Population screening for *Chlamydia trachomatis* infection in the UK: a qualitative study of the experiences of those screened

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**Background.** Screening for *Chlamydia trachomatis* in selected health care settings is underway in the UK despite insufficient evidence about the personal impact of screening.

**Objectives.** To describe men and women’s experiences of being screened for chlamydia as part of the Chlamydia Screening Studies (ClaSS) project, a population-based UK study of postal screening for chlamydia.

**Methods.** We conducted in-depth interviews with 45 purposively sampled participants in the ClaSS project using a checklist of topics relating to their experiences of the screening process. Interviews were audio-tape recorded, transcribed verbatim and analysed using the constant comparison method.

**Results.** Four main themes emerged: initial discomfort with screening arising from an unease with sexual health issues; anxiety, especially after receiving a positive test result, due to the fear of informing sexual partners, the risk of infertility and the possibility of having other undetected infections; women’s concern about being stigmatised for having been infected with chlamydia, which affected how they felt about themselves and how they thought others would perceive them; and recognising the need to balance the harms of screening with the benefits. Despite some reported adverse effects, no one regretted their decision to be screened.

**Conclusions.** Public education and discussion of sexually transmitted infections should help to increase the acceptability of chlamydia screening and destigmatise a diagnosis of chlamydia. Those working in primary care settings are likely to become increasingly involved in chlamydia screening and so must be suitably trained to inform individuals of the potential adverse effects and to deal with their consequences.

**Keywords.** Attitude to health, Chlamydia infections, experiences of screening, mass screening, qualitative research.

**Introduction**

Primary care in the UK is set to play an increased role in the provision of sexual health services following the Department of Health’s National Strategy for Sexual Health.\textsuperscript{1} Reducing rates of *Chlamydia trachomatis* is one of the priorities for the National Health Service (NHS) Plan. Chlamydia is the most commonly reported curable sexually transmitted infection (STI) in the UK.\textsuperscript{2} It is of significant public health concern because the majority of cases are asymptomatic, and thus go largely undetected, and it has serious long-term consequences including pelvic inflammatory disease, chronic pelvic pain, ectopic pregnancy and infertility.\textsuperscript{2} A National Chlamydia Screening Programme is currently being introduced in England focusing...
primarily on sexually active women attending selected health care settings. Limited evidence from pilot studies of the screening programme showed that it was acceptable to those who participated and to health professionals. Screening is due to start in all Primary Care Trusts in April 2006.

Population-based screening programmes involve inviting healthy individuals not attending health services to be screened for a condition. These programmes have been reported to cause increased anxiety and reduced self-perceived health status in people invited to be screened for cervical cancer and hypertension. It has also been suggested that those receiving negative screening test results may interpret this as ‘a certificate of health’ and are consequently less inclined to adopt healthy behaviours. The stigma associated with the unexpected and unsolicited diagnosis of an STI is an additional potential adverse effect of population screening for chlamydia.

The Chlamydia Screening Studies (ClaSS) project was a multicentre study to investigate epidemiological, social, diagnostic and economic aspects of population-based postal screening for chlamydia. We conducted in-depth interviews with ClaSS participants to explore the experiences of the screening process from the perspective of those screened. This enabled the population experience of screening to be studied through the use of a method, which is individually focused.

Methods

The ClaSS project has been described in detail elsewhere, and protocols for the project are available at http://www.chlamydia.ac.uk. In brief, men and women aged 16–39 years randomly selected from 27 general practices were sent an invitation from their GP and mailed a study test pack requesting them to send home-collected urine and vulvo-vaginal swab (if female) specimens for chlamydia testing. Participants who tested positive for chlamydia (and, for research purposes, a minority of those who tested negative) were sent an appointment to receive results and treatment from a nurse at their general practice; all other participants who tested negative received their result by letter. Partner notification for those with positive results was undertaken either by a practice nurse or by a sexual health adviser at a genitourinary medicine (GUM) clinic.

People who provided a specimen for testing were invited to an in-depth interview in one of two ways: a random selection of those with a negative test result were sent a letter from their GP asking if they could be approached for an interview; those with a positive test result were asked by the practice nurse treating them if they could be approached. We sampled interviewees purposively from those willing to be contacted to ensure a mix of gender, age and geographical location, and, in the case of those who tested positive, a mix of those whose partner notification was done at the practice or at the GUM clinic. We continued interviewing until no new themes emerged. All informants gave written consent to be interviewed.

Interviews lasting 45–60 minutes were conducted by NM, GD-W and RC in informants’ homes or on university premises within a few weeks of having been given their results. Interviews were spread evenly throughout the screening period and across participating practices. We used a checklist of topics to ensure that primary themes were covered in each interview. New themes that emerged were added to the topic list and explored in subsequent interviews. Informants were encouraged to relate their expectations, experiences and understanding of the screening process. Specific topics included the arrival of the invitation and study pack, self-testing procedures, test results and, for those who tested positive, the impact of the diagnosis and partner notification on their lives. Informants were also asked about their general and sexual health, knowledge of sexual health issues and background information such as living arrangements and employment status.

Interviews were recorded on audiotape with the informant’s permission. Tapes were transcribed verbatim and any identifiable material was anonymised. Transcripts were thematically coded and indexed using Atlas.ti (Scientific Software Development, Berlin) to facilitate the organisation of the data. We wanted the approach to data analysis to be inductive so that concepts emerged from the data as opposed to being imposed beforehand. This was especially important given that this is a relatively new area of research. Data collection and analysis ran in parallel to enable findings to be tested in subsequent interviews. The coding index was added to or refined and coded material regrouped as new themes and categories emerged from later interviews. Further analysis employed the constant comparison method of grounded theory in which the textual data were scrutinised for differences and similarities within themes, keeping in mind the context in which themes were mentioned in each interview. This analytic approach ensured that findings were systematically compared according to factors, such as the age, gender and marital status of informants, and that they were grounded in the data.

We compiled descriptive accounts, grouping participants with positive and negative results separately, from early analyses and pooled these to write the final account. Analysis was carried out primarily by NM, with checking of coding and interpretation by RC and GD-W. The team met regularly to agree on the thematic categories used to index the interview transcripts and to check the plausibility of the data interpretation.
Results

We interviewed 45 men and women. Figure 1 shows the number of people accepting and refusing the invitation to an interview. Table 1 presents the interview sample by test result, gender, age and source of partner notification. The unequal number of positive men and women interviewees and the fairly narrow age range reflects the fact that more women participated and young adults tested positive in the main screening study. Informants were predominantly white (19/20 ‘negatives’, 23/25 ‘positives’) and single (9/20 ‘negatives’, 21/25 ‘positives’). Fourteen (10 ‘negatives’, 4 ‘positives’) were married or living as married.

Four main themes emerged from the interviews with regard to informants’ experiences of being screened for chlamydia as part of a population-based programme: discomfort, anxiety, stigma and balancing the harms and benefits of screening.

Discomfort

The majority of informants who participated in the screening programme were not offended by the postal invitation to be screened, nevertheless many were slightly uncomfortable with it. This stemmed largely from their embarrassment with sexual health issues and the associations that STIs have with sexual promiscuity:

N02: It [arrival of study pack] was a bit um [laughs] a bit er embarrassing, um well like the
Several informants (both positives and negatives) had some fleeting, but not particularly major, concerns about their test result while they were waiting. They questioned what they would do if the result came back positive. Anxiety was heightened in those invited to see the practice nurse to be told their results, even though they knew that both infected and a selection of uninfected patients were being invited. A minority also expressed concern about the accuracy of testing and the possibility of receiving a false positive or negative result. In general, those who were tested negative expressed the most concern at this stage, although any anxiety was soon relieved after receiving their results:

N12: I expect it to come back negative but you know there’s always that doubt. You’re sort of thinking well what if, what am I going to do? What am I going to say to him? [laughs] [F aged 39, neg]

P09: [After invitation to see the practice nurse to get results] I was stressing out as I thought I’d be positive. [F aged 23, pos]

N20: You need faith in tests, the testing techniques aren’t always what they’re supposed to be. NM: And how much of a concern was this to you? N20: [long pause] Well I mean, yeah I mean basically it would mean it was a false negative wouldn’t it. So yeah that would be a concern. [F aged 30, neg]

Most anxiety arose after receipt of a positive test result. The majority of those who tested positive were shocked and upset initially, regardless of whether they anticipated it or not:

P11: When it came back I was [pause] absolutely [pause] devastated. Absolutely devastated….I think after having the results I was just so upset and I sort of I don’t know I can’t remember a lot after that. I think I was just so sort of god I’ve got this disease um how have I got it? Where have I got it? Who have I given it to?… I, I think I was in such a state…. I was just so sort of shocked about the results and everything. [F aged 24, pos]

One of the most difficult and fear-inducing consequences of having contracted chlamydia, described by informants, was the need to inform current and recent sexual partners. Slightly more men than women expressed concern about doing this, primarily because they thought their partners would be upset (data presented elsewhere11). In most cases, however, their partner’s reactions were not as bad as they had expected.
Informants who were diagnosed with chlamydia also questioned and worried about their health status. Both men and women were concerned about the possibility of having other undetected infections. This was of enough concern to make some want testing for other STIs:

P08: The other thing is as well, it does your head in is that well if I’ve got that what else have I got? [M aged 18, pos]

Of significant concern to a third of the women who tested positive was the possibility of being infertile. They wanted to know more details about exactly how their fertility might be impaired. They were very distressed by their unanswered questions:

P10: There’s still so many questions that I’d like to ask, things like, because I know it can affect my chances of having children and no one said anything about how I could find out or who I should speak to about finding out or whether it’s just a case of you have to wait and see. So that’s still kind of hanging over my head and I just think well I may never be able to have children now. [F aged 21, pos]

Stigma
The stigma surrounding STIs was hinted at in relation to discomfort with the study invitation but it was clearly evident from informants’ response to a positive diagnosis. Men and women reacted differently to having contracted chlamydia: it was more upsetting for women than men. The following extracts illustrate gender differences in response to a question about who they had talked to regarding their test result: the man viewed this exercise as a form of entertainment, while the woman was absolutely petrified about what her partner was going to think of her for having tested positive:

P11: I got home [after given results] and I phoned [partner] and I said it’s bad news and he came straight home. I think I sat in the front room I had the lights off I didn’t have the tele on and I was just crying [starts crying] and I [pause] hhhh I was absolutely petrified that he was gonna turn round and say what have you got? Who have you slept with? I’ve been with you for nearly three years get your stuff, get out, that’s it. Um I really didn’t know how he was gonna react. I know him well but when you sort of come across a situation like this, it’s something you don’t ever expect to have to deal with especially for how long I’ve been with him. I was petrified. I think I phoned my mum and I said what am I gonna do? I was, I was just so scared. [F aged 24, pos]

P02: I told loads of people [about having chlamydia]. In the pub me and [friend] come in together pissed up like, “so what have you caught then” you know, “oh we got the big C haven’t we! We bloody contracted all these diseases and that”. It was a joke, see it wasn’t a problem for me…… It was a laugh. We even went down town to celebrate that we got it, we was chatting about it all night long. It was a good topic of conversation really for that night. It was all part of the fun. [M aged 22, pos]

For a lot of the women, having chlamydia altered how they felt about themselves and how they thought others would see them. They made a distinction between themselves and the sort of people who they believed contracted STIs: such people were labelled ‘slappers’ and ‘tarts’ and were thought of as ‘dirty’. They were, therefore, concerned that people would label them as sexually promiscuous and think of them as ‘dirty’:

P09: 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:…… It does not make you feel nice. …. I’m not like that. [F aged 23, pos]

P10: And then to be produced with the four cards [cards given by nurse to record details of sexual partners], there you go, how many people have you been with. The way there’s so many in the pack you just think oh god now what do people think of me. [F aged 21, pos]

Men expressed relatively little embarrassment or sense of shame at having contracted chlamydia and perceived it to be more of a problem for women:

P07: Well I’m just not embarrassed by things like that. Someone else said to me about it [test result] and I said oh yeah I was positive. I imagine this particular STD is a lot more worrying for women. It doesn’t seem to affect men, it’s more like oh if you get it if you’re a girl it’s really bad, make you infertile. But for a bloke it’s just oh you’ve got chlamydia, get rid of it else you’re
going to infect girls. ... I’m not bothered about it. [M aged 26, pos]

Much of what women described can be categorised as ‘felt stigma’—that is a feeling of shame and fear of discrimination. There were very few examples given of instances of actual discrimination (‘enacted stigma’) as a result of having contracted chlamydia. In many cases the converse was true, partners and family were largely supportive rather than judgemental despite informants’ initial fears. It, therefore, seems that for these informants the fear of being judged, as a result of having had an STI, was more damaging than any actual passing of judgement on their behaviour, which rarely happened.

Women employed various strategies to minimise the perceived damage to their image and to hide their shame after having contracted an STI. Concealment of test results was the main tactic. Some also dissociated the infection from other (reportedly more serious) STIs and compared it to something more socially acceptable such as thrush. Describing chlamydia as resulting from a ‘one-off’ mistake and simply being unlucky was a further tactic employed by women to distance themselves from the types of people whom they perceived caught STIs. Such concealment and dissociation would have minimised the opportunity for enacted stigma:

P21: It may be classed as a sexually transmitted disease but basically to me it’s just like thrush, you take a dose of medicine and it’s cleared up. [F aged 20, pos]

P18: At least if they [health advisers at GUM clinic] think I’m a filthy slapper, I’m not. [laughs] One or two mistakes, not a slapper [laughs]. [F aged 24, pos]

P17: I just consider myself unfortunate, because I don’t sleep around you know. [F aged 26, pos]

Balancing the harms and benefits of screening

Although chlamydia screening had an adverse impact on aspects of some informants’ lives, no one had any regrets about their decision to be screened. Even though the study evoked anxiety and discomfort in some of those who tested negative they were, nonetheless, happy to have participated and pleased that they did not have chlamydia. There was no evidence to suggest that as a consequence of their negative result they were less inclined to adopt healthy behaviours; for some the reverse was true:

RC: Did the test make you think any more about the way that you have sex with someone?
N11: Yeah yeah definitely definitely. It made me realise that it’s so easy to catch a sexually transmitted disease, so I thought I’m just going to be really careful, make sure that I’ve either got protection or they are clear themselves. [M aged 17, neg]

The study had a greater adverse impact on those tested positive than those tested negative. However, most of those who tested positive were actually pleased to have been screened because it meant that they had detected and treated an infection, which would otherwise have gone unnoticed indefinitely. Women expressed a sense of relief at having identified the infection sooner rather than later because they thought it minimised the risk of infertility. Screening did, however, leave them with the unanswered question of whether or not they had fertility problems, which would not have been an issue if they had not been screened. Although this was of great concern to them, they were still glad to have been screened. The detection of chlamydia was also recognised as having positive implications for future sexual relationships, as their previously unknown infection had been treated and they were now much more aware of the risks of unprotected sex:

P10: I was so pleased that I did [the test]. Well because I found out that I had chlamydia and now I don’t know how long I’ve had it or anything but hopefully the antibiotics have got rid of it and I mean I could have gone on for years and years and had it and then as it is I don’t know my chances of having children or anything I’m not sure but if I’d have had it for the next ten years then there’s every chance that I’d never ever have the chance to have children. So I’m glad that I did. [F aged 21, pos]

P18: When I’ve had one too many glasses of wine again I’ll be like “you really should USE A CONDOM PLEASE!” [F aged 24, pos]

Discussion

This study has, for the first time, revealed the psychological and social well-being of men and women who participated in a large UK based population screening programme for chlamydia. Four main themes emerged from the interviews: initial discomfort with participation in screening arising from an unease with sexual health issues; anxiety, especially after receiving a positive test result; women’s concern about being stigmatised for having been infected with chlamydia; and balancing the harms of screening with the benefits. Despite some reported adverse effects, no one regretted their decision to be screened.

There has been little research into the psychosocial impact of being screened for chlamydia. Results from the evaluation of opportunistic chlamydia screening
programmes (i.e. inviting those who present themselves to health services), obtained by conducting in-depth interviews with mostly women.\textsuperscript{4,13-16}largely mirror those found in this study. However, the present study is of particular importance as it entailed understanding the impact of screening from both men and women who had been drawn randomly from the community as part of a population-based screening programme. Ascertainment of the psychological impact of screening is especially important in population screening as people receiving an invitation will not have been expecting it, and the vast majority will either not have the infection or will be unaware of having it. There is thus a greater potential for psychological harm in population screening as opposed to screening people opportunistically while attending health clinics.

One of the key themes to emerge that cut across many cases in the present study was the stigma associated with chlamydia. This shaped people’s feelings towards the screening programme from invitation to test result and accounts largely for the adverse psychosocial impact of screening described mostly by women who tested positive. Stigma is an issue common to the diagnosis of other STIs. Described by Goffman as ‘an attribute that is deeply discrediting’,\textsuperscript{17} it is associated with emotional distress, including guilt, embarrassment, isolation and fear, and it is linked to treatment delays and poor outcome.\textsuperscript{18} The findings from this study parallel those from research into the stigma associated with epilepsy, in which people’s fear of being stigmatised led them to conceal their condition, which in turn was more disruptive to their lives than any actual or enacted stigma.\textsuperscript{12}

Duncan et al.\textsuperscript{19} undertook interviews with women recently diagnosed with chlamydia and attending sexual health and family planning clinics to ascertain the psychosocial impact of a diagnosis. They too revealed the perceived stigma associated with a diagnosis of chlamydia. However, the stigma that the authors noted could have been as much to do with the clinical setting that they were seen in, especially those seen in sexual health clinics,\textsuperscript{20} as to their diagnosis of an STI. It can be seen from the present study, though, that stigma associated with a diagnosis of an STI is still evident even if the diagnosis and treatment are given in a general practice setting and if given as part of a screening programme.

An advantage of this study over other chlamydia screening studies is the inclusion of both men and women. The observation of gender differences in the present study with regard to testing positive through screening is, thus, a novel and important finding. Sex differences in the experience of being diagnosed with chlamydia have also been reported elsewhere, although not in the context of screening.\textsuperscript{21}

Our study design does not allow us to quantify the effect of chlamydia screening on participants’ lives. A separate aspect of the ClaSS study measured the effect of an invitation to be screened for chlamydia and of receiving a negative result on levels of anxiety, depression and self-esteem through the use of established psychometric measures.\textsuperscript{22} The results showed that postal screening for chlamydia did not have a measurable adverse impact at the population level on the psychological well-being of those tested and found to be negative. That analysis, however, reflects average effects of screening for the majority of those without the infection. It is only possible to look in detail at the variation in peoples’ experiences qualitatively, as we did in the present study, which revealed a degree of discomfort at an individual level.

Primary care is likely to be a key setting for the National Chlamydia Screening Programme that is phasing in opportunistic screening to young adults in selected settings in England.\textsuperscript{3} This is potentially a suitable place for opportunistic screening given that most young men as well as women will at some point go to their GP\textsuperscript{23} and that trained practice nurses have been shown to be as effective at partner notification as referral to a GUM clinic.\textsuperscript{24} Nevertheless, a fifth of patients in this setting might not be reached by opportunistic screening alone.\textsuperscript{25} Results of the population-based ClaSS project showed postal screening to be feasible, well accepted and of little psychological harm to the vast majority who do not have the infection.\textsuperscript{11} However, coverage was incomplete, uptake was lower than expected\textsuperscript{11} and aspects of the screening process (primarily receiving a positive test result) tended to adversely affect the psychosocial well-being of some. Postal screening could have an adjunct role in the National Programme by offering screening to people who do not attend settings where opportunistic screening is being offered. Widespread publicity campaigns and increasing familiarity with home testing may well improve the uptake of this type of screening.

Regardless of how screening is offered, it seems that more efforts are needed to guard against the potential damage that screening for chlamydia could have on participants. First, more needs to be done to destigmatise a diagnosis of chlamydia. This has been said before\textsuperscript{19} and we would like to reinforce it. Second, given that the diagnosis of chlamydia means different things to men and women, a screening programme should take account of gender differences, for example with regard to the information given to those invited to be screened and when informing people of their test results. Third, health professionals offering chlamydia screening must be suitably trained to inform individuals of the potential adverse effects; women are particularly vulnerable. Training staff is reportedly one of the more neglected aspects of running screening programmes,\textsuperscript{25} and it is particularly important if screening is to be conducted in non-specialist primary care settings. Finally, thought needs to be given to the best
process for providing and discussing positive test results: a second appointment, allowing the patient time to absorb the news and formulate questions, may be appropriate.

Conclusions

The psychosocial impact of chlamydia screening on participants needs to be taken into account to ensure that the benefits outweigh the harms. On the basis of our research exploring the personal experience of participation in a screening programme for chlamydia we propose the following:

- Further efforts are required to destigmatise a diagnosis of chlamydia.
- Men and women react differently to news of a positive chlamydia result; a screening programme should take this into consideration.
- Health professionals offering chlamydia screening must be suitably trained to inform individuals of the potential adverse effects.
- The best process for providing and discussing positive test results needs to be determined.

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