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### Conceptualising quality of life outcomes for women participating in testing for sexually transmitted infections

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## **Abstract**

Many public health interventions have aims which are broader than health alone; this means that there are difficulties in using outcome measures that capture health effects only, such as Quality Adjusted Life Years (QALYs). Sexually Transmitted Infections (STIs) are a major public health concern both in the UK and globally, with *Chlamydia trachomatis* being the most common bacterial STI worldwide. There is scope for the wider use of qualitative syntheses in health-related research; in this study we highlight their potential value in informing outcome identification, particularly for public health interventions where a broad range of outcomes may need to be considered. This article presents a systematic review and meta-ethnography of qualitative studies that investigated women's experiences of thinking about and participating in testing for chlamydia. The meta-ethnography highlights issues relating to beliefs about STIs and testing, assessing risk and interpreting symptoms, emotional responses to testing, coping with diagnosis, relationship with sex partners(s), informal support, and interaction with health care services. The study findings suggest that women can experience a range of impacts on their health and quality of life. It is important that this range of effects is taken into account within evaluations, to ensure that decision makers are fully informed about the outcomes associated with screening interventions, and ultimately, to make sure that appropriate interventions are available to support women in maintaining good sexual health.

**Key words:** meta-ethnography; sexually transmitted infections; quality of life; public health; health economics.

# **Conceptualising quality of life outcomes for women participating in testing for sexually transmitted infections: a systematic review and meta-synthesis of qualitative research.**

## **Introduction**

As health care resources are scarce, the benefits of alternative interventions or programmes often need to be identified, measured, valued and compared alongside their costs (Drummond et al., 2005). Many decision-making bodies prefer the effects (or benefits) of interventions to be measured in the form of Quality Adjusted Life Years (QALYs) (e.g. National Institute for Health and Care Excellence (NICE), 2013; Pharmaceutical Benefits Advisory Committee, 2008). However, there are difficulties in applying this approach to evaluations of public health interventions (Edwards et al., 2013; NICE 2012). The use of QALYs necessarily implies that the objective of the intervention is to maximize health (Mooney, 2003). Many public health interventions aim to affect broader aspects of quality of life which means that measuring outcomes in terms of QALYs alone may miss important intervention effects (Lorgelly et al., 2010).

Sexually Transmitted Infections (STIs) are a major public health concern globally, with *Chlamydia trachomatis* (chlamydia) being the most common STI in the UK (Public Health England., 2015). Because STIs such as chlamydia are frequently asymptomatic, screening is recommended in many countries; however more evidence is required about the effectiveness and cost-effectiveness of such interventions (Low et al., 2009; Jackson et al. 2014). There is a paucity of standardised tools and guidance about how outcomes should be measured for those accessing sexual health services and about which aspects of health and quality of life should be considered (World Health Organisation, 2010; Stephens et al., 2013).

Exploration of the existing evidence is recommended to identify appropriate outcome measures (Streiner and Norman, 2008). Methods of qualitative synthesis can help to overcome some of the potential limitations associated with narrative literature reviews which can be viewed as susceptible to bias and unsystematic (Campbell et al., 2011). Methods for synthesising qualitative evidence are relatively new and there is scope for their wider use within health-related research (Al-Janabi et al.,

2008; Bennion et al., 2012; Campbell et al., 2011); in this paper we highlight their potential value in informing outcome identification.

A rich body of research exists which explores people's experiences of thinking about the possibility of having an STI and participating in testing. We undertook a synthesis of these qualitative studies to identify key concepts and themes, to identify appropriate outcomes in STI screening for curable diseases such as chlamydia. Our objective was to explore women's experiences of thinking about the possibility of being at risk and undergoing testing/ screening for an STI, and to examine any reported impacts on their health and quality of life. The study addressed these questions primarily through the lens of chlamydia infections and their sequelae. However, this emphasis was not exclusive as chlamydia is often linked with other STIs, and evidence suggests that public knowledge about specific STIs is limited (Chaudhary et al., 2008). We focused on women's experiences of thinking about and participating in STI testing as guidance suggests that gender is a critical factor to take into account when planning, implementing and evaluating interventions in this area (National Chlamydia Screening Programme, 2009).

## **Methods**

As qualitative syntheses represent a relatively new research area, there are no agreed guidelines about how they should be undertaken and a range of approaches are possible (Campbell et al., 2011). We adopted the approach of meta-ethnography (Noblit and Hare, 1988) as adapted to health research by Britten et al. (2002). Meta ethnography is an interpretative approach which involves the 'translation' of studies into each other (Britten 2002). This involves comparing the concepts and their interrelationships in one study with those in another study, whilst respecting original meanings and context. The aim is to generate new theoretical understandings which allow us to better understand the 'whole (organization, culture etc.) based on selective studies of the parts' (Noblit and Hare, 1988, p. 62). Ethical approval was not required for this study as it involved the review and synthesis of existing qualitative studies.

### *Systematic search and screening*

A search was conducted of six electronic databases: MEDLINE, EMBASE, CINAHL, Web of Science, PsycINFO, and Sociological Abstracts to the end of June 2013 by LJ with support from TR (an example of a search strategy is given in Appendix 1) [Insert link to Appendix 1]. This was supplemented by hand searching of key journals and references. The SPICE framework (a generic model for question formulation) was used to guide the literature searching (Booth and Brice, 2004):

- **S**etting: primary care, sexual health centres, or general community settings
- **P**erspective: young women (aged 18-35)
- **I**ntervention: thinking about or undergoing testing for STIs
- **C**omparison: other health concerns, accessing other types of testing / screening
- **E**valuation: attitudes, views, beliefs, emotions, symptoms

We used a three stage process to identify studies for inclusion (Roberts et al., 2002). Initially, papers were screened using the title and abstract to identify potentially relevant papers. Papers were then sorted into five groups (A to E) according to the STIs they were concerned with (Table 1). Papers which were labelled as concerned with experiences of testing for curable STIs (Category A) or potentially relevant (Category D) were analysed further. Those mainly concerned with incurable STIs such as HPV and HIV (Categories B and C) were excluded, as evidence suggests that the perceived permanence of these diseases plays an important role in women's experiences of receiving a positive diagnosis (Nack, 2008). Next, the full texts of potentially relevant studies were read and they were classified into six further groups based on the methods used to conduct the research and whether primary or secondary data was reported (Table 1). We included studies with a variety of epistemological frameworks and examined study perspective as part of our analysis. [Insert Table 1 here]

### *Critical appraisal*

Once potential studies for inclusion had been identified, they were appraised using a modified version of the CASP (Critical Appraisal Skills Programme) checklist. We used an approach outlined by Dixon-Woods et al., (2007), which involves assessing the relevance and value of papers to the synthesis, rather than using reporting quality to exclude papers (Bennion et al., 2012; Campbell et al., 2011; Malpass et al., 2009). Using this method, a double review was undertaken, whereby we independently assessed whether papers were ‘key papers’ (KP) which meant that they were valuable to the synthesis, ‘satisfactory papers’ where they were less conceptually rich but still potentially valuable (SAT), or whether we were ‘unsure’ (?) about the value of the paper to the synthesis. A sensitivity analysis was undertaken to examine the impact of excluding papers on the basis of reporting quality.

### *Translating and synthesising the studies*

Initially we read and re-read the papers in chronological order and recorded details about each study in a data extraction form. Alongside information about the study context and methodology, we also extracted second order constructs we identified within the studies, illustrating them with first order constructs (Malpass et al., 2009). This was done independently by the authors. First order constructs are patients’ views and interpretations of their experiences as reported in direct quotations; second order constructs are the study authors’ interpretations of patient views, and third order constructs represent the interpretations of the synthesisers (Campbell et al. 2003). Working definitions of first and second order concepts were developed, which were subsequently adapted. We created a grid of common and recurring second order concepts (key concepts), which we then completed with the second order interpretations from each paper, illustrated with first order constructs, and included relevant details about the study setting (Britten et al., 2002; Malpass et al., 2009). The grid was used collaboratively to understand how the studies were related to each other and analyse the second and first order constructs (Bennion et al., 2012; Malpass et al., 2009; Shaw, 2011). By comparing the concepts within the papers and our interpretations of them, a ‘reciprocal’ relationship between the studies became evident (Noblit and Hare, 1988). We then continued the process of translating the

studies into one another and further developed the ‘key concepts’ to ensure that they fully encompassed the concepts described in the original papers. We developed third order concepts using a ‘line of argument’ approach which involved considering the translations of the studies and bringing them together to construct an over-arching interpretation (Britten et al., 2002; Campbell et al., 2011). This process was led by LJ, with TR working independently to check and confirm the third order concepts.

## **Results**

The search process identified 525 papers. Exclusion of duplicates and the initial screening of abstract and titles led to 123 papers being assessed for inclusion. A flow diagram is given in Figure 1 which shows the steps undertaken and the number of papers included and excluded at each stage. Further analysis and categorisation of the studies led to 47 papers being read in full to determine their suitability for inclusion and 14 studies (15 papers) were included for critical assessment. Two main groupings were identified in terms of the nature of the testing being considered: papers concerned with people’s experiences of being *offered* opportunistic testing for STIs in a variety of settings and those concerned with people’s experiences of *coming forward* for STI testing in a healthcare setting. Initially these two groupings were considered separately, but detailed assessment of the women’s experiences suggested that the decision making processes were comparable and that the studies could be synthesised together. In the reporting which follows ‘participation in testing’ is used to refer to taking part in all kinds of testing and screening. [Insert Figure 1 here]

### *Critical appraisal*

All the studies were judged to be of at least ‘satisfactory’ quality, although not all provided sufficient information to fully satisfy the requirements of the critical appraisal tool (Appendix 2) [Insert link to Appendix 2]. No papers were excluded on the basis of quality; the tool was used to identify potential limitations in the papers, and to provide information to enrich the synthesis (Dixon-Woods et al. 2007).

### *Theoretical standpoints*

Several studies employed Goffman's stigma framework to interpret women's accounts of thinking about or participating in testing (Balfe and Brugha, 2009; Balfe et al., 2010; East et al., 2010 & 2011; Mills et al., 2006; Mulholland and Van Wersch, 2007). This framework sees stigma as socially defined and relates to attributes or labels which set individuals or groups apart from others and make them inferior. Two of the studies also included theoretical perspectives on gender, with Oliffe and colleagues (2011) adopting a gender relations approach to examine women's engagement with STI testing and East et al. (2010) utilising feminist theories concerned with the social construction of female sexuality.

### *Synthesis findings*

Fourteen studies were selected for synthesis. The aims, participants and methods used in the studies are shown in Table 2. We developed seven over-arching concepts which were important to women's quality of life when thinking about and participating in testing. Table 3 shows the concepts and demonstrates which themes were present in each paper, together with quotes to illustrate the concepts. The concepts we identified were: beliefs about STIs and testing; assessing risk and interpreting symptoms; emotional responses to testing; coping with diagnosis; relationship with sex partners(s); informal support; and interaction with healthcare services. [Insert Tables 2 and 3 here]

*Beliefs about STIs and testing.* The synthesis of the studies revealed that beliefs about STIs underlie all aspects of women's experiences of thinking about and participating in testing. Nearly all of the authors highlighted the role of stigma in framing beliefs about STIs; they were generally assumed to be associated with promiscuous, risky and careless behaviour. The majority of the studies demonstrated that such stigma was gendered and had particular implications for women due to differing social expectations around male and female sexual behaviour. Such 'double standards' were often highlighted by the participants themselves: "if you are a girl who has slept with a lot of people it looks quite bad – for a bloke it is different because men are out and they sleep with a lot of people-it is a manly thing – it is quite good and stuff- but a girl who has slept with a lot of people is viewed as a bit of a tart and a slag." (Mulholland and Van Wersch 2007, p. 22).



Most of the studies argued that prior to undertaking testing, it was generally seen as stigmatised activity, particularly for females, as needing or participating in testing was associated with promiscuity: “There is a risk of going for a test. There’s a big risk of it. You’re afraid to be called a slut or a slag for going for an STI test, even if you were just doing it for a check-up.” (Balfe et al., 2010; p. 139). Alongside such concerns, some authors also reported a lack of awareness of what STI testing involved and a fear that it would be invasive, embarrassing and uncomfortable (Balfe & Brugha, 2009; Balfe et al., 2010; Dixon-Woods et al., 2001; Duncan et al., 2001; Mills et al. 2006; Richardson et al., 2010). Only one study found that a small number of women actively challenged dominant notions of femininity and the stigma associated with STI testing (Olliffe et al., 2012).

*Assessing risk and interpreting symptoms.* The overwhelming majority of studies reported that most women, prior to any participation in testing, felt ‘invulnerable’ to infection. Participants assessed their own risk via comparisons with the assumed behaviour of the ‘type’ of people they believed were at risk of contracting STIs. The assessment of risk associated with sexual partners was also based on comparisons with stereotypical notions of those who contract STIs: “I just thought he wasn’t likely (to have an STI), I mean he was clean, good looking, had a nice car.” (Newby et al., 2012, p. 149).

Several studies reported that any symptoms were generally interpreted with reference to a ‘lay understanding’ of their meaning (Dixon-Woods et al. 2001) and often attributed to other, more ‘innocent’, causes e.g. ‘women’s problems’ and ignored for as long as possible. There were also difficulties reported with understanding that an absence of symptoms didn’t necessarily mean that an STI was not present, although theoretically many women knew that STIs could be asymptomatic, they found this hard to take on board because: “..you’re bound to have something that would tell you.” (Santer et al., 2003, p. 58).

*Emotional responses to testing.* The main emotions reported in the studies were feelings of fear, anxiety and embarrassment. Several of the authors linked this to the stigma associated with STIs (Balfe et al., 2010; Dixon-Woods et al., 2001; Lorimer et al., 2009; Mills et al., 2006; Mulholland & Van Wersch, 2007, Richardson et al. 2009). For example, the authors found that women were worried about being seen by others and for others to know that they were being tested: “at first I felt

like – my God – does everyone know that I’ve got some kind of sexually transmitted disease – and I was looking about thinking don’t let anyone catch my eye – I felt horrible.” (Mulholland and Van Wersch, 2007, p.24-25). For those attending primary care, it was often embarrassing to raise this issue with the GP (Dixon-Woods 2001), and Lorimer et al (2009) reported that women who undertook screening in non-medical settings hid their testing packs inside coats and bags. There were also some positive emotions reported by the women in connection with their testing experiences. For example, Oliffe et al. reported that for some women there was the perception that undertaking testing was part of a woman’s ‘responsibility’ in terms of maintaining a couple’s sexual health, and was connected to their ‘caring’ role within sexual relationships (Oliffe et al., 2012). Balfe and Brugha (2009) reported that participating in testing was seen by some women as ‘moral’ thing to do and made them feel that they were taking control and acting responsibly; for example, one woman reported that as a result of testing she felt “Better. Like I was someone who had done something right.” (Balfe and Brugha, 2009, p.4).

*Coping with diagnosis.* Many of the studies reported that receiving a positive diagnosis was a shock to participants, with impacts on their sense of identity (Duncan et al. 2001, East et al 2010, Mills et al. 2006, Mulholland and Van Wersch 2007). Some of the studies demonstrated that women tended to take on the blame for the infection, even blaming themselves for their partners’ actions (Darroch et al., 2003; Duncan et al., 2001; East et al., 2010). East and colleagues analysed this reaction in terms of dominant discourses around gender which situate females as responsible for male sexual behaviour: “I felt pissed off at myself, because I should have been more careful; and [not] allowed myself to be in that situation where I was at risk...” (East et al., 2010, p.1998).

However, several authors reported that many of those who tested positive also expressed relief that the infection had been found and treated. A number of studies also reported that a minority of women viewed STIs such as chlamydia as a relatively minor infection and were not concerned if they were diagnosed as having it. This was generally seen as a coping mechanism, with women trying to distance themselves from the stigma associated with STIs (East et al., 2010; Mills et al., 2006).

Multiple studies reported that women with a positive diagnosis were anxious about the effect of infection on their future reproductive health (Darroch et al 2003, Duncan et al. 2001, Mills et al. 2006). The uncertainty surrounding the nature and likelihood of future complications added to their anxiety: “So anyway I don’t know ...the things I was worried about she [the doctor] didn’t seem to give me any answers on.” (Duncan et al., 2001, p. 197).

*Relationship with sex partner(s).* Many of the studies highlighted that women who tested positive for chlamydia were anxious about the impacts on their sexual relationships. For those in longer term relationships, the possibility of infidelity created tension and strain in the relationship: “he says it’s not him but I’ve not slept with anyone else, he’s the only one....Yeah I was very upset. I spoke to him on the phone but he just kept saying he didn’t have it, it wasn’t from him.” (Darroch et al., 2003, p.373). Informing previous partners was perceived as difficult, particularly if the relationship had not ended on good terms. Fears about the impact that informing partners about testing and diagnosis meant that some women chose not to disclose their diagnosis to their sex partners, which sometimes led to feelings of guilt. However, for those that did inform partners, in most cases, this was not as bad as the women had anticipated (Mills et al. 2006).

*Informal support.* Multiple studies reported that women were not able to access their usual informal support networks when thinking about and participating in STI testing. Friedman and Bloodgood (2010) linked this to a wider aversion to discuss STIs with friends or family. The majority of women were reluctant to tell many of their family and friends that they were attending for testing and many women who tested positive either concealed their diagnosis or only told selected people, which tended to increase feelings of isolation: “From that point of view you feel very isolated because you can’t really talk about it, I suppose you could but you know other people’s reactions would put you off.” (Duncan et al., 2001, p. 196).

*Interaction with healthcare services.* There were two main areas of focus in relation to interaction with healthcare services in the studies – problems with access and the important role of staff in addressing the stigma associated with STIs. Problems of access involved primary, community and specialist care. For example, multiple authors argued that women were anxious about attending GUM

clinics as these were seen as 'tainted' with the stigma associated with STIs (Dixon-Woods et al., 2001; Duncan et al., 2001; Mulholland & Van Wersch, 2007; Richardson et al., 2010). One participant described a GUM clinic as: "that sort of place, you know, like filthy men go and a lot of men sitting about." (Duncan 2001, p. 196). Infrastructural issues were also raised as reasons for not accessing or delaying testing by some participants; this included factors such as the availability of provision which was non-judgemental, opening hours, waiting times, costs etc. (Balfe and Brugha 2009).

The authors of several included studies argued that participants were particularly sensitive to how they were treated by staff and that staff played a critical role in helping to 'normalise' the testing experience (Balfe & Brugha, 2009; Dixon-Woods et al., 2001; East et al., 2012; Mulholland & Van Wersch, 2007). Many participants in these studies were relieved with how they were treated by staff: "when I first went to a clinic I thought everyone was going to be judgemental of me and it's nice that people aren't" (Mulholland and Van Wersch., 2007, p.24). However, East and colleagues (2011) reported that some of the women they interviewed felt that their experiences with healthcare staff had been negative.

## Discussion

The meta-ethnography highlighted a wide range of factors which were important to women when participating in testing and allowed the development of seven over-arching concepts to inform the identification of appropriate outcomes for chlamydia testing and screening with women. There was some overlap between these concepts, as for example, the synthesis showed that beliefs about STIs and testing meant that women were less able to access their normal informal support networks. The results of this synthesis demonstrate that there can be a range of impacts on quality of life associated with testing and diagnosis for STIs which need to be taken into account within evaluations of interventions which aim to improve sexual health, and that these are broader than health alone. Figure 2 demonstrates how the concepts developed through the meta-ethnography were used to identify appropriate domains for outcome measurement for the purposes of evaluation. [Insert Figure 2 here]

The results of the synthesis also have broader policy implications. The findings demonstrate that the stigma surrounding STIs often affects the way that women think about and experience testing. This highlights the importance of designing interventions which address such issues and ensuring that appropriate support structures are in place.

Only three other reviews were identified which examined the effects of participating in STI testing. Pavlin and colleagues (2006) reviewed both qualitative and quantitative evidence to examine 'what do women think about chlamydia screening'. Their findings support those of this study in relation to the fear, anxiety and stigma which surround STI screening. However, their review was directed at understanding which factors promote and prevent participation in screening rather than exploring women's experiences in depth. Balfe et al. (2012) provided a wide ranging review of men's experiences of chlamydia testing; however, qualitative and quantitative evidence were analysed narratively together. Hood and Friedman (2011) summarised the existing literature on STI stigma and strategies to address its effects. However, this analysis was wide ranging and only a small amount of space was given to discussing the impacts of stigma on those participating in testing. The current synthesis is the first study which adopts a meta-ethnographic approach to understand women's experiences of thinking about and participating in testing and the impacts on their quality of life.

### *Methodological considerations*

The findings of this study underline the potential advantages of meta-ethnography as a method to inform the identification of outcomes that matter to patients, as well as highlighting potential challenges. The main strength of this study is its comprehensive attempt to examine the health and non-health effects of thinking about and undergoing STI testing for women. The search and inclusion strategies were broad and systematic. The meta-ethnography provided a useful framework for engaging with the rich qualitative evidence which exists in this field and facilitated the development of concepts to inform outcome measurement. The results of the study show that meta-ethnography can provide a useful structure to engage with the literature and can help facilitate transparent reporting of the stages involved in the identification of outcomes (Al-Janabi et al., 2008). Meta-ethnography also provides a mechanism for bringing together the findings from diverse studies in order to give a more comprehensive understanding of a particular issue; which is potentially useful, as it is important to ensure that outcome measures are relevant to the majority of those potentially targeted by an intervention (Streiner and Norman, 2008).

There may also be some limitations around the use of methods of qualitative synthesis, and particularly meta-ethnography, to inform outcome development. In this study meta-ethnography was used to synthesise qualitative research in a reductive manner, as the aim was to develop overarching concepts which would encompass all the aspects which women felt were important to their quality of life in this context (Coast and Horrocks, 2007). There may be a tension between this intention and the usual purpose of meta-ethnography to obtain an 'interpretative explanation' of phenomena (Al-Janabi et al., 2008). This tension was particularly evident around attempts to develop over-arching concepts around women's experiences of receiving a positive diagnosis. The final concept of 'coping with diagnosis' was an attempt to convey the complex mix of experiences that women reported. There may also be challenges associated with wanting to include all relevant papers in order to obtain a 'rich' synthesis and the increased time and complexity associated with analysing a large number of studies with diverse aims and foci (Al-Janabi et al., 2008; Coast et al., 2004). The use of qualitative methods

such as meta-ethnography for outcome development also requires additional time and specialist skills compared with other approaches such as literature reviews (Coast et al. 2012).

There were also some limitations associated with this particular study. We found that it was sometimes difficult to identify studies which were concerned with attitudes towards curable STI testing, and so some studies may have been incorrectly omitted from the synthesis. We included studies with a variety of epistemological frameworks and some concerns have been raised about synthesising studies with different epistemological perspectives; however, it has also been argued that including studies with differing approaches can enhance the synthesis (Bennion et al., 2012; Finfgeld, 2003). In addition, the synthesis inevitably reflects the concerns and priorities of the participants in the included studies which may not be relevant to all sub-populations. We also focussed on research conducted in OECD member countries which means that the concepts identified may not be applicable to other parts of the world. This means that further qualitative research with populations of interest may be needed to consolidate outcomes and further develop measures.

## **Conclusions**

This study suggests that thinking about having an STI and participating in testing can have a wide range of impacts on women's health and quality of life; it is unlikely that these factors would be captured using outcome measures which focus on health effects only. It is important that appropriate outcomes are taken into account within evaluations to ensure that decision-makers are fully informed about all relevant costs and benefits (Watson et al., 2009). The findings of this study suggest that syntheses of qualitative evidence can be extremely useful for in informing outcome identification, as well as providing useful contextual information for health policy researchers and decision makers. Maximising the use of existing qualitative research can help to ensure that measures of outcome are informed by what matters to those targeted by interventions, and therefore we would welcome the greater use of qualitative syntheses within health-related research.

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**Figure 1: Flow diagram of studies included and excluded at each stage of the review**

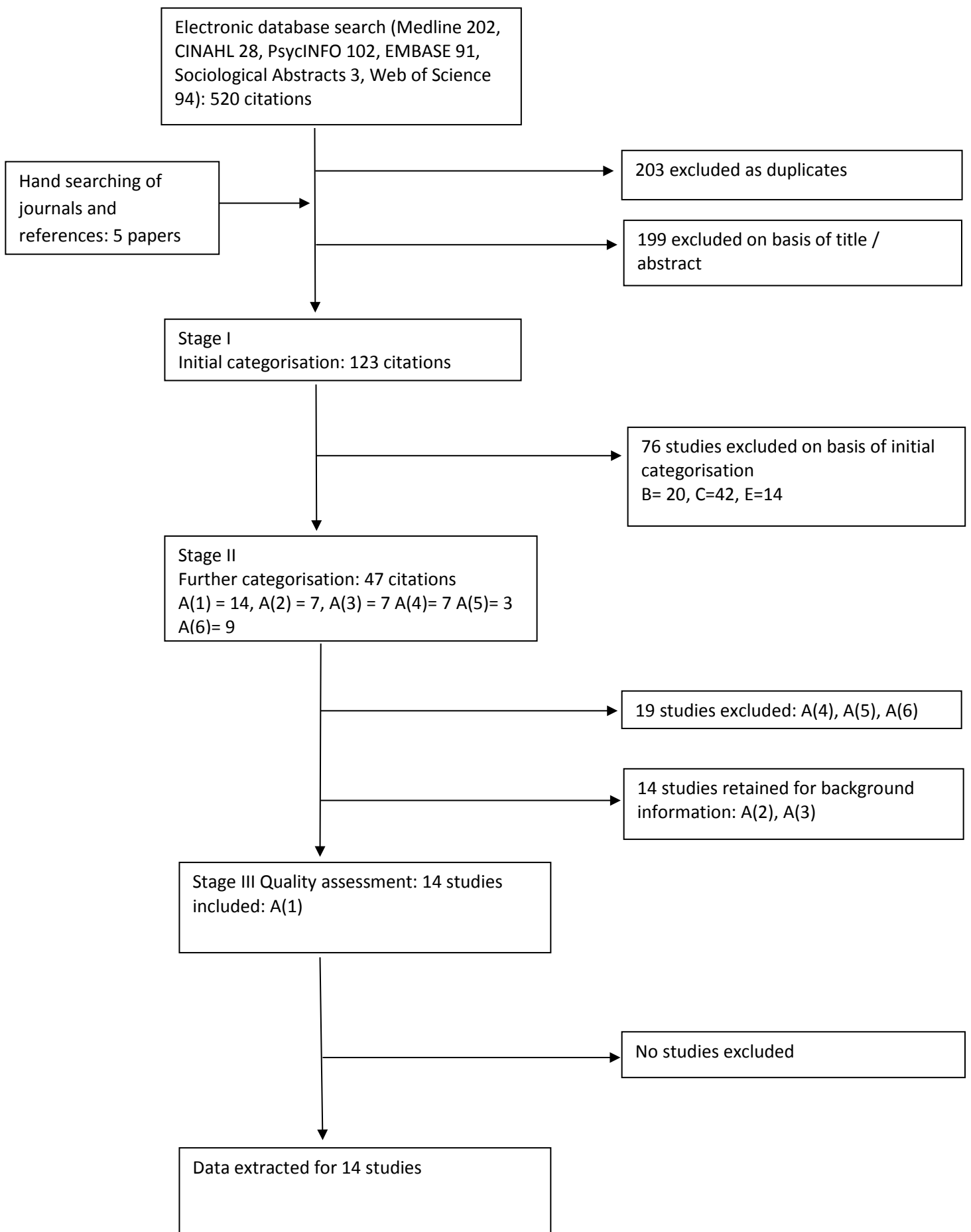
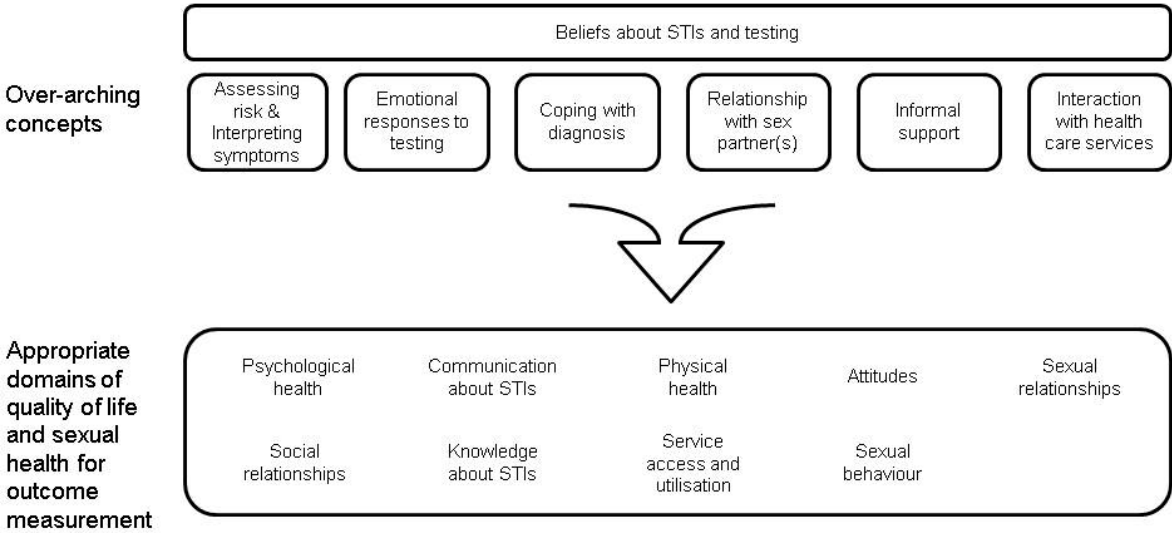


Figure 2: Using meta-ethnography to inform the development of outcome measures for the purposes of evaluation



**Table 1: Categories used to identify studies for inclusion**

<b>Initial categorisation criteria</b>		<b>Further categorisation criteria</b>	
A	Study reports on attitudes and experiences of those undergoing testing for chlamydia or other curable STIs in OECD member countries.	1	Study includes qualitative data on experiences of testing for chlamydia, gonorrhoea or curable STIs.
B	Study reports on attitudes towards and experiences of cervical screening / HPV.	2	Study involves quantitative measurement only.
C	Study reports on attitudes and experiences of those undergoing testing for or living with HIV / Aids.	3	Study primarily concerned with knowledge about STIs / particular healthcare interventions.
D	Study may have useful information but does not obviously fall into A.	4	Study is primarily concerned with perceptions of risk and sexual behavior.
E	Study is not concerned with attitudes and experiences of those undergoing testing for STIs in OECD member countries.	5	Study reports secondary data or is a description of methods only – no primary data.
		6	Study does not contain information relevant to experiences of screening for chlamydia or gonorrhoea.

**Table 2: Included studies: aims, participants and methods**

#	Lead author	Year	Country	Participant details (e.g. number, gender, ethnicity)	Methods	Aim of study
1	Dixon-Woods	2001	England	37 women, aged 15-53, 3 black, 34 white, socially diverse backgrounds from GUM and FP clinics.	Semi-structured interviews	Understand help seeking behaviour and views about specialist sexual health services.
2	Duncan	2001	Scotland	17 women with current or recent diagnosis of chlamydia, aged 18-29 from GUM and FP clinics.	Semi-structured interviews	To investigate the psychosocial impacts associated with a diagnosis with chlamydia.
3	Darroch	2003	UK	24 heterosexual patients diagnosed with genital chlamydia infection at a sexual health clinic, with a mean age of 27 years. 46% white British, 13% Black African. 3% Asian.	Semi-structured interviews	To explore women's and men's accounts of chlamydia testing to investigate differences in attitudes and behaviours.
4	Santer	2003	UK	20 women who had participated in opportunistic chlamydia screening in 8 general practices. Age: 15-31.	Semi-structured interviews	To explore the experiences of chlamydia screening among women with both positive and negative results and women who were still waiting for results.
5	Mills	2006	UK	45 in-depth interviews with men and women aged 16-39.	Semi-structured interviews	To describe men and women's experiences of being screened for chlamydia (postal screening).
6	Mulholland	2007	UK	10 interviews with patients attending a GUM clinic (5 males & 5 females) aged 18-28.	Semi-structured interviews	To explore factors associated with health care seeking behaviours in relation to sexually transmitted infections.

7	Balfe	2009	Ireland	30 young men and women aged 18-29 who had sought STI testing from specialist and community health care settings.	In-depth interviews	To examine the prompts for attending specialist and community health services for STI testing amongst young adults.
8	Lorimer	2009	Scotland, UK	24 men and women aged 18-24 in non-medical settings.	In-depth interviews	To explore the factors associated with men and women's willingness to provide a urine sample for screening in various non-medical settings.
9	East	2010 & 2011	Australia	10 women aged 18-34, with past or present history of an STI, recruited via advertisements in a variety of settings.	On-line interviews	To explore young women's experiences of having an STI.
10	Balfe	2010	Ireland	35 young women aged 18-29 – recruited from 6 GP surgeries and 2 FP clinics.	In-depth interviews	To examine the factors that either prevent or discourage Irish young women from going for Chlamydia testing.
11	Friedman	2010	US	125 women aged 15-25 years. General population - recruited in the community. Latina, Caucasian and African American.	Individual ethnographic interviews	Explore women's understanding of STD and chlamydia testing and STD communications and information sources
12	Richardson	2010	UK	14 young people aged 16-24 declining offer of chlamydia screening test in educational settings.	In-depth interviews	Investigate the psychosocial issues for young people who decline chlamydia testing as part of national chlamydia screening programme.
13	Newby	2012	UK, England	27 young adults aged 16-22 attendees at a hospital based GUM clinic. 12 women and 15 men.	Semi-structured interviews	Improve understanding of how UK GUM patients perceive the risk of chlamydia and identify implications for health education

14	Oliffe	2012	Vancouver, Canada	34 young women (aged 15-24) recruited from clinical and non-clinical sites.	Semi-structured interviews	To explore how women interpret and respond to heterosexual men's sexual health practices.
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Note: GUM = genitourinary medicine, FP = Family Planning, GP = General Practitioner



**Table 3: Qualitative synthesis: themes, subthemes and inclusion in papers.**

<b>Third order concepts</b>	<b>Sub theme (Second order constructs)</b>	<b>First order constructs (Direct quotations)</b>	<b>Studies that included second order constructs (study numbers are given in Table 2)</b>
Beliefs about STIs and testing	'Formal' / clinical information	"They were doing this whole STI thing on TV." (Balfe et al., 2009, p.5)	2, 8, 9, 10, 11, 13.
	'Informal' information and beliefs about sex and STIs	"It's the association that come with STIs. I think there's a sort of stigma around them, like if you might have an STI, it means that you've slept with a lot of people. I don't want to look like I'm that sort of person." (Lorimer et al., 2009 p.202)	1, 2, 3, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14.
	Gendered nature of beliefs about sex and STIs	"It [Chlamydia test] would make you feel like a dirty bitch (laughs)". (Balfe et al., 2010 p.140).	3, 5, 6, 7, 8, 9, 10, 13, 14.
	Disease prevalence & consequences	"Pregnancy is more real. Young people see it more often... STIs are something so hidden." (Balfe et al., 2010, p. 137).	4, 10, 12, 13
	Perceived nature and consequences of testing	"People who have one-night stands ... sleep around stuff like that.. they could probably do with a check up once in a while" (Richardson et al., 2009, p.188),	1, 2, 7, 8, 10, 12.
	Challenging stereotypes	"Go with your partner. If you are sexually active with somebody, get them to go with you. If they won't go with you, maybe you don't want to be sexually active with them.". (Oliffe et al., 2012, p.10)	14
Assessing risk & interpreting	Feelings of invulnerability	"I would say I'm less likely than others (to get chlamydia) ....because I tend to think that I do it safely, and I only have one partner, and there are times when you do have unprotected sex but I try not to as often as	2, 3, 4, 5, 6, 7, 8, 9, 10, 12, 13.

symptoms		possible” (Newby et al., 2012, p.149).	
	‘Known’ partners & risk	“I would have talked to him about his previous partners and he knew all of his partners.” (Balfe et al., 2010, p.136).	4, 7, 8, 9, 10, 12, 13.
	Lay interpretation of symptoms	“I mean, I don’t think I’ve got anything because I know I’d be showing symptoms I mean I think really, so.” p.58 (Santer et al., 2003, p.58)	1, 2, 3, 4, 7, 9, 10, 12, 13
	Delaying testing	“The reason I hadn’t gone before was because of plain mortification.” (Balfe and Brugha, 2009, p. 6)	1, 6, 7, 12
	Prompts for testing	“I don’t know, I just wanted to cleanse myself of everything that had happened in that year. Just be able to close the chapter. Gone.” (Balfe and Brugha, 2009 p.4)	1, 6, 7, 14
Emotional responses to testing	Embarrassment about physical nature of test	“...it’s oh God, I haven’t shaved my legs, do my feet smell?” (Dixon-Woods et al., 2001, p.338)	1, 5.
	Embarrassment / anxiety due to stigma	“really nervous – I told myself I would be able to notice the signs and find it myself without asking anybody where it was because it was embarrassing.” (Mullholland and Van Wersch., 2007, p.25)	1, 5, 6, 8, 10, 12
	Positive feelings	“It doesn’t hurt girls – like its uncomfortable for a couple of minutes but you know it’s going to protect you. .... Most guys don’t want to go through that because it’s uncomfortable and they take great pride in their manhood”. (Oliffe et al. 2013, p.7)	7, 14
Coping with diagnosis	Embarrassment / anxiety due to stigma	“I didn’t think it would be me as it made me feel dirty....only dirty people get things like that, that sleep about..... Well it makes you think you’re like a tart innit....” (Mills et al., 2006 p. 554)	2, 3, 5, 6, 9
	Identity	“It reflects badly on me and on my character and implies that I sleep around a lot” Mulholland and Van Wersch 2007, p.22)	2, 5, 6, 9

	Blame	“I blame myself for selling myself short. I should have been more careful and more choosy.” (East et al., 2010, p.1998).	2, 3, 9.
	Future risks	“So now I’m absolutely petrified that I can’t have kids [starts to cry] ...there’s been no follow up to say you can go for further tests or you can do this.” (Mills et al., 2006, p.554)	2, 3, 5.
	Positive emotions	“I thought at least its chlamydia, it could have been something much worse ...so I’m glad, not glad but relieved...” (Darroch et al., 2003, p.372)	1, 2, 3, 4, 5, 6, 7, 13, 14.
Interaction with health care services	Accessing services for sexual health	“...well going to the clinic...all the people there...it’s fully of skanky 15 year olds” (Richardson et al., 2010, p. 188).	1, 2, 6, 7, 8, 9, 10, 12.
	Interaction with staff	“She [the doctor] was really really nice. She provided me with a lot of information and support. She me feel comfortable.” (East et al. 2011, p. 2262)	1, 6, 7, 9
Informal support	Talking about STIs	“I just think we should just be more aware of, people my age should have been more aware, because it’s something I’ve never heard of before.” (Santer et al., 2003, p.58).	1, 4, 6, 11,13
	Concealment of testing activity & diagnosis	“I just don’t want them to – to think I’m dirty – I think that’s the main thing you know...” (Mulholland and Van Wersch. 2007, p. 25).	2, 5, 6, 9, 13.
Relationship with sex partners(s)	Anxieties about attitudes of partners	“It wasn’t a very pleasant experience ... that I think what hurt him was the fact that I hadn’t told him [about a previous partner], [he was] just very shocked.” (Duncan et al., 2001, p. 197).	2, 3, 4, 5, 6, 9, 11.