passing urine more often than usual
3. Genital wart / lump
4. Genital ulcer / sore
5. Abnormal vaginal discharge
6. Unpleasant odour associated with vaginal discharge
7. Vaginal pain during sex
8. Abnormal bleeding between periods
9. Bleeding after sex (not during a period)
10. Lower abdominal or pelvic pain (not related to periods)
11. None of these

Hypothetical STI care preference: STDTrt
If *you thought that you might have an infection that is transmitted by sex, where would you **first** go to seek diagnosis and/or treatment?*

1. General practice (GP) surgery
2. Sexual health clinic (GUM clinic)
3. NHS Family planning clinic / contraceptive clinic / reproductive health clinic
4. NHS Antenatal clinic / midwife
5. Private non-NHS clinic or doctor
6. Pharmacy / chemist
7. Internet site offering treatment
8. Youth advisory clinic (e.g. Brook clinic)

9. Hospital accident and emergency (A&E) department
10. Somewhere else

Previous attendance at a sexual health clinic: STDClin
Have you ever attended a sexual health clinic (GUM clinic)?
1. Yes
2. No

IF STDClin=Yes THEN
WhnClin
When was that?
(The last time if more than once.)

1. Less than 1 year ago
2. Between 1 and 5 years ago
3. Between 5 and 10 years ago
4. More than 10 years ago

Perceived STI risk: STIRisk
CARD EE, again
*People are also at risk of getting other sexually transmitted infections. What do you think about the risks to **you**, personally, with your present lifestyle of getting a sexually transmitted infection that is not HIV?*
Just tell me the letter that corresponds to your answer.
1. (H) Greatly at risk
2. (B) Quite a lot
3. (W) Not very much
4. (S) Not at all at risk
5. Don't know

Participant agreement to be re-contacted: IntAgain
"It is possible that we may want to contact you again to obtain further information about some of the topics covered in this study. Would you be willing for a researcher from the study team to contact you again about taking part in another interview?"
IF NECESSARY ADD: You do not have to say now whether you would actually do an interview, just whether it would be OK for us to contact you about it.
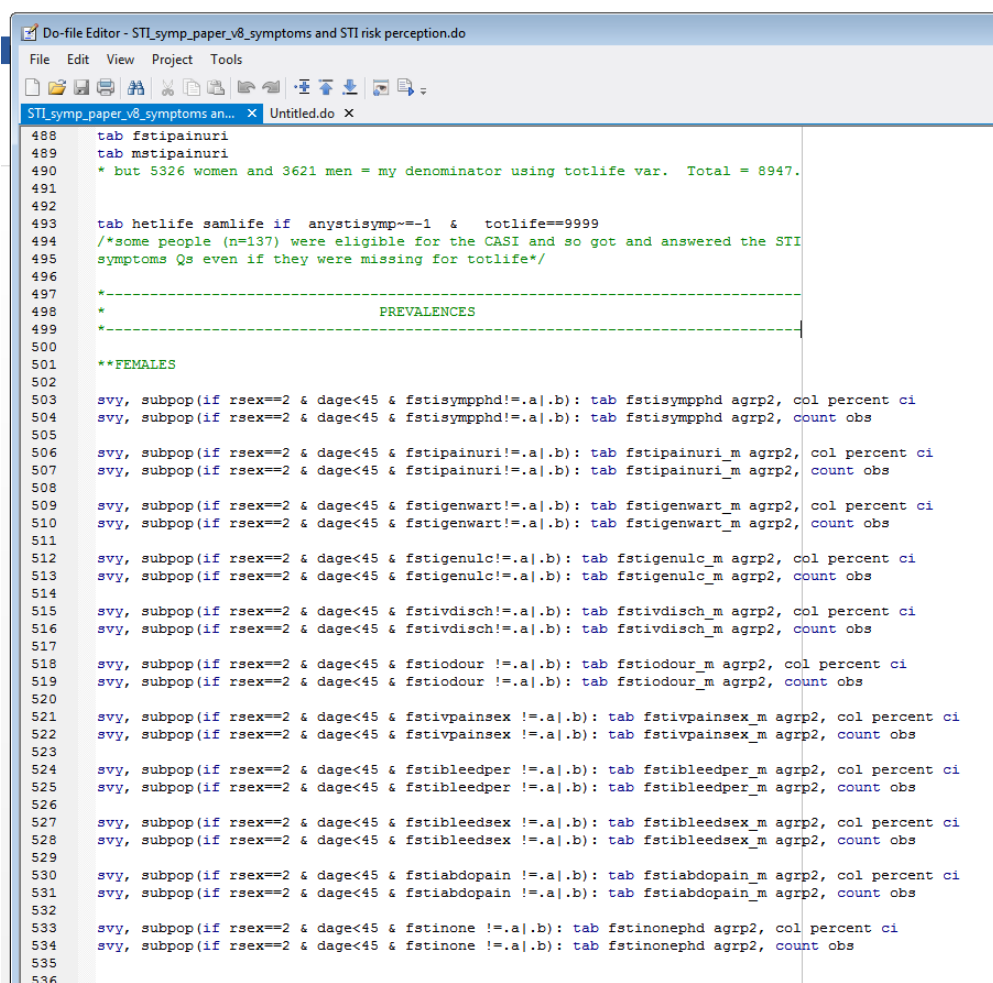*The study team is a team of researchers at the National Centre for Social Research, University College London, and the London School of Hygiene and Tropical medicine.*

1 Yes
2 No

Appendix C: Example Stata coding

Example Stata code for calculating symptoms prevalence estimates for females.

```
110    gen fstisympphd = .
111    replace fstisympphd = 1 if fstipainuri==1 | fstigenwart==1 | fstigenulc==1 | fstivdisch==1 | fstiodour==1 | fstivpainsex==1 | fstibleedper==1 | fstibleedsex==1 | fstiabdopain==1
112    replace fstisympphd = 0 if fstipainuri==0 & fstigenwart==0 & fstigenulc==0 & fstivdisch==0 & fstiodour==0 & fstivpainsex==0 & fstibleedper==0 & fstibleedsex==0 & fstiabdopain==0
113    replace fstisympphd = .a if fstipainuri==-1 & fstigenwart==-1 & fstigenulc==-1 & fstivdisch==-1 & fstiodour==-1 & fstivpainsex==-1 & fstibleedper==-1 & fstibleedsex==-1 & fstiabdopain==-1
114    replace fstisympphd = .b if fstipainuri==9 & fstigenwart==9 & fstigenulc==9 & fstivdisch==9 & fstiodour==9 & fstivpainsex==9 & fstibleedper==9 & fstibleedsex==9 & fstiabdopain==9
115
116    label var fstisympphd "Female STI symptoms excl passing urine more frequently"
117    label define fstisympphd 0 "No" 1 "Yes" .a "Not applicable" .b "Not answered/missing"
118    label values fstisympphd fstisympphd
119    tab fstisympphd, m
120    ** total = 1182 women who reported symptoms in Natsal3 (some reported more than 1); 4095 reported no symptoms and 135 didn't answer
121
```

```
Do-file Editor - STI_symp_paper_v8_symptoms and STI risk perception.do
File  Edit  View  Project  Tools

STI_symp_paper_v8_symptoms an...  ×   Untitled.do  ×
488      tab fstipainuri
489      tab mstipainuri
490      * but 5326 women and 3621 men = my denominator using totlife var.  Total = 8947.
491
492
493      tab hetlife samlife if  anystisymp~=-1  &   totlife==9999
494      /*some people (n=137) were eligible for the CASI and so got and answered the STI
495      symptoms Qs even if they were missing for totlife*/
496
497      *-------------------------------------------------------------------------------
498      *                          PREVALENCES
499      *-------------------------------------------------------------------------------
500
501      **FEMALES
502
503      svy, subpop(if rsex==2 & dage<45 & fstisympphd!=.a|.b): tab fstisympphd agrp2, col percent ci
504      svy, subpop(if rsex==2 & dage<45 & fstisympphd!=.a|.b): tab fstisympphd agrp2, count obs
505
506      svy, subpop(if rsex==2 & dage<45 & fstipainuri!=.a|.b): tab fstipainuri_m agrp2, col percent ci
507      svy, subpop(if rsex==2 & dage<45 & fstipainuri!=.a|.b): tab fstipainuri_m agrp2, count obs
508
509      svy, subpop(if rsex==2 & dage<45 & fstigenwart!=.a|.b): tab fstigenwart_m agrp2, col percent ci
510      svy, subpop(if rsex==2 & dage<45 & fstigenwart!=.a|.b): tab fstigenwart_m agrp2, count obs
511
512      svy, subpop(if rsex==2 & dage<45 & fstigenulc!=.a|.b): tab fstigenulc_m agrp2, col percent ci
513      svy, subpop(if rsex==2 & dage<45 & fstigenulc!=.a|.b): tab fstigenulc_m agrp2, count obs
514
515      svy, subpop(if rsex==2 & dage<45 & fstivdisch!=.a|.b): tab fstivdisch_m agrp2, col percent ci
516      svy, subpop(if rsex==2 & dage<45 & fstivdisch!=.a|.b): tab fstivdisch_m agrp2, count obs
517
518      svy, subpop(if rsex==2 & dage<45 & fstiodour !=.a|.b): tab fstiodour_m agrp2, col percent ci
519      svy, subpop(if rsex==2 & dage<45 & fstiodour !=.a|.b): tab fstiodour_m agrp2, count obs
520
521      svy, subpop(if rsex==2 & dage<45 & fstivpainsex !=.a|.b): tab fstivpainsex_m agrp2, col percent ci
522      svy, subpop(if rsex==2 & dage<45 & fstivpainsex !=.a|.b): tab fstivpainsex_m agrp2, count obs
523
524      svy, subpop(if rsex==2 & dage<45 & fstibleedper !=.a|.b): tab fstibleedper_m agrp2, col percent ci
525      svy, subpop(if rsex==2 & dage<45 & fstibleedper !=.a|.b): tab fstibleedper_m agrp2, count obs
526
527      svy, subpop(if rsex==2 & dage<45 & fstibleedsex !=.a|.b): tab fstibleedsex_m agrp2, col percent ci
528      svy, subpop(if rsex==2 & dage<45 & fstibleedsex !=.a|.b): tab fstibleedsex_m agrp2, count obs
529
530      svy, subpop(if rsex==2 & dage<45 & fstiabdopain !=.a|.b): tab fstiabdopain_m agrp2, col percent ci
531      svy, subpop(if rsex==2 & dage<45 & fstiabdopain !=.a|.b): tab fstiabdopain_m agrp2, count obs
532
533      svy, subpop(if rsex==2 & dage<45 & fstinone !=.a|.b): tab fstinonephd agrp2, col percent ci
534      svy, subpop(if rsex==2 & dage<45 & fstinone !=.a|.b): tab fstinonephd agrp2, count obs
535
536
```

Appendix D: Factors associated with reporting any genito-urinary symptoms in women and men aged 16-44 years

Variable choice informed by semi-structured interview findings and epidemiological risk factors from the literature (Sonnenberg *et al.*, 2013)

	Women						Men					
	Prevalence of reported symptoms	Crude OR	p value	Age-adjusted OR	p value	Denominators: unweighted, weighted¤	Prevalence of reported symptoms	Crude OR	p value	Age-adjusted OR	p value	Denominators: unweighted, weighted¤
Sociodemo-graphic factors												
Age (years)			<0.0001		-				0.0839		-	
16-24	27.9 (25.6, 30.3)	1.00	-	-	-	1740, 968	6.9 (5.6, 8.5)	1.00	-	-	-	1375, 1003
25-34	23.3 (21.4, 25.2)	0.78 (0.67, 0.92)	-	-	-	2397, 1323	6.0 (4.7, 7.5)	0.85 (0.62, 1.18)	-	-	-	1456, 1304
35-44	15.8 (13.7, 18.2)	0.49 (0.40, 0.60)	-	-	-	1189, 1425	4.4 (3.1, 6.1)	0.62 (0.40, 0.94)	-	-	-	790, 1395
IMD (quintiles)			0.0413		0.118				0.7019		0.0868	
1-2 (least deprived)	19.6 (17.7, 21.7)	1.00	-	1.00	-	1818, 1344	5.2 (4.0, 6.7)	1.00	-	1.00	-	1309, 1370
3	23.8	1.28	-	1.24	-	1037, 742	6.1		-	1.18	-	693, 722

	% (95% CI)	OR (95% CI)		OR (95% CI)		N, N	% (95% CI)	OR (95% CI)		OR (95% CI)		N, N
	(21.0, 26.9)	(1.04, 1.57)		(1.01, 1.52)			(4.4, 8.5)	(0.77, 1.86)		(0.76, 1.83)		
4-5 (most deprived)	22.3 (20.4, 24.3)	1.17 (0.99, 1.39)	-	1.11 (0.94, 1.33)	-	2471, 1630	5.8 (4.6, 7.3)	1.13 (0.78, 1.63)	-	1.09 (0.76, 1.57)	-	1619, 1610
Relationship status		<0.0001		0.0005				0.0032		0.018		
Married or civil partnership	17.4 (15.5, 19.6)	1.00	-	1.00	-	1592, 1492	3.6 (2.6, 5.1)	1.00	-	1.00	-	929, 1412
Co-habiting (with partner of opposite or same sex)	22.7 (20.2, 25.5)	1.39 (1.13, 1.72)	-	1.19 (0.95, 1.48)	-	1135, 809	5.8 (4.1, 8.1)	1.63 (0.98, 2.70)	-	1.56 (0.92, 2.63)	-	707, 761
Not co-habiting (but has 'steady' partner of opposite or same sex	30.2 (27.1, 33.5)	2.05 (1.66, 2.53)	-	1.59 (1.26, 2.01)	-	1163, 605	6.4 (4.7, 8.7)	1.81 (1.11, 2.95)	-	1.76 (1.03, 3.02)	-	780, 595
Not in 'steady' relationship	21.8 (19.5, 24.3)	1.32 (1.08, 1.61)	-	1.10 (0.89, 1.36)	-	1406, 794	7.9 (6.3, 10.0)	2.28 (1.47, 3.53)	-	2.22 (1.35, 3.64)	-	1190, 921
Sexual behaviours												
Number of sexual partners in past year		<0.0001		0.0003				<0.0001		0.0001		
0	13.6 (9.6, 18.8)	1.00	-	1.00	-	293, 192	6.5 (3.3, 12.2)	1.00	-	1.00	-	196, 177
1	20.6 (19.2, 22.1)	1.65 (1.11, 2.46)	-	1.56 (1.05, 2.33)	-	3844, 2836	4.5 (3.7, 5.5)	0.68 (0.33, 1.41)	-	0.68 (0.33, 1.41)	-	2332, 2624

	% (95% CI)	OR (95% CI)		aOR (95% CI)		N	% (95% CI)	OR (95% CI)		aOR (95% CI)		N
2	26.2 (22.1, 30.7)	2.25 (1.44, 3.54)	-	1.89 (1.20, 2.97)	-	508, 296	5.2 (3.3, 8.0)	0.79 (0.34, 1.80)	-	0.75 (0.33, 1.73)	-	437, 370
≥3	31.1 (27.0, 35.4)	2.87 (1.85, 4.43)	-	2.28 (1.47, 3.53)	-	610, 338	11.2 (8.5, 14.7)	1.83 (0.86, 3.90)	-	1.74 (0.81, 3.75)	-	616, 489
Number partners in past year, no condom used		<0.0001		<0.0001				<0.0001		0.0001		
0	14.7 (12.4, 17.3)	1.00	-	1.00	-	1032, 692	5.7 (4.1, 8.1)	1.00	-	1.00	-	876, 792
1	21.5 (20.0, 23.0)	1.59 (1.29, 1.96)	-	1.65 (1.34, 2.03)	-	3632, 2646	4.6 (3.7, 5.5)	0.79 (0.52, 1.19)	-	0.82 (0.53, 1.27)	-	2144, 2419
≥2	38.2 (33.6, 43.0)	3.60 (2.72, 4.76)	-	3.15 (2.39, 4.17)	-	577, 319	11.8 (8.8, 15.7)	2.19 (1.34, 3.57)	-	2.15 (1.31, 3.52)	-	525, 421
Number of occasions of sexual intercourse in past 4 weeks~		0.0001		0.005				0.349		0.472		
0	18.1 (15.7, 20.8)	1.00	-	1.00	-	1148, 765	7.0 (5.1, 9.4)	1.00	-	1.00	-	835, 780
1-4	19.8	1.11	-	1.13	-	1980, 1463	5.5	0.77	-	0.81	-	1361, 1512

	% (95% CI)	OR (95% CI)		aOR (95% CI)		n, n	% (95% CI)	OR (95% CI)		aOR (95% CI)		n, n
	(17.9, 21.9)	(0.91, 1.37)		(0.92, 1.40)			(4.3, 7.0)	(0.51, 1.18)		(0.53, 1.24)		
5-8	23.5 (20.7, 26.7)	1.39 (1.10, 1.76)	-	1.34 (1.06, 1.71)	-	979, 689	4.2 (2.7, 6.3)	0.58 (0.33, 1.01)	-	0.60 (0.34, 1.04)	-	632, 668
9-12	28.6 (23.9, 33.9)	1.81 (1.35, 2.43)	-	1.65 (1.23, 2.21)	-	449, 303	5.6 (3.6, 8.8)	0.80 (0.45, 1.43)	-	0.81 (0.45, 1.46)	-	354, 361
≥13	26.2 (21.3, 31.9)	1.61 (1.17, 2.20)	-	1.38 (1.00, 1.91)	-	345, 217	6.8 (4.3, 10.4)	0.97 (0.55, 1.70)	-	0.92 (0.52, 1.62)	-	302, 257
Perceived risk of STIs to self	<0.0001			<0.0001			<0.0001			<0.0001		
Not very much, not at all	20.9 (19.7, 22.3)	1.00	-	1.00	-	5074, 3562	5.1 (4.4, 6.0)	1.00	-	1.00	-	3353, 3484
Greatly or quite a lot	39.9 (32.7, 47.6)	2.51 (1.82, 3.46)	-	2.19 (1.59, 3.01)	-	220, 132	15.0 (10.1, 21.8)	3.28 (2.01, 5.33)	-	3.07 (1.84, 5.12)	-	251, 200
Perceived risk of HIV to self	0.0598			0.0814			0.4792			0.578		
Not very much, not at all	21.4 (20.1, 22.7)	1.00	-	1.00	-	5117, 3575	5.6 (4.8, 6.5)	1.00	-	1.00	-	3429, 3547
Greatly or quite a lot	28.1 (21.2, 36.3)	1.44 (0.99, 2.10)	-	1.39 (0.96, 2.03)	-	176, 118	6.9 (3.9, 11.8)	1.24 (0.68, 2.28)	-	1.19 (0.65, 2.17)	-	172, 136

Health factors

	% (95% CI)	OR		Adj. OR		N, N	% (95% CI)	OR		Adj. OR		N, N
Self-reported health		<0.0001		<0.0001				0.0002		0.0001		
Very good, or good	20.6 (19.3, 22.0)	1.00	-	1.00	-	4663, 3262	5.1 (4.3, 6.0)	1.00	-	1.00	-	3191, 3283
Fair, bad or very bad	29.2 (25.3, 33.3)	1.59 (1.29, 1.96)	-	1.64 (1.33, 2.02)	-	663, 454	10.1 (7.3, 13.9)	2.11 (1.42, 3.13)	-	2.20 (1.48, 3.26)	-	430, 420
Genital health condition*		0.1462		0.0003						Excluded~~		
No	21.0 (19.6, 22.5)	1.00	-	1.00	-	4029, 2707	-	-	-	-	-	-
Yes	23.3 (20.7, 26.1)	1.14 (0.96, 1.36)	-	1.42 (1.17, 1.71)	-	1296, 1008	-	-	-	-	-	-
Ever been pregnant		<0.0001		0.023						N/A		
No	26.4 (24.2, 28.8)	1.00	-	1.00	-	1969, 1253	-	-	-	-	-	-
Yes	19.2 (17.7, 20.8)	0.66 (0.57, 0.77)	-	0.82 (0.70, 0.97)	-	3347, 2453	-	-	-	-	-	-
Ever had abortion		0.0011		0.0001						N/A		
No	20.8 (19.4,22.2)	1.00	-	1.00	-	4476, 3136	-	-	-	-	-	-
Yes	26.8	1.40	-	1.51	-	824, 559	-	-	-	-	-	-

	(23.4, 30.5)	(1.14, 1.71)		(1.23, 1.85)							
Ever diagnosed with STI [*]			<0.0001		<0.0001				<0.0001		<0.0001
No	16.0 (14.5, 17.5)	1.00	-	1.00	-	3022, 2059	4.5 (3.8, 5.4)	1.00	-	1.00	-	3101, 3172
Yes	28.8 (26.7,31.0)	2.13 (1.83, 2.48)	-	2.38 (2.02, 2.79)	-	2260, 1621	12.9 (9.8, 16.8)	3.15 (2.20, 4.50)	-	3.30 (2.29, 4.76)	-	500, 505

95% Confidence Intervals shown in ();Denominators vary across variables because of item non-response and survey skip pattern; ¤ Denominator is all sexually experienced women and men aged 16-44 years; ~ sexual intercourse is defined as vaginal, oral or anal sex in participants who had at least one opposite or same sex partner; *Conditions include: hysterectomy, bladder surgery, genital or gynaecological surgery, caesarean section, abdominal surgery, broken hip or pelvis bone, hip replacement; ˚STIs: herpes, trichomoniasis, gonorrhoea, syphilis, chlamydia, pubic lice / crabs, hepatitis B, non specific urethritis, epididymitis, genital warts, pelvic inflammatory disease, thrush, bacterial vaginosis and reported previous diagnosis with STD but can't remember which one; ~~ data excluded due to small numbers; N/A = not applicable

Appendix E: Recruitment letter and information sheets for participants

Dear xxxx,

RE: Participation in Natsal Follow-up Study

You may remember being interviewed for the Natsal survey. We hope you enjoyed the experience and we would like to thank you for your contribution to this important national research.

At that time, you said that you would be willing for a member of the research team to contact you again. We are getting in touch because we'd like to invite you to take part in a follow-up study.

This time, the interview will involve a conversation with a trained researcher. We would like to find out more about some of the survey topics in more detail. For instance, we are interested in how people perceive sexually transmitted infections (sometimes called venereal disease), experience of symptoms and the choices people make about going to healthcare services. The interview will focus on topics that are relevant to your personal experience.

A member of the Natsal team will call you in the next week or so, on the telephone number you provided, to ask you if you would like to take part and. We can then arrange the interview for a time and place that suits you either at your home or in another suitable location. There is no obligation to take part if you would prefer not to. If you do not want us to call you, you can let us know by telephoning Fiona Mapp on [mobile number given] or emailing [email address given].

I would like to assure you that any information you give us will be treated in strict confidence and the results of the study will never include any personal details. The information collected is used for research purposes only. Your comments will be made anonymous and we will not use your name at any time, nor link the information you give us with details about you as an individual.

In our work we rely on people's voluntary co-operation. However, we find that most people enjoy the experience. As a thank you for your time, we will give you a £20 high street voucher.

Thank you again for your help so far.

Yours sincerely,

Fiona Mapp

Natsal survey follow-up study
study information sheet

We would like to thank you for your contribution to the Natsal survey which you completed some time ago. At that time, you said that you would be willing for a member of the research team to contact you again. We have now reached the next stage of the study and hope that you will be able to help us again. Before you decide whether you would like to, please read this information so you know what the study is about and what taking part means for you.

What is the study about?
The Natsal survey involves 15,000 people from all over Britain. The results will allow us to look at changes in sexual and reproductive health since 2000 and therefore to plan health education and services that can respond to current needs. We are following up a smaller number of people to find out how sexual experiences affect health and well-being and this is what we would like your help with.

Who is carrying out this study?
Researchers from the London School of Hygiene and Tropical Medicine (LSHTM), a University of London medical school (see www.lshtm.ac.uk). These researchers are part of the team who designed the Natsal survey you completed. The study is funded by the Medical Research Council (see www.mrc.ac.uk).

Why have I been asked?
You were one of the many people who said they would be willing to be contacted again. We would like to know more about people's experiences. For instance, we are interested in how people perceive sexually transmitted infections (sometimes called venereal disease), experience of symptoms and the choices people make about going to healthcare services. The interview will focus on topics that are relevant to your personal experience.

What does taking part involve?
We would like you take part in a one-to-one interview with one of the research team. This would be at a time and place convenient for you and would last between an hour and an hour and a half. The interview will be different from the survey you

took part in last time as we would like to discuss your views, opinions and experiences in greater detail. To allow us to link information from the survey with that from the interview, we would like your permission for members of the research team to have access to your responses to the Natsal 3 survey.

Do I have to take part?
Your contribution is very important to us but it is entirely up to you. If you do take part, you don't have to answer all the questions and you can end the interview at any time.

What will happen to the information I give?
This study will help health professionals to improve services relating to sexual health, family planning and health education. Everything you tell us will be **strictly confidential**. No one will be able to trace anything said in the interview back to you as an individual. Data and results from this study will not include any names or identifying information and will be stored securely in line with the research team's policies.

What's in it for me?
We have found that people often enjoy being interviewed. It's an opportunity to talk about your life to an attentive listener. At the same time you will be contributing to research of national importance. A £20 voucher will be given to participants on completion of the interview as recompense for travelling expenses and/or loss of earnings, in line with the original Natsal-3 project.

What do I do if I am interested in taking part?
One of the research team will phone you in the next week or so to talk to you about whether you would like to take part in an interview.

If you have any questions or would like to know more, please contact:

Fiona Mapp
London School of Hygiene & Tropical
Medicine
15-17 Tavistock Place
London WC1H 9SH
phone: [mobile phone number given]
email: [email address given]

Appendix F: Consent form for participants

Natsal survey follow-up study
consent form

Please read the following statements, initial those you agree with in the box on the right, and then sign your name at the end:

1.	I confirm that I have read the information sheet for the above study and have had the opportunity to ask questions.	
2.	I agree to take part in an interview.	
3.	I agree to the interview being audio recorded.	
4.	I understand that all information I give during the interview will be strictly confidential.	
5.	I understand that the results of the study will be anonymised. This means that no one will be able to trace anything I say during the interview back to me.	
6.	I understand that anonymised, unidentifiable quotes of mine may be used in reports of the study.	
7.	I understand that my participation is voluntary and that I can stop the interview at any time without giving any reason.	
8.	I am willing for members of the Natsal research team to have access to my responses to the Natsal 3 survey.	
9.	I understand that anonymised information I give may be reviewed by the authorities responsible for regulating the study (the London School of Hygiene & Tropical Medicine, UCL and NatCen).	
10.	I am willing for the anonymised information that I give to be stored in a secure data repository if required.	

Name of participant	Signature	Date

If you would like more information, please contact:
Fiona Mapp
London School of Hygiene & Tropical Medicine
15-17 Tavistock Place
London WC1H 9SH
email: [email address given]

Appendix G: Topic Guide for semi-structured interviews

Rapport building at the start:

- What you do (education/work)?
- Who do you live with?
- How long have you lived in the area?
- Current partner?

<mark>**Sign 2x consent forms</mark>

INTRODUCTION

We're carrying out these interviews as an extra part of the survey you took part in, to flesh out the information provided in those. You have been selected to take part from the answers you gave in that survey. The aim is to find out <u>what people think about sexual health services and sexually transmitted infections with the aim of improving healthcare options in the future.</u>

So I'd like to get your thoughts and views on both sexual health services and sexually transmitted infections, or sexually transmitted diseases. There are <u>no right or wrong answers</u> as it is your opinion and views that I am interested in. You <u>don't have to answer any of the questions</u> I ask you if you don't want to and you don't have to tell me why you don't want to answer them either; <u>you can stop the interview</u> at any time and you can <u>contact me after the interview</u> if you are worried about something you said. Everything you tell me will be kept <u>confidential</u> and if you do say anything that could be used to identify you, it will be <u>anonymised</u> in the transcript of the interview and in any quotes taken from the transcript.

Just to confirm I haven't seen the answers you gave in the original Natsal survey so <u>apologies if you find yourself repeating</u> things you said then. We will start with some general questions and then move on to talking about how we think about sexually transmitted infections which will include a short exercise using flash-cards which I will explain a bit more about when we get to it.

Any questions before we start?

<mark>**TURN ON RECORDER**</mark>

Why did you agree to take part in the interview?

Can you remember when you completed the big Natsal survey (the first time you were interviewed)?

……

I'd like first of all to get a sense of what comes into your head when you think about STIs.

Spontaneous response, then probe:

- Is this the word you'd use for them or do you have any other words or phrases to describe them?
- Do you know of any other terms?

Then prompt: **(have you heard of) 'venereal diseases', 'VD', 'genitourinary infections';**

What do those terms make you think of?

- Any connotations, or associations?
- Do different terms have different associations?
- Could you think of any differences in the way we label these infections or diseases as opposed to other types of infections?
- Why do you think that is?

Probe: meanings/comparisons/preference for use of STDs or VD terminology (differences between names for this group of conditions)

Do people think differently about STIs, do you think?

- In what ways might that be?' OR 'What makes you think that?
- And you, do you yourself think differently about STIs and other types of infections?
- In what ways, would you say?
- (If they mention DIRTY…tell me some other things that you think are dirty)

Have perceptions changed at all, over time? In what way?

**GIVE LIST OF SYMPTOMS

Have you ever experienced any of the following (give male/female card) OR ANY OTHER ABNORMAL THINGS OR PROBLEMS WITH YOUR GENITALS/PRIVATE PARTS?

NOTE RESPONSE:

Was this at the same time or on separate occasions?

Can you tell me a bit about your experiences of having these symptoms?

How did that make you feel (one at a time if more than one)?

   - Prompt: worried, confused, angry, upset, surprised

   - Prompt: how did it feel physically – uncomfortable, painful, constantly aware of it?

   - Probe: did you have an idea then as to what might have caused them?

What do you think other people would think of you if they knew about these symptoms?

Did you tell anyone about these issues?

- Prompt: partner, friend, relative, doctor/nurse

If **yes:** probe:

      - what made you choose that person to tell?

If **no:** probe:

      Why did you not?

Would you normally tell someone if you had something wrong with you?

What was the difference do you think?

Did you do anything else about the (state reported symptom)?

- Look on internet, go and get advice from somewhere?

Probe: **Tell me more…**

How do you feel about all of these symptoms – are there any that are worse than others (which would you least like to have)?

Probe: part of normal body function, any more worrying or more extreme than others?

- are any of them likely to affect other parts of the body

Have you experienced any other things, abnormalities, problems around your private parts/genitals?

Have you been to / did you attend a sexual health service to have them seen to? – Here I mean a [use the word they have identified earlier] or any other service for sexual health?

- Tell me more about this experience

IF <u>YES</u>:

What made you go to this particular service?

Probe: location, accessibility, knew about it, convenient opening hours, someone recommended it to you, only option

- When was this (before or after Natsal survey)?

- Can you tell me more about your visit there (staff/other patients/tests or treatment)?

- How did you feel after going or after being treated?

Have you been to any other services for sexual health?

If <u>NO</u>: (and has reported having had STI symptoms in this interview)

Could you tell me why you do you think this is / why you have chosen not to?

Spontaneous answer, then probe. **Tell me more? Why was that?**

- Were you at all worried about what the staff might think of you?
- Were you worried in case someone might see you there, and think badly of you?

Have you used any other services for sexual health?

FOR YES'S AND NO's

Do you think people generally feel differently about getting help for STIs?

Why do you think you/people would not seek help with genital symptoms?

What is it about STIs, do you think, that makes people feel like this?

Prompt:

- How they're caught
- Where on the body the symptoms appear
- What kinds of people get them
- Does it affect your reputation?
- Are there any other areas of health that make people feel like this, where there are parallels, say?

What makes you think that?

Has anyone you know been to a sexual health clinic?

- Prompt: friends, relatives, partners, celebrities

What do you/did you think visiting a sexual health service would be like?

Probe:

- Reasons for this – friends, media, other information sources

- How would you feel if you had to go to a sexual health clinic or a GUM clinic today?

What do you think about having GUM clinics as part of the healthcare service for testing and treating people who might have been at risk for a sexually transmitted infection?

Probe:

- Personal choice of where to go for care?

- Are there any negative things about going?

Prompt: barriers – distance, time, unknown environment, type of people that would be there, embarrassment/fear judgement, confidentiality concerns

Is there anything that would make it easier for people to go to a sexual health service?

Probe: testing at home/self-care?

If you were diagnosed with a sexually transmitted infection, what would that mean to you?

Probe: change sexual behaviour, emotions (angry/upset/confused/worried/normal)

      - individual/other people

Can you tell me some STIs that you have heard of?

    - Probe: what do you know about these STIs?

FLASH CARD EXERCISE – COMPARISON OF STIS:

(Use paper-based continuums and flash cards)

Which of these have you heard of [SHOW FLASH CARDS one at a time – Y/N pile]?

**READ NAMES OUT

(Remove any flash cards that the participant hasn't heard of from the exercise)

Continuums: (NOTE: order participant places cards in gaps below especially first one, any problematic ones) _**** Ask participant to think out loud.**_

Prevalence: common – uncommon

Infectiousness: easy to catch – hard to catch

Concealability: visible (obvious) – invisible (hidden)

Severity of impact: mild – serious/ life threatening

Treatability: easy to treat – hard to treat

Personal responsibility or blameworthiness: completely the person's fault – not at all the person's fault

    -    Probe: is there another word or phrase you would use instead?

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(After choosing the order on each continuum)

Could you tell me why you have chosen to put the cards in this order?

- Probe: which ones you chose to do first and last; the two extremes; any equal positions, hard/easy decision to make

Probe: how did you interpret the question?

How are symptoms experienced (inside/outside   visible/hidden

How are infections treated – tablets and cream etc?

Can anyone get an STI do you think?

- Why do you say that?

What kind of person do you think would be most likely to get an STI?

- Prompt: age, gender, sexual behaviour/number of partners

- Probe: Why do you think they would be more at risk?

Do you/ in what ways do you think people diagnosed with an STI are treated differently from other people?

- Probe: physically, psychologically, emotionally – negative/positive

- Guilt/embarrassment/shame/fear/ignorance/other emotions/different behaviours

- individual/society perceptions

- Probe: discrimination, exclusion, isolation, gossiped about, change social interactions and sexual behaviour

- Who would treat them differently?

It is often said that STIs are stigmatised, can you tell me what you think about this?

- What do you understand by stigma?
- Why does it exist?
- Who is responsible for creating this stigma?
- Examples of the type of stigma that exists?

- How long does the stigma last/how big an impact does stigma have on the person and their behaviour?

- Prompt: negative perceptions, labelling, sex is taboo topic, role of media, stories/anecdotes

Do you think there are any positive things about having symptoms of an STI?

- Probe: change behaviour, prompt care-seeking, feelings about knowing, contact sexual partners

Is there anything else you would like to talk about in relation to STIs and sexual health clinics?

**Give infographic

I'm not sure if you've seen any of the press coverage about the results from the original study but I've brought with me some of the infographics which are quite a nice summary of what the survey found out. (Any thoughts)

COMMENT:

How did you find doing the interview?

Why did you want to or agree to take part?

Thank participant and end interview

**Give voucher and sign voucher form

Appendix H: Natsal-3 Infographics and signposting sheet

Sexual attitudes and lifestyles in Britain: Highlights from Natsal-3

We interviewed 15,162 men and women aged 16–74 between September 2010 and August 2012. They provided us with valuable information about their experiences, behaviours, and views which will shape our understanding of sexual health in Britain. Here we present highlights from our initial findings. The full articles can be found in *The Lancet* (www.thelancet.com/themed/natsal) and details of the study methodology are on the Natsal website (www.natsal.ac.uk). More results will be published in the coming months, so please check the Natsal website for updates.
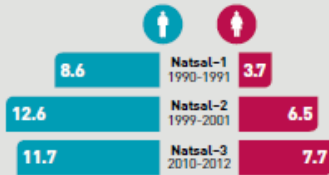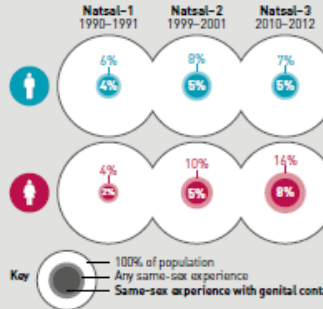
Changes in sexual behaviour

This is the third Natsal survey that has been carried out in Britain: the first survey was undertaken in 1990–1991 and the second survey in 1999–2001.

Over the 1990s, we saw an increase in the number of opposite-sex partners people reported, and more people reporting same-sex experience. Over the last decade, we have only seen further increases for women, so the gender gap is narrowing.
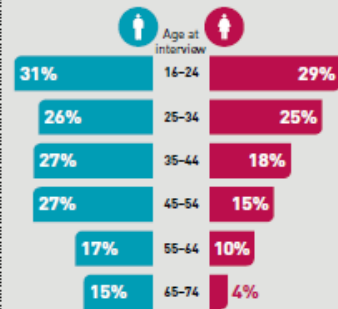
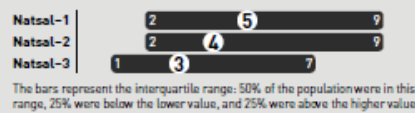**Average (mean) number of opposite–sex partners, lifetime (people aged 16–44)**

8.6	Natsal–1 1990–1991	3.7
12.6	Natsal–2 1999–2001	6.5
11.7	Natsal–3 2010–2012	7.7

Percentage of the population who have ever had same-sex experience (people aged 16–44)

	Natsal–1 1990–1991	Natsal–2 1999–2001	Natsal–3 2010–2012
Men	6% / 4%	8% / 5%	7% / 5%
Women	4% / 2%	10% / 5%	14% / 8%

Key: 100% of population / Any same-sex experience / Same-sex experience with genital contact
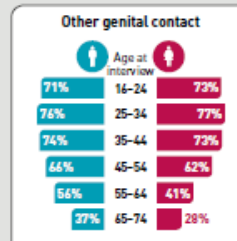
Median (middle) number of occasions of sex in the past 4 weeks (people aged 16–44)

Natsal–1	2	5	9
Natsal–2	2	4	9
Natsal–3	1	3	7

The bars represent the interquartile range: 50% of the population were in this range, 25% were below the lower value, and 25% were above the higher value.

On average over the past two decades there has been a decrease in how often people say they have sex.

Percentage who had sexual intercourse with someone of the opposite sex before age 16

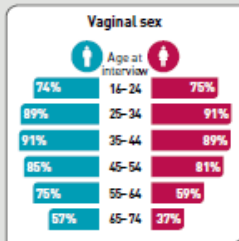| Men	Age at interview	Women
31%	16–24	29%
26%	25–34	25%
27%	35–44	18%
27%	45–54	15%
17%	55–64	10%
15%	65–74	4%

Different types of sex with people of the opposite-sex, past year

Vaginal sex

Men	Age at interview	Women
74%	16–24	75%
89%	25–34	91%
91%	35–44	89%
85%	45–54	81%
75%	55–64	59%
57%	65–74	37%

Given/received oral sex

Men	Age at interview	Women
71%	16–24	71%
80%	25–34	80%
80%	35–44	76%
71%	45–54	63%
52%	55–64	35%
30%	65–74	19%

Anal sex

Men	Age at interview	Women
19%	16–24	17%
17%	25–34	16%
15%	35–44	13%
14%	45–54	8%
8%	55–64	4%
3%	65–74	4%

Other genital contact

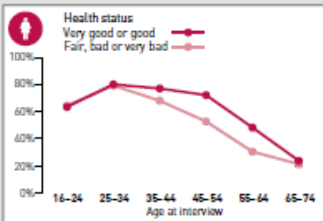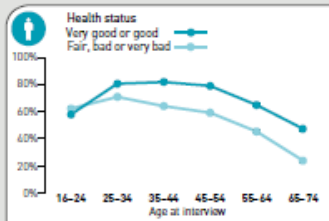| Men	Age at interview	Women
71%	16–24	73%
76%	25–34	77%
74%	35–44	73%
66%	45–54	62%
56%	55–64	41%
37%	65–74	28%

People continue to have sex at all ages, but the frequency and range of sexual practices decrease with age. While most people have had vaginal sex in the past year, other practices are less common, especially anal sex.
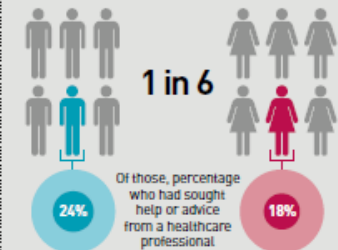
Sex and health

Overall, more than 60% of people reported having sex recently and over 60% of people said they were satisfied with their sex life. People in poorer health were less likely to have had sex recently, and less likely to say that they were satisfied. This was true even after taking age and whether people were in a relationship into account.

However, ill health does not necessarily mean the end of an active or satisfying sex life: more than one in three people in bad or very bad health had had sex recently, and around half were satisfied with their sex lives.

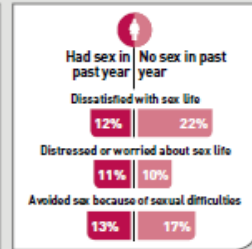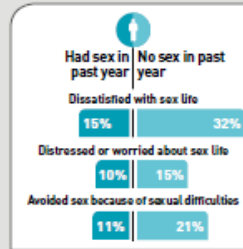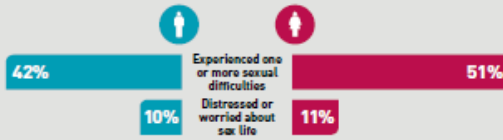**Percentage reporting recent sexual activity (in past four weeks)**

Health status: Very good or good / Fair, bad or very bad
(Men chart, Women chart — Age at interview 16–24, 25–34, 35–44, 45–54, 55–64, 65–74)

Percentage reporting a health condition that affected their sex life in the past year

1 in 6

Of those, percentage who had sought help or advice from a healthcare professional: 24% (men) / 18% (women)

Almost one in six people said they had a health condition that affected their sex life in the past year, yet less than one in four of these men and one in five of these women said that they had tried to get help or advice from a healthcare professional. Those who had were most likely to have talked to their GP.

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Sexual function

We asked men and women who had had sex in the past year whether they had experienced any sexual difficulties lasting three or more months in the past year, including lack of interest in having sex, feeling anxious during sex, pain during sex, vaginal dryness, and problems getting or keeping an erection.

Sexual difficulties were common, even in young people. However, it was much less common for people to say that they were distressed or worried about their sex lives.

	Had sex in past year	No sex in past year
Dissatisfied with sex life	15%	32%
Distressed or worried about sex life	10%	15%
Avoided sex because of sexual difficulties	11%	21%

	Had sex in past year	No sex in past year
Dissatisfied with sex life	12%	22%
Distressed or worried about sex life	11%	10%
Avoided sex because of sexual difficulties	13%	17%

Experienced one or more sexual difficulties: 42% / 51%

Distressed or worried about sex life: 10% / 11%

People who hadn't had sex in the past year were more likely to say that they were dissatisfied with their sex life, and that they had avoided sex because of sexual difficulties (either theirs, or a partner's), compared with people who did have sex in the past year. However, only a minority of people who had not had sex in the past year said they were dissatisfied, distressed, or avoiding sex.

1 in 4 men and women who are in a relationship do not share the same level of interest in sex as their partner.
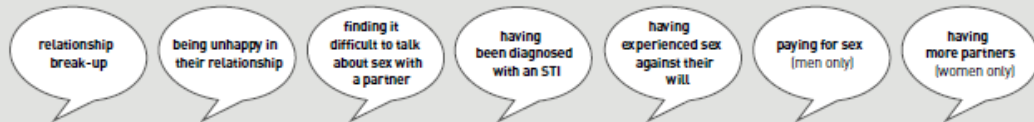
1 in 5 men and women who are in a relationship said that their partner had experienced sexual difficulties in the past year.

We created a sexual function score that took account of people's experience of sexual difficulties, their sexual relationship and how they rate their sex life.

People with a lower sexual function score were more likely to report:

- relationship break-up
- being unhappy in their relationship
- finding it difficult to talk about sex with a partner
- having been diagnosed with an STI
- having experienced sex against their will
- paying for sex (men only)
- having more partners (women only)

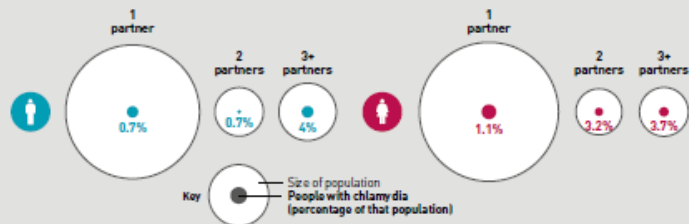## Sexually transmitted infections (STIs)

We collected urine from a sample of men and women aged 16–44 which we tested anonymously for sexually transmitted infections (STIs), including chlamydia, gonorrhoea, human papillomavirus (HPV), and HIV. These findings are for men and women who have ever had sex.

HPV was the most common STI, followed by chlamydia. HIV and gonorrhoea were found in around one in a thousand people.

For more information about these STIs and where you can test for them you can visit the NHS website: www.nhs.uk/Livewell/STIs/Pages/STIs-hub.aspx
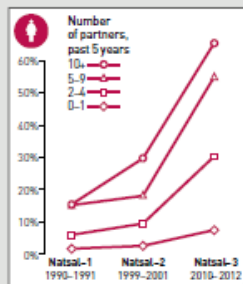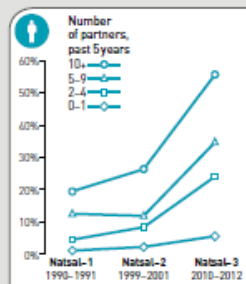
Overall, around one in a hundred people aged 16–44 had chlamydia, although this varied by age, peaking at almost one in twenty women aged 18–19 and one in thirty men aged 20–24. Although people who reported more partners in the past year were more likely to have chlamydia, a lot of the chlamydia was found in people who reported only one partner in the past year, because most people only had one partner.

Percentage of people in the population with chlamydia

1 partner — 0.7% | 2 partners — 0.7% | 3+ partners — 4%

1 partner — 1.1% | 2 partners — 3.2% | 3+ partners — 3.7%

Key: Size of population / People with chlamydia (percentage of that population)
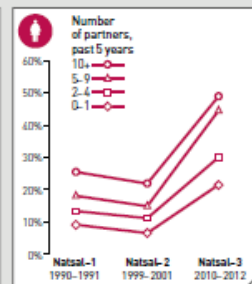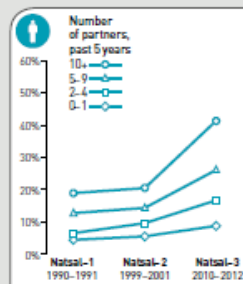
Over the past decade, national sexual health strategies in Britain have aimed to increase access to sexual health services and STI / HIV testing. Compared with the previous survey (1999–2001), more people reported having an HIV test or going to a sexual health clinic in the past 5 years. It is encouraging to see that these increases were even larger in those at highest risk, such as people who reported more partners.

Sexual health clinic attendance, past 5 years (people aged 16–44)

Number of partners, past 5 years: 10+, 5–9, 2–4, 0–1

Natsal-1 1990–1991 | Natsal-2 1999–2001 | Natsal-3 2010–2012

HIV testing, past 5 years (people aged 16–44)

Number of partners, past 5 years: 10+, 5–9, 2–4, 0–1

Natsal-1 1990–1991 | Natsal-2 1999–2001 | Natsal-3 2010–2012

Non-volitional sex

We asked men and women "since the age of 13, has anyone made you have sex with them, against your will?" which we refer to as 'non-volitional sex'. One in 10 women and one in 71 men said that they had experienced non-volitional sex since age 13.

Proportion of men and women who have experienced non-volitional sex

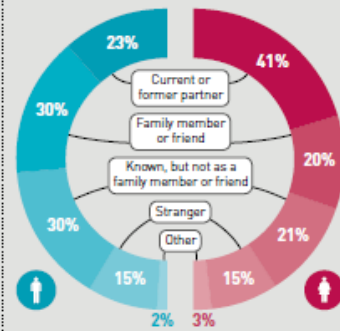**1 in 71** (1.4%)

1 in 10 (9.8%)

Experiencing sex against your will could happen at any age, but it was more common at younger ages.

Median age at most recent occurrence of non-volitional sex

16   18

Person responsible at most recent occurrence

23%

41%

30%

20%

30%

21%

15%   15%

2%   3%

- Current or former partner
- Family member or friend
- Known, but not as a family member or friend
- Stranger
- Other

In most cases the person responsible was someone known to the individual.

We found that people who said they had experienced sex against their will were more likely to report potentially harmful health behaviours and poorer physical, mental and sexual health, including treatment for depression or another mental health condition in the past year, a long-term illness or disability, and a lower sexual function score. We do not know whether these things happened before or after experiencing sex against their will.

Unplanned pregnancy

10% of women aged 16-44 had been pregnant in the past year (given birth, miscarried, or had an abortion in the past year). An estimated one in six of these pregnancies were unplanned, two in six were ambivalent and three in six were planned.

Percentage of women who have been pregnant in the past year

Key: Planned, Ambivalent, Unplanned

(Age groups: 16–19, 20–24, 25–29, 30–34, 35–39, 40–44)
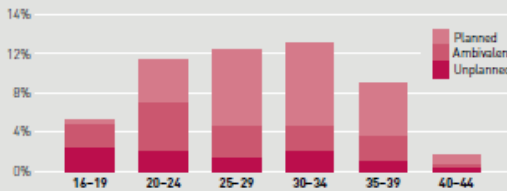
Although pregnancies among 16-19 year old women were more likely to be unplanned than those among older women, most unplanned pregnancies were in women aged 20-34, simply because that is when most women become pregnant.

Age profile of unplanned pregnancies

16–19	20–24	25–29	30–34	35–39	40–44
21%	23%	16%	23%	12%	5%

We found that unplanned pregnancy was less common than has been found in studies done in some other high income countries such as the USA. This may in part reflect the fact that contraception is provided free of charge in Britain under the NHS.

Over the past 60 years, the gap between the age people start having sex, the age they first live with a partner, and the age they have their first child has widened – so there is now a longer period in women's lives where efforts are needed to prevent unplanned pregnancy.

Median age at first intercourse, first live-in relationship and birth of first child

Age

(Year of birth: 1935–39, 1940–44, 1945–49, 1950–54, 1955–59, 1960–64, 1965–69, 1970–74, 1975–79, 1980–84, 1985–89, 1990–96)

Key:
- Birth of first child
- First live-in relationship
- First intercourse

*Some data not shown because less than 50% of age group had experienced event

Natsal-3 is a collaboration between:

UCL · LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE · NatCen Social Research that works for society · Public Health England · MANCHESTER 1824 The University of Manchester

The study was funded through grants from:

MRC Medical Research Foundation · wellcometrust

With additional funding from:

Department of Health · E·S·R·C ECONOMIC & SOCIAL RESEARCH COUNCIL

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Further information

If you would like information or advice about the topics covered in the Natsal study, you can contact one of the organisations below.

NHS website
This website provides information about sexual health and allows you to search for your nearest sexual health service.

⊕ www.nhs.uk/livewell/sexualhealth

Your registered GP
They can provide consultations and refer you to specialist agencies. You can find a GP on the NHS website:

⊕ www.nhs.uk/Service-Search/GP/ LocationSearch/4

Family Planning Association
Provides guidance on where you can seek help for a wide range of issues relating to health, sexual and personal relationships

⊕ www.fpa.org.uk
☎ Helpline 0845 122 8690

British Association for Counselling
Can suggest a local counsellor

⊕ www.bacp.co.uk
☎ 01455 883300

Samaritans
The Samaritans provide counselling and support on any issue of concern

⊕ www.samaritans.org
✉ jo@samaritans.org
☎ Helpline: 08457 909090

Marie Stopes International
Advice and information on a range of topics including family planning, abortion, contraception, sexually transmitted diseases and menopause

⊕ www.mariestopes.org.uk
✉ services@mariestopes.org.uk
☎ Helpline: 0845 300 8090

Men's advice line
Provides advice and support for men in abusive relationships

⊕ www.mensadviceline.org.uk
✉ info@mensadviceline.org.uk
☎ Helpline: 0808 801 0327

London Gay/Lesbian Switchboard
Provides support and information to lesbian, gay, bisexual & transgendered communities throughout the UK

⊕ www.llgs.org.uk
⊕ For info on local lines: www.switchboard.org.uk
✉ admin@llgs.org.uk
☎ Helpline: 020 7837 7324

Relate
Provides counselling and advice on relationship and sexual problems

⊕ www.relate.org.uk
✉ enquiries@relate.org.uk
☎ Helpline: 0300 100 1234

Safeline
Support for adults who have been sexually abused as children

⊕ www.safeline.org.uk
✉ office@safeline.org.uk
☎ Helpline: 01926 402498

Rape Crisis
Provides counselling and help for people who have been raped or sexually assaulted
⊕ www.rapecrisis.org.uk
✉ info@rapecrisis.org.uk
☎ Helpline: 0808 802 9999

The Havens
Provides counselling and help for people in London who have been raped or sexually assaulted

⊕ www.thehavens.co.uk
☎ Camberwell branch: 020 3299 1599
☎ Paddington branch: 020 3312 1101
☎ Whitechapel branch: 020 7247 4787

Sexual Advice Association
(formerly the Sexual Dysfunction Association)
Advice and information on male and female sexual problems

⊕ www.sda.uk.net
☎ Helpline: 020 7486 7262

Appendix I: Flash Card Activity data excerpt

Analysis by participant:

i17

Dimension										
Prevalence	**Common**	Thrush	Chlamydia	Pubic lice		Genital warts	Gonorrhoea	Syphilis	HIV/AIDS	**Uncommon**
Infectiousness	**Easy to catch**	HIV/AIDS	Genital warts Pubic lice Genital herpes Syphilis		Gonorrhoea	Chlamydia		Thrush		**Hard to catch**
Visibility	**Visible**	HIV/AIDS	Genital herpes Genital warts Pubic lice						Syphilis Chlamydia Thrush Gonorrhoea	**Hidden**
Severity	**Mild**	Thrush Pubic lice	Genital warts Genital herpes		Gonorrhoea	Chlamydia			HIV/AIDS Syphilis	**Serious/life-threatening**
Treatability	**Easy to treat**	Thrush Pubic lice Genital warts Genital herpes			Gonnorhoea Chlamydia			Syphilis	HIV/AIDS	**Hard to treat / untreatable**
Personal blameworthiness	**Completely the person's fault**			Syphilis HIV/AIDS		Genital warts Gonorrhoea Chlamydia Pubic lice			Thrush	**Not at all the person's fault**

i18 did not complete flashcard activity

Analysis by continuum theme:

		Other demographics?	Visible							Hidden	STIs removed from activity	Comments
Visibility												
Participant number	Gender											
1	M	x	x	x	x	x	x	x	x	x	x	x
2	F		Pubic lice Genital herpes Genital warts			Gonorrhoea				Thrush HIV/AIDS Chlamydia	Syphilis	
3	F		Chlamydia	HIV/AIDS	Gonorrhoea Genital herpes		Thrush		Syphilis Genital warts	Pubic lice		
4	F		Genital warts	Genital herpes	Pubic lice	Thrush	Chlamydia	Gonorrhoea	Syphilis	HIV/AIDS		
5	x	x	x	x	x	x	x	x	x	x	x	No i5 – withdrew before interview
6	F		Chlamydia	Syphilis	Genital warts Genital herpes	Pubic lice Gonorrhoea				HIV/AIDS Thrush		
7	F		Pubic lice Genital warts Genital herpes Thrush							Chlamydia Gonorrhoea HIV/AIDS Syphilis		
8	F		HIV/AIDS	Thrush	Gonorrhoea	Syphilis		Genital herpes	Genital warts	Chlamydia	Pubic lice	
9	F		Thrush Genital warts Genital herpes Pubic lice			Syphilis Gonorrhoea		HIV/AIDS	Chlamydia			
10	M		Genital warts	Genital herpes	Thrush	Pubic lice		Syphilis Gonorrhoea	Chlamydia HIV/AIDS			
11	M		Genital herpes Pubic lice	Gonorrhoea Genital warts Thrush			Syphilis		Chlamydia	HIV/AIDS		
11 – after googling			Syphilis Genital herpes Pubic lice	Gonorrhoea Genital warts Thrush					Chlamydia	HIV/AIDS		Unsure about syphilis, googled it and then moved the syphilis flashcard to encompass new knowledge
12	F		Pubic lice Genital warts Genital herpes Chlamydia Thrush						HIV/AIDS Syphilis Gonorrhoea			
13	M		Genital warts Pubic lice	Thrush Genital herpes	Syphilis			Chlamydia HIV/AIDS Gonorrhoea				
14	M		Thrush Pubic lice Genital warts Gonorrhoea Syphilis						Chlamydia HIV/AIDS Genital herpes			

Appendix J: Coded transcript excerpt

[Handwritten annotation, left margin: "Spontaneously named HIV"]
[Handwritten annotation: "quite frowned upon' phrase used to hide lack of knowledge / = mild way lack of articulation →nothing it]"
[Handwritten annotation: "Hesitancy, uncertainty around topic"]

I don't know, if you've got like HIV or stuff, and stuff like that it's kind of quite frowned upon I guess to say the least, you're, I don't know, like I say I guess I've never really sort of thought about it.

[Handwritten: "'re-emphasising STIs not something I/he thinks about"]

[Handwritten, right margin: "Not thinking ab STIs → type f"]

Any other sort of STIs that you can think of specifically?

[Handwritten: "? still some uncertainty / hesitancy"]

[Handwritten, left margin: "After prompting, warming up, names STIs individually"]

Chlamydia, gonorrhoea, I don't know, you get genital warts don't you?

[Handwritten, right margin: "Uncertainty over topic → draw th out of ppt."]

Yeah. And do you think these kind of things are thought about differently to like other kind of diseases like a cold or like the flu or something?

[Handwritten, left margin: "STIs different from other disease"]

Yeah.

Why do you think that is?

[Handwritten, right margin: "Colds as common unpreventable,"]

[Handwritten, left margin: "colds are common experience + unpreventable (fatalism) ?applies to everyone (different ages etc)! Common human experience"]

[Handwritten, left margin: "behavioural component of STIs → enables blaming (target) personal responsibility"]

I don't know, I guess colds are more common aren't they? Everyone gets a cold, you know, you can't really prevent a cold but if you're safe and everything you can prevent STIs and things like that.

[Handwritten: "onus on you to prevent STIs"]

[Handwritten, right margin: "Personal respo to prevent / pr yourself from S"]

Do you think there's anything else specifically about STIs that make them really different from other infections? *[Handwritten: "again, individual responsibility"]*

[Handwritten, left margin: "STIs can be used almost like a weapon —spread maliciously, concealed from sex partners (but also issue of unknown infection status)"]

I don't know. I guess people sometimes spread them on purpose or not, not knowingly or they might not tell people.

[Handwritten, right margin: "Invisibility + concea of STIs. Power in act of tran"]

Anything else you can think of? No. Okay, brilliant. And why do you think specifically it is kind of it's like so different? Is it kind of to do with the way they're spread or…?

[Handwritten, left margin: "pick up a cold' - incidental get (catch) STI"]

I guess so, yeah. Because a cold you pick up easily don't you? Whereas, yeah, there's certain notions you have to go through to get STIs. *[Laughs]* *[Handwritten: "hiding the sex act"]*

[Handwritten, right margin: "Concealing mention of sexual activity"]

So it's more a sort of behavioural thing, maybe you've chosen to do?

Yeah.

Yeah, brilliant. Right. So do you think perceptions have changed over time about STIs?

Appendix K: Emergent themes from analysis of semi-structured interview data

Through iterative refinement of my coding and the ordering, organisation and synthesis of emergent themes, I consolidated my analysis. This process enabled me to move from multiple descriptive codes summarising my data to in-depth, interpretative understanding and fewer, higher level interpretation themes. I have presented the themes listed as groups for clarity, but in the data, these themes inter-acted within and across groupings to form a more complex web of relationships.

Themes underpinning empirical results papers:
- STIs as dirty
    - Dirt as a physical, tangible mark
    - Dirt as moral judgement
    - Dirt as vulnerability, susceptibility, contamination
    - Stigmatising dirty sex
    - Silencing and concealing dirt
    - STIs distinguished from other health issues
    - Dealing with dirt – prevention
    - Dealing with dirt – healthcare-seeking
- Seeking and re-gaining control
    - Dimensions of meaning of genito-urinary symptoms
        - Physicality of genito-urinary sensations
        - Boundaries of (ab)normality
        - Searching for causes in relation to concern
    - Strategies to re-gain control over everyday realities
        - Dismissal of care needs
        - Normalising sensations and de-coupling from medical causes
        - Seeking information
        - Choosing, triaging and accessing care within a complex health system
- Concealment and visibility
    - Hiddenness of symptoms and STIs

- Silencing through non-disclosure
- Not seeking help

Inter-secting themes for empirical results papers:

- Time
    - Experiences embedded within a specific social and cultural context
    - Experiences in relation to the life course
    - Ongoing lived realities filtered through time bound methods
- Gender
    - Differences and similarities
    - Physiological experiences of symptoms related to anatomy
    - Gendered opportunities for help-seeking
- Use of and engagement with the internet
    - The internet as a cultural reference point and contested source of knowledge
    - Shared anonymous experiences
    - Mediating understanding and sign-posting

Themes from the flash card activity:

- Disrupting stereotypes of STIs
- Consolidating fractured narratives
- Catalysing spontaneous sense-making
- Legitimising STIs as the subject through adoption of biomedical terminology
- Differentiation and homogenisation of infections
- Forming and re-forming perceptions

Appendix L: Examples of diagrams used to help develop relationships between themes

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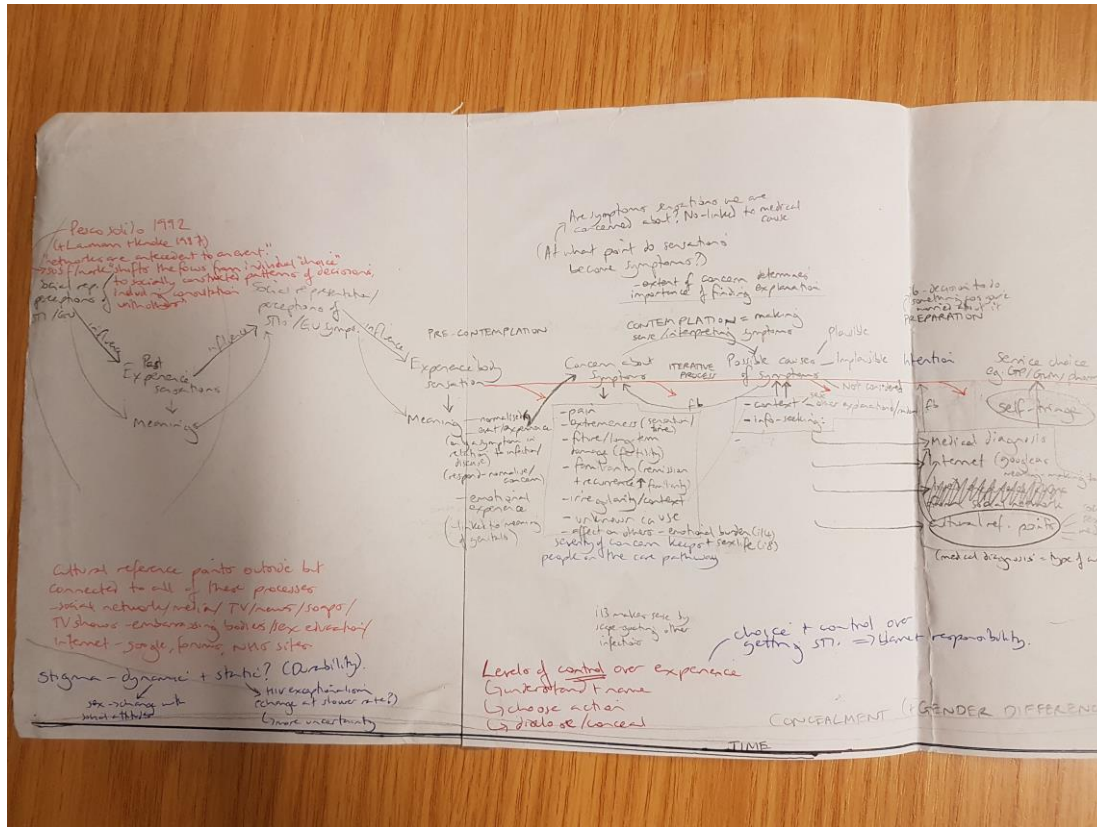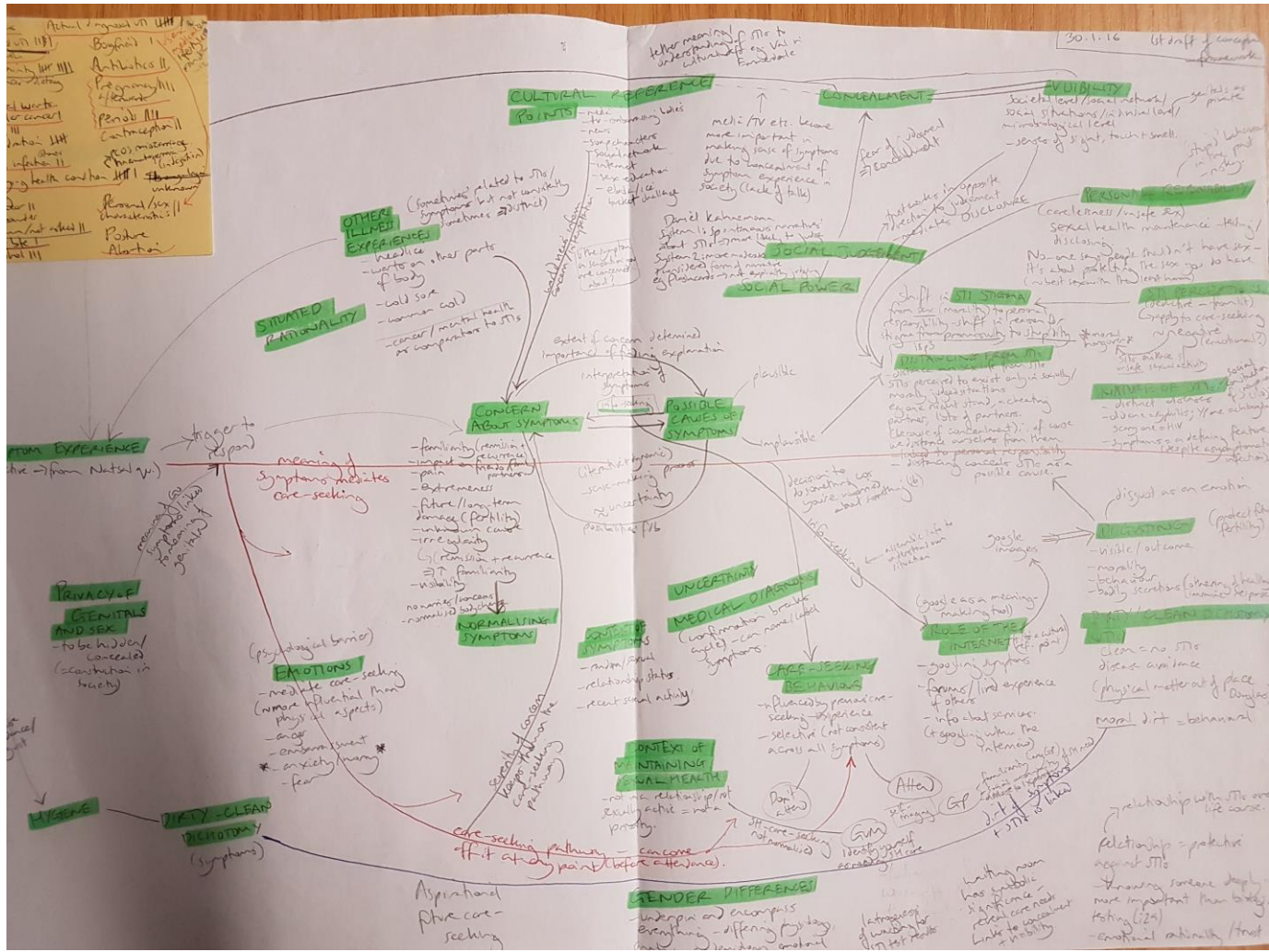
Appendix M: MMAT and GRAMMS appraisal

I have used both the MMAT and GRAMMS frameworks for appraising my use of mixed methods in this thesis. These give similar outputs but with different foci – MMAT gives more of an overview of methodological quality and GRAMMS assesses the implementation and description of the study with greater emphasis on the integration and inferences of combining the data than MMAT. Both were useful for guiding the study and structuring discussion of the limitations. From this appraisal, this study is limited by the response rate of 57% for Natsal-3. This is in line with declining response rates in other social surveys (de Leeuw and de Heer, 2002; Williams *et al.*, 2016). The statistical analyses conducted about non-attendance at sexual health clinics were amended slightly to prevent overlap with another Natsal-3 paper on service use although this did not affect the overall story of the help-seeking paper significantly as this is a mixed methods study with a dominant qualitative component and the emphasis was on exploring different types of help-seeking to expand survey findings. Finally, the expertise and skill employed to carry out this study is commensurate with my experience as a researcher and I have developed these skills through doing this PhD.

MMAT appraisal of this study adapted from Part 1 MMAT criteria & one-page template (Pace *et al.*, 2012)

Types of mixed methods study components or primary studies	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions	• Are there clear qualitative and quantitative research questions, or a clear mixed methods question?	x			The overall empirical research questions for the study are mainly qualitative reflecting the dominant qualitative component; there is a methodological mixed methods question as well; each research paper has specific research questions
	• Do the collected data address the research questions?	x			Survey data produced prevalence estimates and odds ratios for key variables and semi-structured interview data explored sense-making of lived experiences of stigma, symptoms and help-seeking
1. Qualitative	1.1 Are the sources of qualitative data relevant to address the research question?	x			Interview data explored STIs, symptom experiences, help-seeking and STI stigma
	1.2 Is the process for analysing qualitative data relevant to address the research question?	x			IPA focusses on understanding participants' lived experiences and how they make sense of their everyday reality

	1.3 Is appropriate consideration given to how findings relate to the context?	x			Contextual details about participants are given; findings re discussed in relation to individual experiences and socio-cultural environment
	1.4 Is appropriate consideration given to how findings relate to researchers' influence?	x			Reflexivity is a theme that runs through this thesis and collated in section 6.6
2. Quantitative (descriptive)	2.1 Is the sampling strategy relevant to address the quantitative research question/quantitative aspect of the mixed methods question?	x			I used a sub-set of Natsal-3 data from sexually experienced participants aged 16-44 who reported symptoms in the past month
	2.2 Is the sample representative of the population under study?	x			The sample is weighted to 2011 census data and is broadly representative of the British population but excludes those not resident in a private household
	2.3 Are measurements appropriate?	x			The survey was developed using cognitive interviewing and psychometric testing
	2.4 Is there an acceptable response rate (60% or above)?		x		Response rate was 57% in line with similar surveys
3. Mixed methods	3.1 Is the mixed methods research design relevant to address the qualitative and quantitative research questions or the qualitative and quantitative aspects of the mixed methods question?	x			Explanatory sequential mixed methods study design

	3.2 Is the integration of qualitative and quantitative data relevant to address the research question?	x			Convergent coding matrices, mixed methods matrices and joint displays used to integrate findings according to the research questions of the paper (research papers 5 and 6)
	3.3 Is appropriate consideration given to the limitations associated with this integration?	x			Full discussion of the limitations of integration and impact on findings is presented in section 6.2

GRAMMS appraisal of this study - adapted from O'Cathain, Murphy and Nicholl (2008)

	Item	Yes	Yes, but	No	NEI/NA	Comments
	1. Assessment of the success of using mixed methods					
1.1	Is the quantitative component feasible?	x				
1.2	Is the qualitative component feasible?	x				
1.3	Is the mixed methods design feasible?	x				
1.4	Have both qualitative and quantitative components been completed?	x				
1.5	Were some quantitative methods planned but not executed?		x			Slight amendment to planned analyses for profile of non-attenders due to overlap with another Natsal-3 paper on service use
1.6	Were some qualitative methods planned but not executed?			x		
1.7	Did the mixed methods design work in practice?	x				
	2. Assessment of the mixed methods design					
2.1	Is the use of mixed methods research justified?	x				See section 2.2.1 in methodology, chapter 2
2.2	Is the design for mixing methods described? - Priority - Purpose - Sequence	x				See study protocol paper

		- Stage of integration					
2.3	Is the design clearly communicated?	x					See figure 1 in study protocol paper
2.4	Is the design appropriate for addressing the research questions?	x					
2.5	Has rigour of the design been considered (proposal) or adhered to (report)?	x					
3. Assessment of the quantitative component							
3.1	Is the role of each method clear?	x					
3.2	Is each method described in sufficient detail?	x					
3.3	Is each method appropriate for addressing the research question?	x					See explanation of research questions in section 1.7 in introduction, chapter 1 and the research questions included in research papers 4-6.
3.4	Is the approach to sampling and analysis appropriate for its purpose?	x					
3.5	Is there expertise among the applicants/authors?		x				I have undertaken training in statistical methods and mixed methods during my PhD and my skills are commensurate with my experience as an early careers researcher
3.6	Is there expertise on the team to undertake each method?	x					My supervisors and advisory committee have helped guide and shape this study from the initial idea through data collection and analysis to writing up

3.7	Have issues of validity been addressed for each method?	x				
3.8	Has the rigour of any method been compromised?			x		
3.9	Is each method sufficiently developed for its purpose?	x				
3.10	Is the analysis sufficiently sophisticated?	x				
4. Assessment of the qualitative component						
4.1	Is the role of each method clear?	x				
4.2	Is each method described in sufficient detail?	x				
4.3	Is each method appropriate for addressing the research question?	x				
4.4	Is the approach to sampling and analysis appropriate for its purpose?	x				
4.5	Is there expertise among the applicants/authors?		x			I have conducted qualitative studies using interviews before this PhD study. My skills in qualitative research have been further developed through workshops, seminars and reading relevant literature
4.6	Is there expertise on the team to undertake each method?	x				As per item 3.6
4.7	Have issues of validity been addressed for each method?	x				

4.8	Has the rigour of any method been compromised?			x		
4.9	Is each method sufficiently developed for its purpose?	x				
4.10	Is the analysis sufficiently sophisticated?	x				
5. Assessment of integration						
5.1	Is the type of integration stated?	x				
5.2	Is the type of integration appropriate to the design?	x				
5.3	Has enough time been allocated for integration?	x				
5.4	Is the approach to integration detailed in terms of working together as a team?			x		As this is a PhD, I have undertaken all of the analyses and integration by myself
5.5	Does the dissemination strategy detail how the mixed methods will be reported in final reports and peer-reviewed publications?				x	
5.6	Are the personnel who participate in the integration clearly identified?	x				
5.7	Did appropriate members of the team participate in integration?				x	
5.8	Is there evidence of communication within the team?				x	

5.9	Has rigour been compromised by the process of integration?			x		
6.	Assessment of the inferences made					
6.1	Is there clarity about which results have emerged from which methods?	x				
6.2	Are inferences appropriate?	x				
6.3	Are the results of all the methods considered sufficiently in the interpretation?	x				

NEI – not enough information; N/A – not applicable

Appendix N: Accepted conference abstracts 2015 - 2017

Sociology of diagnosis, LSHTM, May 2015 (oral presentation): *An unwelcome diagnosis – the case of sexually transmitted infections*

22nd Congress of the World Association for Sexual Health, Singapore, July 2015 (two oral presentations): *Experience and meaning of genital symptoms to people in Britain: Findings from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)*

22nd Congress of the World Association for Sexual Health, Singapore, July 2015 (two oral presentations): *Dirty, disgusting but not always deviant: an exploration of the complex narratives and perceptions about STIs and HIV in Britain*

Applied Qualitative Health Research symposium "Modern Dilemmas in Qualitative Health Research," London, May 2016 (oral presentation): *Why do people Google STI symptoms?*

British Association of Sexual Health and HIV annual conference, Oxford, July 2016 (poster presentation): *Why don't people with genito-urinary symptoms go to sexual health clinics? A mixed methods study about meanings of symptoms and care-seeking using the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)*

Mixed Methods International Research Association Conference, Durham, August 2016 (oral presentation): *The untapped potential of national survey data in mixed methods research: using Britain's third National Survey of Sexual Attitudes and Lifestyles (Natsal-3) as an example*

British Sociological Association Medical Sociology Group Annual Conference, Birmingham, September 2016 (poster presentation): *Making sense of genito-urinary symptoms: a mixed methods study*

Society for Social Medicine Annual Conference, York, September 2016 (poster presentation): *Extending conceptualisations of care-seeking behaviour: qualitative findings from follow-up interviews with participants from the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)*

The International Interpretative Phenomenological Analysis Conference, Glasgow, May 2017 (oral presentation): *Seeking care, seeking control: mixed methods exploration of STI care-seeking behaviour*

23rd Congress of the World Association for Sexual Health, Prague, May 2017 (oral presentation): *Seeking care, seeking control: mixed methods exploration of STI care-seeking behaviour*

Symptom Research in Primary Care 2017, Netherlands, September 2017 (oral presentation): *Making sense of sexually transmitted infection symptoms: a mixed methods study*

Making sense of genito-urinary symptoms

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1. Introduction

Genito-urinary symptoms can be caused by gynaecological cancers, urinary tract infections or sexually transmitted infections. Mis-recognition and mis-interpretation of symptoms can delay care-seeking and increase the risk of negative health outcomes. However, we don't know how individuals experience and make sense of symptoms outside of medical settings.

Genito-urinary symptoms: Pain urinating, Genital ulcer, Odour with discharge, Painful testicles, Bleeding between periods, Abdominal pain, Genital wart, Abnormal vaginal discharge, Penile discharge, Painful sex, Bleeding after sex

2. Research questions

- How common are genito-urinary symptoms?
- How do people make sense of symptoms?
- What are the lived experiences of genito-urinary symptoms?

3. Methods

Explanatory sequential mixed methods design

Secondary analysis (n=8,947) of the third National Survey of Sexual Attitudes and Lifestyles (Natsal-3)

Semi-structured interviews with Natsal-3 participants (16 women, 11 men) using principles of Interpretative Phenomenological Analysis

Study protocol:

The cause-concern cycle

4. Results

22% of women and **6%** of men had experienced symptoms in the past month
**Pain urinating** was the most common symptom: 7% of women and 3% of men

Participants made sense of their sensations and symptoms through an iterative, mutually informative process oscillating between **concern** about symptoms and possible **causes** of symptoms (shown in the cause-concern cycle diagram).

The level of concern determined the importance in finding an explanation for the experience which led to a range of possible causes being considered. The most likely causes in turn fed back into the level of concern expressed about symptoms.

Meanings are imported from other sources:
"You come up to [internet] forums and stuff where people have had some sort of problem like that and they discuss it so it's getting an answer back from someone who's kind of experienced the same thing rather than going to a doctor. (I27, female, aged 29, abnormal vaginal discharge)"

Meaning enables control over experience:
"Of course it was horrendous and all that but I felt I was in control…I felt that I know what it is, I don't need to be scared. (I25, female, aged 47, pain urinating)"
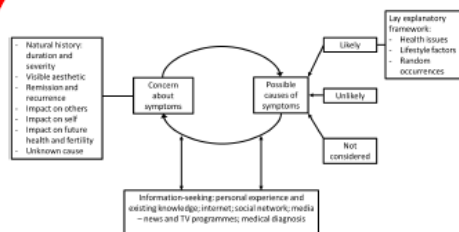
5. Conclusion

Genito-urinary symptoms are more commonly reported by women than men, however the meanings attributed to bodily sensations mediate interpretation of the experience.

The cause-concern cycle helps explain how meanings about symptoms are generated and how individuals use meanings to gain control over their lived experience of symptoms.

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Mixing up mixed methods research

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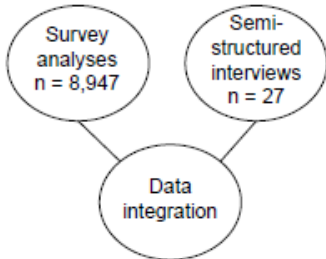[1]London School of Hygiene & Tropical Medicine, UK, [2]University College London, UK

❶ Definition of mixed methods research

Mixed methods research combines elements of **qualitative** and **quantitative** research approaches to achieve **breadth** and **depth** of **understanding** and **corroboration**.

❷ The problem with mixed methods research

Data integration is integral to mixed methods research but is poorly done. I present two integration approaches I used in my PhD exploring stigma, STI symptoms and help-seeking: **convergence coding matrix** and **joint displays**.

❸ Methods

Survey analyses n = 8,947

Semi-structured interviews n = 27

Data integration
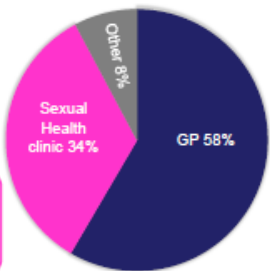
❹ Convergence coding matrix

Purpose: Integrate survey and semi-structured interview findings **at research question level**

Research question	Survey findings (quantitative)	Semi-structured interview findings (qualitative)	Integration
What are the service preferences of people with STI symptoms?	• 59% of women and 54% of men preferred the GP • Sexual health clinics preferred if previously attended (OR 8.0 women and OR 7.2 men)	• Participants preferred familiarity of GP • Different help-seeking for different symptoms • Complex service choice decision-making in response to symptoms	GP generally preferred for STI symptom care. Previous attendance and familiarity at sexual health clinics prompted future attendance. Service choice is important in sexual healthcare provision

❺ Joint display

Purpose: Integrate survey and semi-structured interview findings **visually to develop new insights**

"it's more convenient to just Google it [symptoms] and self-diagnose" (I16, woman, aged 25-29)

"Yeah, there was a delay...it wasn't straight to the clinic...I wasn't in a rush [to get rid of genital warts] and I wasn't sexually promiscuous" (I13, man, aged 20-24)

Other 8%
Sexual Health clinic 34%
GP 58%

"if you don't know you've got the symptoms for that particular disease, you don't know to go to a sexual health clinic" (I11, man, aged 16-19)

Service preference for STI care

❻ Conclusion

- Matrices and joint displays are useful analytical and presentation tools for integrating qualitative and quantitative data
- Continued innovation is needed, focussing on bringing data together visually to draw out inferences

❼ References

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