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# The National Chlamydia Screening Programme (NCSP) Value For Money (VFM) study

Understanding user experiences

Prepared for the National Audit Office (NAO)  
Health Team

*April 2009*

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## Table of contents

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<b>1. Introduction</b> .....	<b>4</b>
1.1 Context of this research.....	4
1.2 Research aims.....	4
1.3 Methodology .....	4
1.4 Report structure .....	8
<b>2. Executive summary</b> .....	<b>9</b>
<b>3. Before testing</b> .....	<b>12</b>
3.1 General sexual health testing knowledge.....	12
3.2 Knowledge and understanding of chlamydia.....	13
3.3 Awareness of the NCSP .....	16
3.4 Reasons for being tested.....	18
3.5 Reasons why someone might decide not to get tested.....	21
3.6 Sources of information, advice and guidance .....	24
<b>4. Testing itself</b> .....	<b>29</b>
4.1 Testing settings.....	29
4.2 Features of different testing settings .....	37
4.3 The testing experience .....	39
4.4 Information, advice and guidance.....	42
<b>5. After testing</b> .....	<b>44</b>
5.1 Future testing behaviour.....	44
5.2 Future sexual behaviour generally .....	46
<b>6. Narrative case studies</b> .....	<b>49</b>
6.1 Rosie: Advocating more information for young people (GP).....	49
6.2 Jemma: A patient left in the dark (family planning) .....	50
6.3 Greg: The confident clubber (nightclub testing) .....	51
6.4 Susanne: The clinic that had no answers (GUM).....	52
6.5 Anne: Moving from one good service to another (GUM to NCSP postal).....	53
6.6 Olivia: Home-based testing with a difference (home-based/professional visit).....	54
6.7 Amina: Using the web and a GP to keep up to date (GP testing).....	55
6.8 Helen: A scholar gives a ten out of ten to testing at school (NCSP school test).....	56
6.9 Daniela and the Facebook download (self-administered home-based test).....	57

## Table of Figures

---

Figure 1: Phased research plan .....	4
Figure 2: For each of these conditions, which are you most worried about? (Multi-code).....	12
Figure 3: How do you think you would know if you were infected with chlamydia? (Multi-code) .....	14
Figure 4: Where did you hear about NCSP? (Multi-code).....	16
Figure 5: Which of the following options best describes your reason for being tested last time?.....	18
Figure 6: These are some reasons why someone might decide not to get tested for chlamydia. For each of these reasons please indicate how relevant it is to you. ....	21
Figure 7: Here are some sources of help or information on sexual health. Please rank in order the 5 sources you are most likely to use, where 1 is your preferred option. (Multi-code).....	24
Figure 8: Can you explain why you are most likely to use your preferred option for help or information? (Multi-code) .....	25
Figure 9: Can you explain why you are most likely to use your preferred source of information.....	26
Figure 10: These are some settings where you might get tested for chlamydia. Rank your preferred choices from 1 to 5 where 1 is your most preferred option. (Multi-code).....	29
Figure 11: Where did you get your test? .....	31

Figure 12: Can you briefly explain why you are most likely to use your selected venue for a chlamydia test? (Multi-code) .....	37
Figure 13: Can you briefly explain why you are most likely to use your selected venue for a chlamydia test? .....	38
Figure 14: Please tell us the results of your test? .....	39
Figure 15: To what extent do you agree with the following about your experiences of being tested? (Multi-code) .....	40
Figure 16: When you were tested, what advice did you receive about sexual health? (Multi-code).....	42
Figure 17: Do you think you will get a chlamydia test in the next year? .....	44
Figure 18: Would you get tested for chlamydia again? Why do you say that? .....	45

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# 1. Introduction

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## 1.1 Context of this research

FreshMinds were commissioned by the National Audit Office (NAO) Value For Money (VFM) health team to input to their forthcoming VFM report on the National Chlamydia Screening Programme (NCSP). FreshMinds provided research consultancy services around NCSP user experiences, helping to identify both good practice and barriers to success.

## 1.2 Research aims

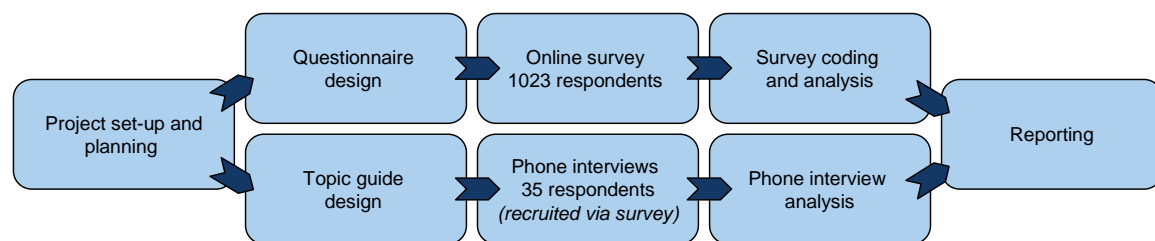
The key aims of this study are to:

- Understand the experiences and perceptions of NCSP users
- Identify the most common and most preferable settings and communication strategies for testing
- Reveal the barriers discouraging people from being tested
- Follow the user 'customer journey', identifying any key recommendations to improve it

## 1.3 Methodology

To achieve these aims FreshMinds has conducted a phased research plan built around two data collection methods – firstly an **online survey** of 1023 respondents and then follow-up in-depth **phone interviews** with 34 of those respondents.

**Figure 1: Phased research plan**



Source: FreshMinds

Our approach incorporated a number of research tools:

- Quantitative - both the online survey and the phone interviews contained some closed quantitative questions based on rankings and ratings, especially in the online survey
- Qualitative - a large proportion of the telephone interviews consist of open qualitative questions, with some open 'qualitative' questions also featured in the online survey
- Unprompted v. prompted - some responses are initially tested unprompted then compared with prompted responses where options and facts are revealed

### 1.3.1 Online survey

FreshMinds used Toluna plc, a trusted online panel supplier that we use very regularly, to recruit respondents to this online survey. Online panel providers utilising incentivised respondents are an efficient method for conducting such research. Further details on this supplier and its quality processes can be found in the box below.

Toluna plc is a global leading online market research panel and survey technology company with a highly profiled, responsive and rigorously maintained online panel of 2.4 million active members covering 30 countries. The UK Panel currently stands at 502,678 active panellists, an active panel member being a unique individual that has responded to at least one survey invitation in the last 6 months.

Toluna are governed by both the ESOMAR and MRS guidelines for managing panels. To ensure Toluna's panels are un-biased and representative of each country's population, panellists are recruited on an ongoing basis through multiple media sources using a broad array of techniques that attract unique and responsive members. Various recruitment methods and ad formats (banners, e-mails, keywords, text links, referrals, search engine), using a variety of ad messages and a broad range of partners are used to ensure an overall balanced membership, broadly reflecting each local market. Toluna can always extract a census representative sample for each location.

To enrol in the panel each prospective member must complete a detailed registration form, opt-in to accept Toluna's Terms and Conditions then click a validation link in a registration email. Certain registration information is then checked through postcode validation / email validation and coherency checks. Individual survey responses can then be cross-validated with those provided at the registration phase with discrepancies noted and repeat offenders permanently struck from the panel. The membership database is constantly cleaned and freed of duplicates or invalid details with regular checks on name/last name/address before panellists are added to a new survey sampling frame. Accounts with high incentives are double checked as part of quality procedures. For each individual survey, sample is drawn as a random selection of unique panelist ID numbers within the quota criteria.

The panellist incentive scheme is based around points that can be cashed in for vouchers, such as Amazon, Halford, HMV and also various discounts and monthly prize draws for those who participated in a survey in that month. The amount of points a panelists receives is based on the length of the questionnaire, so completing this 15min questionnaire awards 80p worth of points.

The initial sample frame and online questionnaire can both be found in the separate Online Questionnaire document. Details of the final sample actually surveyed are provided below:

- 1023 respondents in total
- 15 min online survey
- In field for 11 days Fri 06 Mar – Tue 17 Mar
- Respondents located in England only
- With the following non-interlocking sub-groups (*not mutually exclusive*)
  - 467 respondents who have been tested for chlamydia, regardless of result
  - 500 respondents aged 16-19 (49%)
  - 523 respondents aged 20-24 (51%)
  - 220 male respondents (22%), under-represented due to low response rates
  - 121 ethnic minority respondents (12%), slightly over-represented

In order to make the most of the captured data, FreshMinds is inclusive in its approach to survey responses and gives a full consideration to all respondents who answered any questions in the survey. Although this means that the response bases are not always

consistent throughout, it gives us the opportunity to record and analyse the views of the widest possible number of responses. Base numbers are therefore listed for each individual question answered with a total of 1023 individuals responding overall.

### 1.3.2 Telephone interviews

During the online survey, respondents were given the option of leaving a contact number and opting in to a short follow up in-depth interview. 221 (22%) respondents left their number and we prioritised calls to those who told us they tested 'positive' as they were not only more likely to be open about their experience but had completed the whole customer journey including treatment. Again, the topic guide can be found in the separate Topic Guide document, with basic profiling details on the final respondents below:

- 34 respondents in total
- 15 min phone interview
- In field for 4 days Mon 16 Mar – Thu 19 Mar
- Respondents located in England only
  - With the following non-interlocking sub-groups (not mutually exclusive)
  - 34 respondents who have been tested for chlamydia, regardless of result
  - 10 who tested positive
  - 8 respondents aged 16-19
  - 26 respondents aged 20-24
  - 5 male respondents, again under-represented due to low response rates
  - 2 ethnic minority respondents

### 1.3.3 Data processing

- **Coding:** Wherever possible, FreshMinds used retrospective coding techniques to quantify the open-ended responses obtained from the online survey.
- **Multi-code questions:** In all cases it is made clear if multi-coding (more than one answer allowed per respondent) is used with separate base numbers provided. For these questions the individual answer counts show the number of responses and the percentages are taken from the base number of **respondents**, not responses. This allows for statements such as “25% of respondents selected option B”. Note that this means that total percentages can equal more than 100%.
- **Quotations:** Where relevant, key quotes have been drawn out from the qualitative responses, with colour-coding used for these individual responses as detailed below
- **Tag cloud analysis:** FreshMinds used an innovative analytical technique – the tag cloud analysis – to represent some of the qualitative responses. This type of analysis allows an accessible visual representation of the responses whereby the size of 'tag words' varies depending on the recurrence of these words in the analysed text. The more often a word crops up in the sample text the larger it appears in the tag cloud
- **Data splits:** In order to maximise the insight from the survey results, where relevant the responses are split by different key criteria such as gender, ethnicity, age, tested/not-tested, negative/positive and testing setting
- **Comparison:** Where appropriate we shall include some commentary on where our findings align or differ from the partially related 'Define Report' on 'Chlamydia Screening and Sexual Health Marketing – Young People' carried out by Define Research & Insight Ltd for the Department of Health (DH) in 2008

In order to preserve respondent anonymity, only age and region are used to identify direct quotations throughout.

This summary report includes only the most significant and interesting themes stemming from analysis of the results by the different data splits discussed above following guidance from the NAO. The separate FACT Sheet and Telephone Interview Analysis Excel documents contain the raw data used in the analysis.

### 1.3.4 Interpretation

FreshMinds interpreted the data to understand the experience of NCSP users in terms of:

- **Central themes:** gender, ethnicity, age, tested/not-tested, negative/positive and testing setting
- **Customer journey:** the experiences of users have been plotted along an approximate customer journey, looking at three key stages; before testing, testing itself and after testing. This enables the study to understand user experiences at each point along the testing process – allowing an in-depth investigation across their customer journey. Six case study narratives are included as an Appendix to illustrate this point.

Finally some other features of this report may require clarification:

Reference to **base figures**. These represent the number of *respondents* who responded to each question. For multi-code questions, with more than one answer allowed, the total number of responses will also be listed. Base figures are sometimes sub-divided into further categories, such as by setting. These are useful to provide a context for the percentage figures shown on the charts. However, base numbers below 30 should be treated with caution as they move into the ‘anecdotal’ end of the reliability spectrum and may be influenced by more extreme ‘outlier’ opinions. Given the small size of the phone interview sample, the base numbers are correspondingly small throughout, making these sections more reliant on softer qualitative data and interpretation rather than hard quantitative statistics. Both real numbers and percentages are used throughout.

Individual **qualitative comments** in the report are presented in three colour-coded boxes. The green indicates positive comments, while the red signifies negatively-oriented responses. The beige represents neutral or mixed comments.



Finally some charts have been **annotated** to highlight particularly interesting findings.

## 1.4 Report structure

This report contains three main sections, broadly following a customer journey through the NCSP:

### Before testing

In this section of the report FreshMinds gauges respondents' understanding and awareness of chlamydia prior to testing. Therefore, results in this section analyse feedback from both respondents who had taken chlamydia tests as well as those who had never done so. In order to evaluate respondents' understanding of chlamydia, the report also explores general STI and sexual health awareness. More specifically, this section looks at the following topics:

- Familiarity with STIs
- Levels of concern about different STIs
- Knowledge and understanding of chlamydia, particularly:
  - Chlamydia related advertising
  - Incidence of chlamydia among 16-24 year olds
  - Ways of contracting chlamydia
  - Detection of chlamydia
  - Symptoms of chlamydia
  - Perceptions of own levels of understanding about the effects of chlamydia
  - Actual knowledge of Chlamydia symptoms
  - Treatment options for chlamydia
- Awareness of the NCSP
- Reasons for being tested for chlamydia
- Barriers to being tested for chlamydia
- Sources of help or information on sexual health
- Reasons for preferred sources of help or information on sexual health

### Testing itself

This section of the report explores both actual 'customer journeys' experienced by respondents who undertook chlamydia tests as well as some more hypothetical stated preferences by those that have not been tested. It is divided into the following sections:

- Preferred chlamydia testing settings
- Reasons for preferred chlamydia test settings
- Actual test settings used by respondents
- Satisfaction levels with the testing experience or 'customer journey'
- Actual results of chlamydia tests taken by respondents
- Advice given to respondents during the testing process
- Sexual health professionals supplying the advice
- Partner notification if chlamydia test results are positive
- Experiences of actual testing as well as associated activities such as results notification and information, advice & guidance

### After testing

Lastly, this section explores respondents' future behaviour in relation to both future testing and general sexual health. It concentrates on the topics below:

- Attitudes to future testing
- Opinions of reminders for future chlamydia tests
- Reasons for taking future chlamydia tests and barriers to future testing
- Thoughts on future sexual health behaviour



## 2. Executive summary

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The following summarises experiences of Chlamydia and STI testing at three stages – before the test takes place, the test itself, and the experience after the test.

### **Before testing:**

This section of the report explored respondents' general STI and sexual health awareness. More importantly it gauged respondents' perceptions of their knowledge and understanding of chlamydia.

More than 90% of online respondents had heard of HIV/AIDS, chlamydia, genital herpes, genital warts, gonorrhoea, pubic lice, and hepatitis B. Respondents were not only most aware of HIV/AIDS (972, 95%) and chlamydia (953, 93%), but were also most commonly worried about these two infections {HIV/AIDS (543, 53%) and chlamydia (552, 54%)}.

Many respondents had been exposed to some form of chlamydia related advertising, with 87% (890) having seen or heard about the STI through the following mediums; television (682, 67%), posters (324, 32%), leaflets (298, 29%), radio advertising (269, 26%) online advertising (256, 25%) and newspaper or magazine advertising (247, 24%).

Overall, when asked 'In a group of 100 people aged 16-24, how many do you think have chlamydia?' the average answer given was 33 people. Early results from testing under the NCSP showed that one in ten of young people tested were positive, and this therefore represents a perception amongst young people that chlamydia is three times more prevalent than best estimates would suggest. 20% of respondents answered that they thought over 50 of 100 young people would have chlamydia.

Awareness of the ways in which chlamydia can be contracted varied according to gender. 84% (673) of women stated that some form of sexual intercourse was a possible method of contracting chlamydia, in comparison to 74% (163) of males. Only 17% (134) of women and 10% (23) of men thought chlamydia could be contracted through other types of sexual contact that are not oral sex or sexual intercourse.

The most common testing methods respondents thought could be used to detect chlamydia were; genital swabs (690, 67%), urine sample (635, 62%), examination by a doctor (266, 26%) and blood samples (229, 22%). However 73% (590) of women compared to 45% (100) of men believed genital swabs were a method of detection. They may be in part a result of women being offered a chlamydia test whilst having other routine tests such as smears.

Respondents believed the most common symptoms of chlamydia were itchininess/cramps/general sickness (177, 21%) and discharge (174, 21%). Only 18% (154) of respondents knew that chlamydia is often symptomless.

It appears that respondents had a higher level of awareness of the long term effects of chlamydia than they thought. Only 30% (308) of respondents felt they understood the effects of chlamydia '*quite well*' or '*very well*'. Despite this 75% of respondents (644) stated infertility was a possible long term effect and 5% (46) stated Pelvic Inflammatory Disease (PID) was a possible long term effect.

More women (705, 88%) than men (155, 70%) knew that an antibiotic in tablet form was used as treatment for chlamydia. Interestingly 32% (329) also believed antibiotic cream was a possible treatment.

Approximately one third (371, 36%) of respondents had heard of the NCSP. It is worth noting that of those tested 46% (27) of men and 29% (82) of women believed they were tested as part of the NCSP. Furthermore 45% (54) of 16-19 year olds thought they took a test as part of the NCSP, compared to only 25% (55) of 20-24 year olds. Educational establishments were the most likely place respondents were exposed to information about the NCSP (108, 32%).

The most common reasons people took chlamydia tests were; concern about chlamydia (89, 23%), the test was part of another test such as smear tests (86, 22%) and the test was offered as part of another appointment (68, 17%). As expected, more women (80, 21%) than men (6, 2%) were offered the test as part of another test.

A number of barriers discouraged people from taking a test. The most common were that respondents felt they were not at risk of contracting chlamydia (429, 42%), they were worried about having their genitals examined (365, 36%) and they feared telling their partner if diagnosed positive (304, 30%). Other noteworthy barriers to testing were respondents' fear of family or friends discovering they had taken the test, in addition to their fear of disclosing personal details. Barriers related to fears about being discovered (by friends, family etc.) taking a chlamydia test were more relevant to the younger respondents (aged 16-19 years) than older respondents (aged 20-24 years).

The internet was clearly the preferred source of sexual health information amongst respondents (632, 62%), followed by GPs/doctors (551, 54%) and sexual health/GUM clinics (476, 47%). However the phone interviews revealed that friends played a significant role also.

Many of the reasons respondents would choose not to have a test were reiterated when respondents listed the reasons for their preferred sources of sexual health information or help. Confidentiality/privacy/lack of embarrassment was the most common reason respondents would opt for a certain source of sexual health information. In light of this, confidentiality/embarrassment can be viewed as both a barrier to testing when it is not provided, but conversely when guaranteed it can be a strong pull factor, encouraging more people to be tested.

### **Testing itself**

This section of the report explored both actual 'customer journeys' taken by respondents who undertook chlamydia tests as well as hypothetical future 'customer journeys' from those who had not.

More 20-24 year olds had taken an STI test (309, 59%) than 16-19 year olds (206, 41%). Similarly, more than half of the respondents in the older age group (279, 53%) had taken a chlamydia test, in comparison to 38% (188) of respondents in the younger age bracket.

Respondents' preferences for sources of sexual health information or help mirrored their preferences for test settings. These test settings were; sexual health/GUM clinics (787, 77%), GP surgeries (679, 66%) and family planning/contraceptive services (445, 43%). One quarter (258, 25%) of respondents chose the home test kit as their first testing option, often sourcing it through the internet which was in turn the most preferred source of information on sexual health (632, 62%).

Nightclubs/bars/pubs were one of the least commonly preferred test settings (24, 2%). Furthermore, although respondents would be unlikely to take a chlamydia test at school/university/college, with only 13% (136) choosing this as one of their top three settings, they were most likely to have heard about NCSP at an educational institution.

Again the reasons for respondents' preferred sources of sexual health information or help echoed the reasons behind their preferred chlamydia test settings. These were: privacy/confidentiality (366, 36%), trustworthiness and access to more information (269, 27%), specialist centres/knowledge (236, 23%) and ease of access/free (225, 22%).

Similarly, the most commonly preferred settings in which respondents took a chlamydia test were also the places respondents most preferred to take a chlamydia test; sexual health/GUM clinics, GP surgeries and family planning/contraceptive services.

It would appear that respondents broadly had a positive experience when they took a chlamydia test as more than half of all respondents either '*slightly agreed*' or '*totally agreed*' with a list of statements which gauged their level of satisfaction with the testing experience. Despite this, there are still areas of possible improvement when screening for chlamydia. Only 58% (269) '*slightly agreed*' or '*totally agreed*' that they were not overly embarrassed by the process. This is interesting as a lack of embarrassment/privacy was the most important factor for respondents when choosing a source of information for sexual health problems (40%, 407) as well as when choosing a test setting (36%, 366). Age was also an important factor affecting satisfaction levels, with younger respondents (aged 16-19 years) less satisfied with their testing experience than older respondents (aged 20-24 years). Of the 109 respondents who thought they were tested under the NCSP, a higher proportion (70%, 76) '*slightly agreed*' or '*totally agreed*' with the statement that 'overall the experience was good' than among the 231 who thought they were not tested as part of NCSP (42%, 98).

The online survey also revealed that people who take chlamydia tests, and more worryingly those testing positive, are often not receiving sufficient information about chlamydia. Although some advice is provided more could be offered in the opinion of many respondents. To elaborate; only 48% (224) of those tested were given advice about contraception, 39% (180) received advice about chlamydia, 35% (163) received advice on other STIs, 32% (150) received advice about testing and 28% (129) received advice about the prevention of chlamydia infection. It is worth noting that 26% (120) of respondents did not receive any form of advice at all during the testing process. Males and females received similar levels of advice. Those who thought they had been tested as part of the NCSP were almost half as likely to receive no advice, with 17% (19 of 109) versus 30% (70 of 231).

#### **After testing:**

This section seeks to understand respondents' future sexual health behaviour exploring both future testing behaviour and general sexual behaviour.

Approximately one third of all respondents would take a chlamydia test in the next twelve months (315, 31%), approximately one third would not take a test (305, 30%) and one third was unsure if they would do so (340, 33%). Additionally, approximately one third (159, 34%) of those tested wanted to receive a reminder to take future tests.

More than half of the respondents (56%, 267) said they would take chlamydia tests in order to remain fertile, healthy and safe. This was true for more men (51, 72%) than women (216, 54%). Other reasons for future testing included having a new partner (43, 9%) and suspecting infidelity (16, 3%).

When probed about future sexual behaviour 60% (291) of respondents said they did not change their behaviour in any way after taking a chlamydia test, while 16% (77) said they were more careful and practised safer sex.

### 3. Before testing

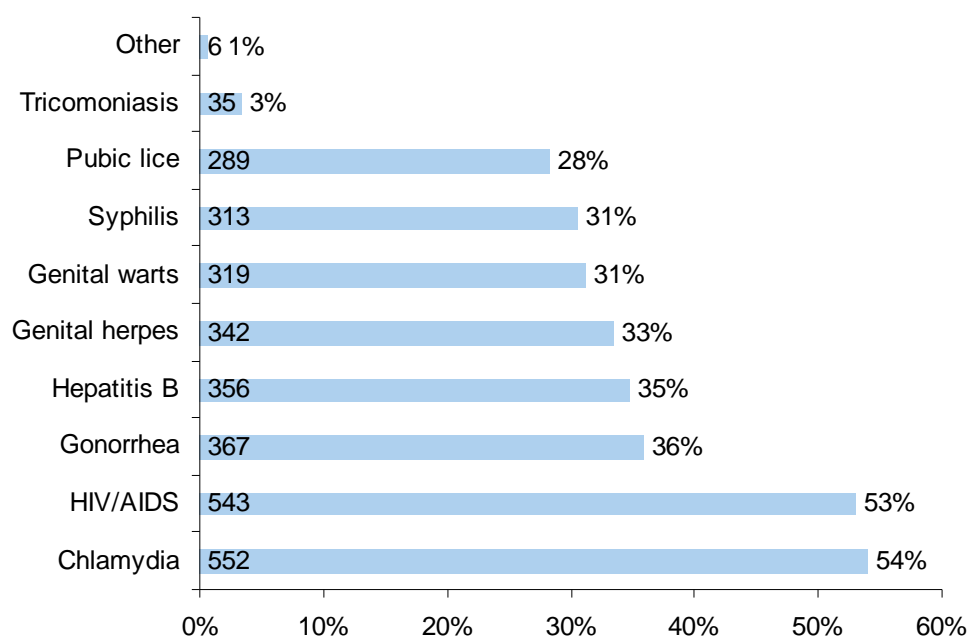
#### 3.1 General sexual health testing knowledge

Online respondents generally felt that they were familiar with most of the common sexually transmitted infections (STIs). More than 90% of respondents had heard of HIV/AIDS, chlamydia, genital herpes, genital warts, gonorrhoea, pubic lice, and hepatitis B. However, fewer respondents were familiar with syphilis and trichomoniasis. Similarly, the Define Report also demonstrated very good and consistent awareness of chlamydia amongst its target audience.

It seems that the level of concern about an STI reflected respondents' level of awareness about the infection. Respondents were not only most aware of HIV/AIDS (972, 95%) and chlamydia (953, 93%), but also most commonly worried about HIV/AIDS (543, 53%) and chlamydia (552, 54%). As can be seen in Figure 2 below, approximately one third of all respondents were also concerned about each of the other STIs with which they were familiar. However, the findings of the online survey differ from the findings of the Define Report. The report states that all respondents were aware of HIV/AIDS, which was reported as the only 'real' concern: standing out from other STIs as a permanent condition that leads to death.

It is interesting to note that if respondents had tested positive for chlamydia, their concern for STIs in general rose. Of the 44 respondents who told us they tested positive for chlamydia, 77% (34) remained worried about this STI, 73% (32) were worried about HIV/AIDS and 61% (27) were worried about hepatitis B.

**Figure 2: For each of these conditions, which are you most worried about? (Multi-code)**



Respondents: 1023 Responses: 3122

Source: FreshMinds

Multi-code means that respondents were given the option of providing more than one answer.

The percentages refer to the total number of respondents rather than responses.

Respondents could only state concern about infections that they were aware of.

## 3.2 Knowledge and understanding of chlamydia

### Chlamydia related advertising

Many respondents had been exposed to some form of chlamydia related advertising, with 87% (890) having seen or heard about the STI. The most common forms of advertising through which respondents had heard of chlamydia were; television (682, 67%), posters (324, 32%), leaflets (298, 29%), radio advertising (269, 26%) online advertising (256, 25%) and newspaper or magazine advertising (247, 24%).

As expected, certain mediums of advertising were more commonly preferred by women than men. These included posters, leaflets and newspapers or magazines. One may assume that women are more likely to see posters or pick up leaflets in clinics when seeking advice or assistance for contraception or other 'female only' tests, such as smears. Similarly, chlamydia advertising may be more prominent in girls' / women's magazines. Surprisingly however, a higher percentage of women (231, 29%) than men (38, 17%) had been exposed to radio related chlamydia advertising, though this may reflect higher awareness levels generally among females.

### Incidence of chlamydia in the 16-24 year age bracket

Overall, when asked 'In a group of 100 people aged 16-24, how many do you think have chlamydia?' the average answer given was 33 people. Early results from testing under the NCSP showed that one in ten young people tested positive for chlamydia, and this therefore represents a perception amongst young people that chlamydia is three times more prevalent than best estimates would suggest. 20% of respondents answered that they thought over 50 of 100 young people would have chlamydia.

### Contracting chlamydia

Awareness of the ways in which chlamydia can be contracted varied according to gender. 84% (673) of women stated that sexual intercourse was a possible method of contracting chlamydia, in comparison to 74% (163) of males. 36% (293) of women and 30% (66) of men believed oral sex was a method of transmitting the infection, while 17% (134) of women and only 10% (23) of men thought chlamydia could be contracted through other types of sexual contact. Of those who mentioned intercourse, a similar proportion of both women (131, 16%) and men (28, 13%) specifically stated that chlamydia could be passed onto others when practicing unprotected sex.

### Detection of chlamydia

The most common testing methods respondents mentioned which could be used to detect chlamydia were: genital swabs (690, 67%); urine sample (635, 62%); examination by a doctor (266, 26%) and a blood sample (229, 22%). However a noticeable difference when comparing the data according to gender was that 73% (590) of women and 45% (100) of men believed genital swabs were a method of detection which may in part be a result of women being offered a chlamydia test whilst having other routine tests such as smears.

### Symptoms of chlamydia

Figure 3 below shows respondents' understanding of possible symptoms of chlamydia. Respondents were asked how they thought they would know if they were infected with Chlamydia and given the option of listing up to three symptoms. The most common responses were itchiness/cramps/general sickness (177, 21%) and discharge (174, 21%).

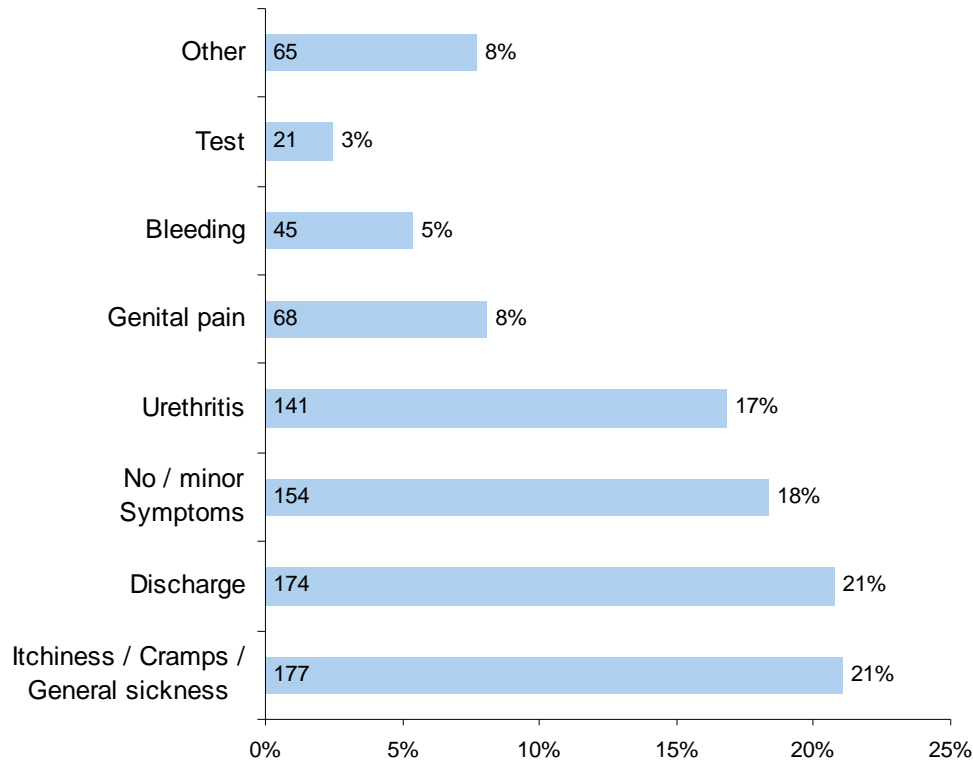
It is important to note that only 18% (154) of respondents answered that Chlamydia is often symptomless. Some of the respondents' comments highlight this issue.

*"It's known as the silent infection; you don't really know you have it."*  
West Midlands, 18

*"There are no symptoms. That is why it is important to get tested."*  
 South East England, 18

*"As far as I am aware, there are little or no symptoms, especially in women."*  
 North West England, 22

**Figure 3: How do you think you would know if you were infected with chlamydia? (Multi-code)**



Respondents: 839 Responses: 845

Source: FreshMinds

Multi-code means that respondents were given the option of providing more than one answer.

The percentages refer to the total number of respondents rather than responses.

### Perceived understanding of the effects of chlamydia

It is worth noting that respondents were conservative in gauging how familiar they were with the effects of chlamydia. Only 30% (308) of respondents felt they understood the effects of chlamydia 'very well' or 'quite well'. Furthermore, 50% of men (109) and 34% (272) of women claimed their understanding was 'not at all well' or 'not that well'. As one would logically expect, people who had tested positive for chlamydia thought they had a better understanding of the effects of the infection. 82% (36) of the 44 that tested positive stated that they understood the effects of chlamydia 'quite well' or 'very well' compared to 39% (153) of the 385 that tested negative.

### Actual understanding of the effects of chlamydia

It is vital to note that despite respondents' conservative estimates of their understanding of the effects of chlamydia, actual understanding of the long term effects of the infection were much higher. From 859 respondents and 872 responses, 75% (644) stated infertility was a long term effect of chlamydia and 5% (46) said PID was a possible long term effect. It is also worth mentioning that of 685 respondents, 88% (605) stated that infertility was a long term effect of the infection, as the first out of three possible long term symptoms.

Therefore, it appears that respondents have a higher level of awareness of the long term effects of chlamydia than they believe they have. One may hypothesise here and claim that this informed understanding of effects of chlamydia may be related to the high level of exposure to chlamydia related advertising, with 87% (890) having seen or heard about the STI.

### **Treatment for chlamydia**

General understanding of treatment for chlamydia was quite high. An antibiotic in tablet form was the most commonly selected form of treatment chosen by 84% (860) of respondents. However, other treatment methods selected by respondents included: antibiotics in cream form (329, 32%); abstinence from sexual activity (108, 11%) and washing the affected area regularly (101, 10%).

It is worth pointing out that some variations exist according to gender. Firstly, a higher percentage of women (705, 88%) than men (155, 70%) knew that an antibiotic in tablet form was used as treatment for chlamydia. Secondly, and somewhat mysteriously, the third most commonly preferred treatment listed by men was injections. This was selected by 15% (34) of men as opposed to only 4% (31) of women.

### **What they said in the interviews**

When telephone interviewees were asked about their knowledge of chlamydia testing before they were tested, the vast majority mentioned they were either well aware or vaguely aware of the infection. This correlates with the 87% (890) of online survey respondents who felt they were aware of chlamydia. Indications are that posters and leaflets distributed at colleges, schools, GPs and, to a lesser extent, nightclubs were the most recognised campaigns.

*"Just saw the Chlamydia one [campaign]. They had posters in the clubs, leaflets – I remember seeing them; they made an impact."*  
West Midlands, 20

*"They [the NCSP] have lots of posters at school and they've done presentations. They talked about getting screened."*  
East Midlands, 18

It is important to note that in the online survey respondents noted advertising was the second most prominent place where they saw information about the infection and screening. However, it emerged in the telephone interviews that the placing of that advertising could be important. Most of the interviewees said they saw the advertising in surgeries, night clubs or at educational establishments, while only 2 of the 34 interviewees said they had seen information in the print media. Targeted advertising therefore seems to be particularly efficient.

Television advertisements were also an important source of information, but none of the respondents noted these as having a strong impact on their decision to get tested.

*"Saw some stuff on TV but it was more about awareness. I didn't know about the screening until I went for a smear test at my surgery."*  
London, 24

Some interviewees were strongly affected by the advertised information they received, to such an extent that they proactively pursued a chlamydia test, or at least were primed for the test when it was offered to them by a healthcare professional.



*“The first time I did the test I had little information about chlamydia. I went to my GP and saw information on his door and decided to get it when he said it was a free kit.”*  
 London, 21

*“Yes, I heard about it before. At college. The local centre came in and told us about it, in a lecture theatre. It was half an hour, but that made me think about having the test done.”*  
 North-West, 23

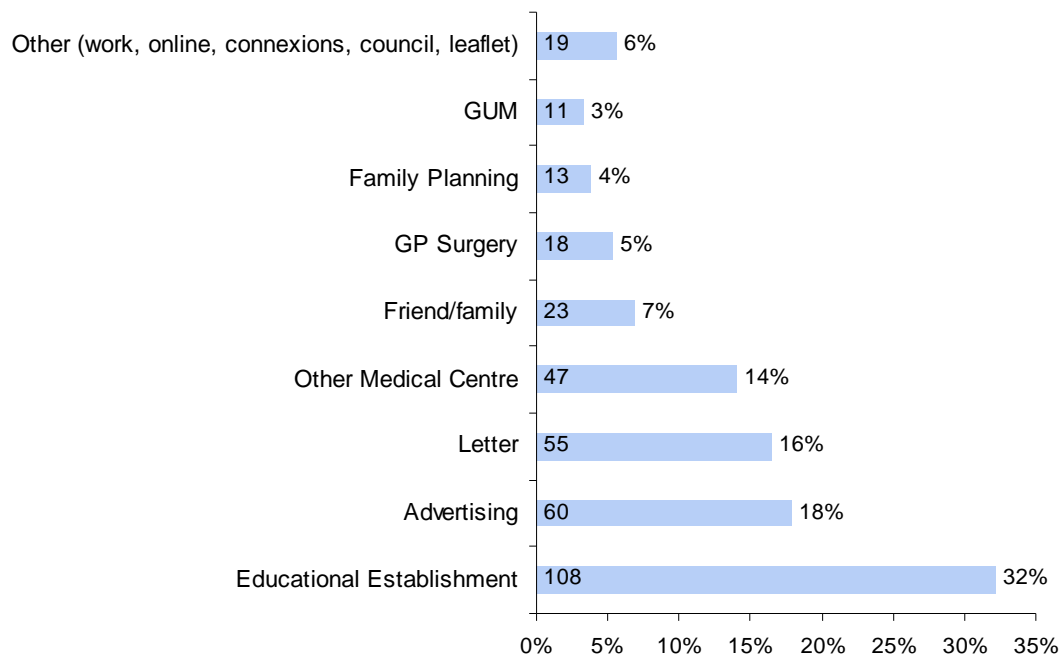
From the interviews it appeared as if advertising in print and on television created a general awareness of the infection, but that it more often than not took personal contact with a healthcare professional or NCSP officer to deepen understanding of chlamydia as an infection and of the screening process. Posters and leaflets in surgeries, schools and colleges most likely have a variable effect. People that read them in detail know more about the infection and its effects, while others only build up general knowledge of chlamydia as a health concern.

### 3.3 Awareness of the NCSP

The online survey revealed that approximately one third (371, 36%) of respondents had heard of the NCSP. Interestingly, a higher percentage of men than women believed they were tested as part of the NCSP, 46% (27) compared to 29% (82) respectively. Furthermore, 45% (54) of 16-19 year olds thought they took a test as part of the NCSP, compared to only 25% (55) of 20-24 year olds.

Respondents had heard of NCSP from a number of places. Figure 4 below reveals that educational establishments were the most likely place where respondents were exposed to information about the NCSP.

**Figure 4: Where did you hear about NCSP? (Multi-code)**



Respondents: 341 Responses: 354

Source: FreshMinds

Multi-code means that respondents were given the option of providing more than one answer.

The percentages refer to the total number of respondents rather than responses.



The quotes below highlight the different ways that NCSP was promoted in educational institutions.

*"Through a sexual health event with school. Haven't heard much, just told it existed."*  
South East England, 16

*"They came into my college and offered free tests and a prize draw. "Wee for a wii!"*  
South West England, 17

*"University Fresher's Week. It gives free chlamydia testing kits."*  
West Midlands, 21

*"At uni, we organised a Safer Sex Ball and were handing out chlamydia tests in the queue for tickets."*  
South West England, 19

Advertising, letters and medical centres (other than GP surgeries and family planning/GUM clinics) were also places mentioned as promoting NCSP.

*"I saw an advert in my local newspaper which said all people aged between 18-24 years will be receiving a free chlamydia test through the post. I also had two people from the NHS offer me a free chlamydia test in a local nightclub."*  
South East England, 21

*"I've heard of people getting given free stuff to take chlamydia tests in clubs and I've been invited to take part in a free test from family planning clinics."*  
Yorkshire and Humberside, 18

*"Radio - every 18 to 24 year old will get a free chlamydia testing kit that they can send back and get the results back as soon as possible."*  
London, 19

*"I heard about it on the television. I am aware that it is a national campaign to encourage young people to get themselves regularly screened if they are sexually active."*  
South West England, 21

When asked what they had heard about NCSP, two thirds (47, 66%) of respondents stated they knew free testing was available and 20% (14) were aware that the test could be taken either at home or with a doctor.

#### **What they said in the interviews**

As with the online survey, interviewees who said they were familiar with the NCSP were most likely to have come into contact with the programme at school or college with a higher proportion than the survey aware through their GP.

However, some confusion seems to exist amongst interviewees as to whether or not they were tested as part of the NCSP programme. 11 of the 34 interviewees (32%) offered one response in the online survey when asked if they had been tested within the NCSP, and gave another answer in the telephone interviews. A further 4 (11%) openly told us they were not

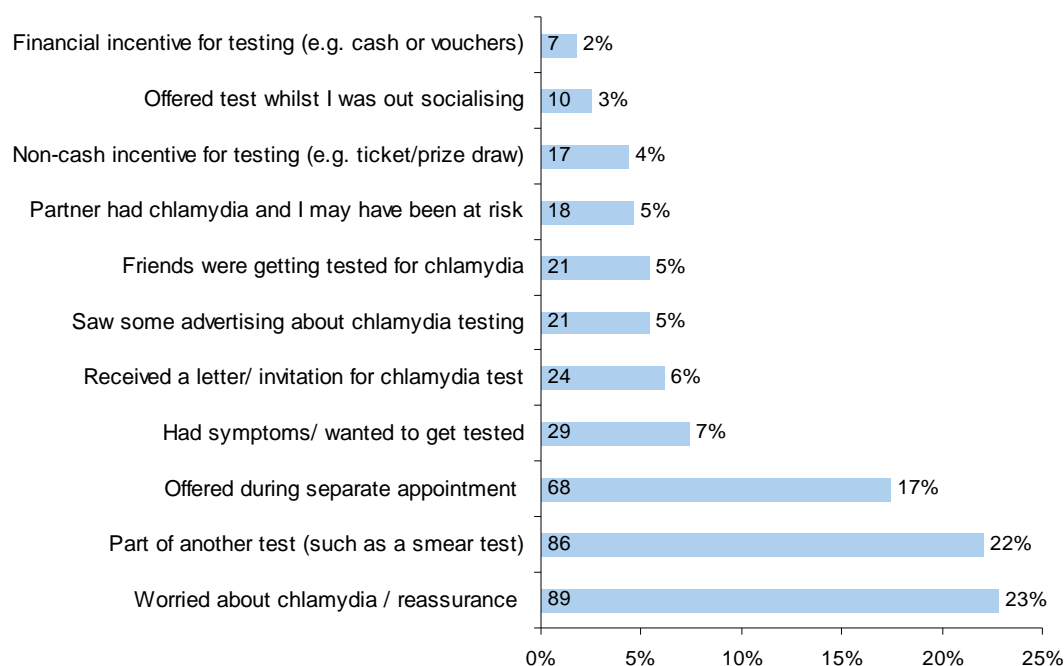
sure about the details. There could be a number of reasons for this confusion. Firstly, some interviewees were aware that they had been tested as part of a programme, but could not say with certainty that this was the National chlamydia Screening Programme. Secondly, interviewees could very well have been tested within the NCSP programme at family planning and sexual health clinics, but because these clinics did not overtly associate the testing process to the NCSP brand, the participants could not be sure of the details.

*"I knew you could get tested, but I didn't know it's a specific body."*  
Yorkshire & Humberside, 22

The respondents that were consistent across the survey and interviews in associating their test with the NCSP received information about the programme from a professional, at school, at college or in some cases a GP. It is easy to understand why; most of these interviewees completed the self-administered test immediately after receiving the information from a health professional they associated with the NCSP, creating a strong linkage between the test and the programme.

### 3.4 Reasons for being tested

**Figure 5: Which of the following options best describes your reason for being tested last time?**



Responses: 390

Source: FreshMinds

As can be seen from Figure 5 above, the most common reasons people were tested for chlamydia were; firstly concern about chlamydia (89, 23%); secondly where the test was part of another test such as a smear test (86, 22%) and lastly where the test was offered as part of another appointment (68, 17%). As can be expected, more women (80, 21%) than men (6, 2%) were offered the test as part of another test. Moreover, respondents aged 20-24 years were more likely to take the chlamydia test as part of another test, than those aged 16-19 years, 17% (68) compared to 5% (18), respectively.

Some female comments include:

*"I was ill and the doctor thought it could be chlamydia even though I knew it wasn't."*  
North West England. 17

*"It's compulsory in our PCT before getting a coil put in."*  
London. 24

*"I was going for a general sexually transmitted disease test."*  
Yorkshire and Humberside. 20

*"I had to because I wanted an abortion."*  
East of England. 19

Of interest was a comment from one woman who said: *"I went to the family planning clinic with my boyfriend for the emergency contraceptive pill, and we were told about the programme. The staff recommended that we should be screened since it was free. We tested negative"*. It would thus be interesting to explore in future research whether men are more likely to take a chlamydia test if they are in a relationship or at a setting with their partner as opposed to being single.

The reasons for taking the test varied slightly for those who had tested positive for the STI. Just under one quarter (9, 24%) of those who tested positive were proactive and took the test as a result of general concern about chlamydia. However, over one third behaved in a reactionary manner, as 18% (7) took the test because their partner had been diagnosed with the infection and a further 18% (7) had symptoms and wanted to get tested.

#### **What they said in the interviews**

In the online survey the most cited reason for getting tested for chlamydia was that individuals were worried about the infection and wanted reassurance. At face value, this seems a fairly straightforward response, but a number of factors emerged during the interviews which complicate the issue.

The high number of respondents who said they got tested because they were worried about the infection and wanted reassurance suggests that they were proactively pursuing testing, but indications from the telephone interviews are that this was in most cases a psychological predisposition and that some additional tipping point needed to be introduced before people got tested. In 16 out of 34 cases this appeared to be a diversion by a healthcare practitioner into a screening programme.

*"I went to the GP for something else. When the symptoms looked similar, he suggested the test."*  
East Midlands, 18

*"The receptionist [at the clinic] offered the free packs. I could self-test at home or do it right there. So I thought, 'may as well'."*  
North-East, 23

In another 11 cases the tipping point happened to be a recruitment drive by the NCSP at schools, colleges, nightclubs or through postal recruitment. In one case, NCSP officials were conducting home visits with self-administered tests.

*"The only reason why I got tested was because someone came to the door."*  
West Midlands, 20

*"They were handing out free pizza so I decided I might as well do it as no harm in knowing. I did the test and handed it back in."*  
East Midlands, 19

*"I moved to university and we registered with a doctor in the hall. They said every female was entitled to a test so we got one automatically."*  
East England, 24

Other interviewees readily told us that they wanted a chlamydia test because they had a new sexual partner or after unprotected sex.

*"I chatted with the receptionist and she told me about the pack. I did the test while waiting for my general test. Me and my partner just got together, and we both wanted to get checked over before we had unprotected sex."*  
North-East, 23

*"I went with my partner to make sure we were clean."*  
East Midlands, 23

An elevated general awareness of chlamydia and the screening process should not be ignored as a powerful factor that may break down barriers and make people more open to the idea of testing, as this respondent noted:

*"It never occurred to me to get tested, but they're making a fuss about it now, more than in the past."*  
East Midlands, 22

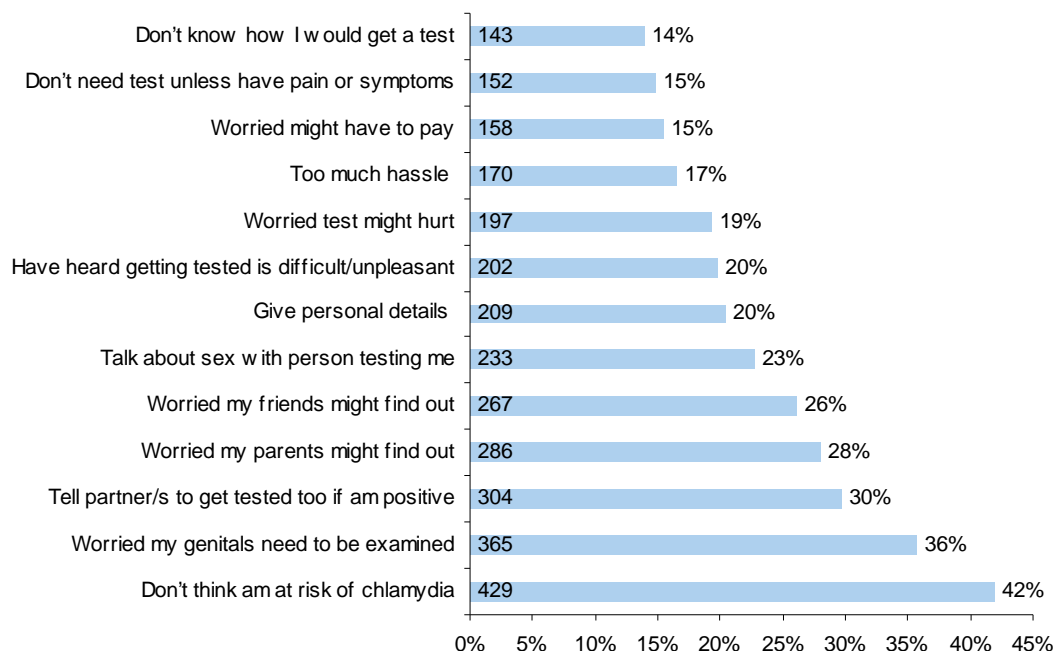
A small number of interviewees noted at the beginning of their interviews that they got tested because they wanted reassurance, but later changed their answer and told us that a previous partner had tested positive and they needed to get checked out. This implied that even with the relative anonymity of telephone interviews, self-censorship on this difficult topic could kick into play, and further underlined that getting tested for 'reassurance' has multiple facets.

Probing in the interviews revealed that only 8 of the 34 interviewees could be considered truly proactive in their pursuit of STI testing, i.e. they arrived at a clinic with the specific intention to get a test without NCSP recruitment or a healthcare professional drawing them into the programme. Four of these visited GUM clinics for broader STI screening, and even amongst these interviewees, some only opted to include chlamydia screening when told about it. This perhaps underlines how critical NCSP and GUM programmes are for channelling people into testing.

### 3.5 Reasons why someone might decide not to get tested

Respondents to the online survey gave a range of reasons why they may have been reticent getting tested, underlining how complex the decision-making process can be.

**Figure 6: These are some reasons why someone might decide not to get tested for chlamydia. For each of these reasons please indicate how relevant it is to you.**



Respondents: 1023 Responses: 3115

Source: FreshMinds

Respondents were asked to provide a ranking for each reason listed using the following 1-5 scale:

1. Not at all relevant
2. Not relevant
3. So so
4. Relevant
5. Very relevant
6. Don't know

Totals and percentages shown are the sum of 'relevant' and 'very relevant' responses.

Respondents were asked to state whether the above reasons for not being tested for chlamydia were relevant to them, by choosing which statement most applied to them from the following: *not at all relevant, not relevant, so so, relevant, very relevant, don't know and did not answer*. The above percentages are the sum of 'relevant' and 'very relevant' responses.

It seems there are a number of barriers discouraging people from being tested. Over two fifths (429, 42%) of all respondents felt they were not at risk of contracting chlamydia. This is reinforced by the Define Report which states "personal inertia towards the problem of chlamydia appears largely driven by an overall sense of low relevance to" interviewees.

The second most cited barrier to testing was worry related to having genitals examined (36%, 365) followed by a fear of telling partners if diagnosed positively (30%, 304). Furthermore 28% (286) of respondents would be reluctant to take a chlamydia test based on fear of their parents finding out. Similarly, 26% (267) of respondents would not take the test as they feared their friends would find out.

Interestingly, these noteworthy barriers to testing, that is, respondents' fear of family or friends discovering they had taken the test, in addition to their fear of disclosing personal details, reinforce the importance of 'confidentiality' and 'lack of embarrassment' as the most important reason respondents would opt for certain test settings (see Figure 8 below). Again, the Define

Report also highlighted the importance of concerns about partner notification and confidentiality in test settings as potential barriers to testing.

It is also necessary to draw attention to the importance of age when reviewing barriers to testing. Barriers related to fears about being discovered (by friends, family etc.) taking a chlamydia test were more relevant to the younger respondents (aged 16-19 years) than older respondents (aged 20-24 years). These barriers were: worry that parents may find out, 39% (193) compared to 18% (93); a worry that friends might find out, 32% (162) compared to 20% (105); and lastly, not wanting to tell partner/s to get tested if they tested positive, 34% (170) compared to 26% (134). Of the 32 respondents that had never been tested for chlamydia, these barriers were not significantly more or less relevant than the average for all respondents.

Although they had all been tested, the group that was interviewed by telephone reflected the concerns of the larger online survey group, though the reasons for them not getting tested in the first place could be grouped more concisely. The primary reason for not getting tested appeared to be embarrassment and an expectation that one's privacy would be invaded. Often these anxieties were broadly identified as it being "awkward" or uncomfortable, from an emotional point of view rather than physical.

*"It's one of those things where you have to expose yourself and it's a bit embarrassing"*  
East England, 24

*"The main thing for me was privacy. It's very intrusive and that's what I was thinking about."*  
North-West, 24

*"You think they'll look at you weird but they don't."*  
North-West, 18

It needs to be noted that in most of these instances interviewees were most likely thinking of their expectations about testing generally rather than specific settings. The same can be said when they referred to expectations that the experience would be painful.

*"I was expecting it to be more brutal, but there weren't any scary instruments."*  
Yorkshire & Humberside, 22

The second most cited barrier was that interviewees did not think testing applied to them. There are a variety of reasons for this perception, which can be categorised into high and low risk opinions. One respondent who might fall into the low risk category was a woman who had been married until recently, and who got tested when she changed partners. Other such low risk respondents might be those who are in a stable long-term relationship. But there are those who might be deemed a high risk group. One respondent thought it did not apply to her because she "wasn't very sexually active". Another thought testing only applied to those that were very promiscuous.

A third barrier, as often sighted in the interviews as the first two, was a lack of knowledge about chlamydia testing. Not knowing about any stage of the process was likely to discourage people – not knowing where to go, who to ask, and what the test might entail.

*"I just didn't know how to get hold of test or how to do it."*  
North-West, 23



*"I needed to get tested, because I hadn't gone before. I'm a student living in the centre of (university town) and the nearest GUM clinic is out of town. It's not easy to go. I also wouldn't know who to ask and embarrassing to just ask anyone."*  
South East, 20

*"It's embarrassing, really. I was worried that it might be uncomfortable. I didn't know what the test would comprise. They did make me comfortable but it was still embarrassing."*  
South East, 22

The last two quotes illustrate that multiple barriers to testing may be at play and can be unique to a person's situation. It appears from the majority of interviews that these barriers were most often overcome by healthcare professionals presenting screening as a mandatory element of contraceptive fittings, general STI testing, or as part of a process of elimination when treating symptoms that may be related to chlamydia. In these cases, it seems unlikely that a younger patient would turn down the professional advice given by a doctor to get tested.

But what of the interviewees that voluntarily opted into the program, through testing at schools, colleges or home-based testing, where an authority figure did not necessarily have the same level of control over the direction of a person's decision to get screened? In five cases, they opted to get tested because a partner came back positive, or two partners decided to get tested for reassurance. These are strong forces of self-preservation that do not need an authority figure. Others had unprotected sex or "needed to get tested", implying a similar mechanism where the need to know one's status could outweigh psychological barriers, like embarrassment or perceptions of an invasive procedure. In two more cases, both of them men, the interviewees were convinced to get tested by the goodies on offer, suggesting material gain was an incentive.

The fact that none of the respondents specifically stated that they pursued testing because they saw a television or print advert suggests that this form of advertising could be creating awareness, but may not necessarily be enough to encourage people to get tested. Material gain, self-preservation and authority intervention appear to be the strongest forces convincing interviewees to get tested.

Furthermore, it appears as if interviewees responded to psychological barriers in two ways. Some in the group wanted the reassurance of testing within a healthcare framework, (see for example Rosie's narrative in the appendix), while others were shy of personal contact. The first group tended to think of screening as just another health check-up, though they favoured self-administered tests within the healthcare setting, while the second group were generally unsatisfied by the lack of privacy, self-administered swab or not.

The mixed results therefore suggest that the NCSP currently has no easy way to predict people's responses to barriers and testing preferences. Hence, it appears sensible that as many testing choices as possible exist for individuals in this age group, even if medical practitioners exhibit the highest potential of attracting young people into the screening process.

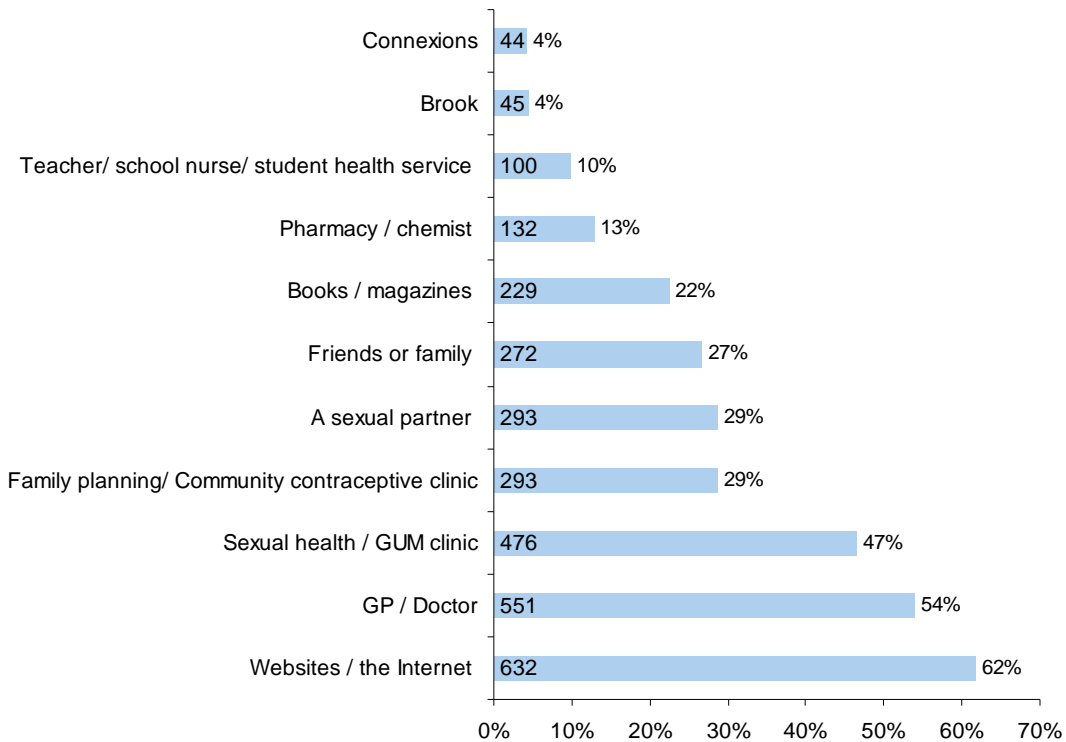
Only 2 of the 34 interviewees felt that no barriers existed for them, and that they got tested when the need arose. Still, this implies that they first needed to build up enough knowledge about the infection and screening process to be able to make that informed choice.

*[Where there any barriers to you getting tested?] No, not at all. Not even when I went the first time, five years ago.”*  
 East Midlands, 20

### 3.6 Sources of information, advice and guidance

Figure 7 below highlights the sources of information or assistance which respondents are most likely to access for sexual health related matters. The large number of respondents makes it easy to deduce that the internet (632, 62%) is clearly the most commonly preferred source of sexual health information amongst respondents, and thus perhaps more widely amongst people aged between 16-24 in the UK. The most commonly preferred sources of online information were NHS (244, 31%), Google (209, 26%), Wikipedia (45, 6%) and the BBC (33, 4%). Interestingly, few respondents who listed 'Google' as an online source of information clearly stated that they would use it in order to find a medically reputable source of information on sexual health.

**Figure 7: Here are some sources of help or information on sexual health. Please rank in order the 5 sources you are most likely to use, where 1 is your preferred option. (Multi-code)**



Respondents: 1023 Responses: 3067

Source: FreshMinds

Respondents were asked to rank their five preferred options.

Totals and percentages shown are the sum of first, second and third ranked responses.

Other accepted sources of sexual health information or help were the GP/doctor, selected by 54% (551) of respondents and sexual health/GUM clinics, preferred by 47% (476) of respondents.

Many of the reasons respondents would choose not to have a test (see Figure 6 above) were reiterated when respondents listed the reasons for their preferred sources of sexual health information or help. Figure 8 below shows that confidentiality/privacy/lack of embarrassment



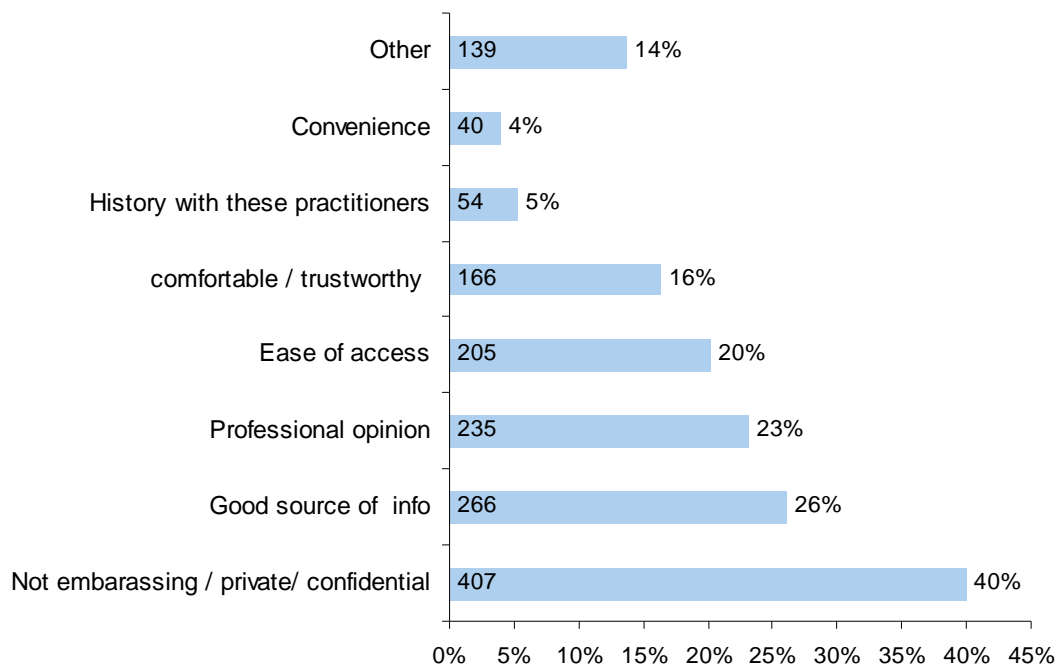
was the most common reason respondents would opt for a certain source of sexual health information.

In light of this, confidentiality/embarrassment can be viewed as both a barrier to testing when it is not provided, but conversely when guaranteed; it can be a strong pull factor, encouraging more people to be tested.

Other reasons respondents preferred certain sources of sexual health information were because: firstly they felt it was a *good source of information* (266, 26%); secondly they wanted a *professional opinion* (235, 23%); thirdly they liked the *ease of access* (205, 20%) and lastly they were assured of *comfort/trustworthiness* (166, 16%).

Breaking this down further, we then analysed respondents' first choice sources for help or information on sexual health with the reasons they gave for choosing that source. Among the 16% (167/1023) of respondents who chose GPs as their first choice source for help or information, the top three reasons (proportionately) were; *convenience* at 59% (32/54), *ease of access* at 26% (61/235) and *professional opinion* at 17% (29/166). Among the 36% (366/1023) who chose websites/the internet as their first choice the following three reasons were most common; *good source of info* at 76% (155/205), *comfortable/trustworthy* at 61% (247/407) and slightly confusingly *history with these practitioners* at 49% (130/266). Among the 18% (187/1023) who chose sexual health/GUM clinics as their first choice source, the following reasons were most commonly given; *ease of access* at 45% (106/235), *history with these practitioners* at 18% (49/266) and *convenience* at 15% (8/54).

**Figure 8: Can you explain why you are most likely to use your preferred option for help or information? (Multi-code)**



Respondents: 1017 Responses: 1512

Source: FreshMinds

Note: Respondents were given the option of providing more than one answer.

The percentages refer to the total number of respondents rather than responses.

The tag cloud below provides a visual confirmation highlighting the reasons respondents were likely to use their preferred source of information or help on sexual health. The larger the word, the more often it appeared as the basis for respondents' choices. As can be seen, the tag cloud reinforces the importance of information, confidentiality, ease and being able to talk to professionals.



*"I heard horror stories. People probably exaggerated, but I heard them. Brooke is really uncomfortable. I didn't want anyone knowing my business."*  
London, 20

*"I heard about Chlamydia and the NCSP's home-based testing from my sister ... [The first time I went] was after a friend had gone to the Hope clinic."*  
South West, 22

*"I went to a sexual health clinic, because I'd heard about it from a friend. She'd said the testing wasn't too bad."*  
South East, 18

The results from the telephone interviews therefore indicate that significant others may play a larger roll in shaping perceptions than might be expected in a world where information is readily accessible online, and that valuable information held at sexual health clinics may not necessarily be accessed if prevailing perceptions are so negative that a person is discouraged from going there for testing or information.

Because so many of the participants in the telephone interviews were diverted into the programme when presenting at various clinics for other needs (i.e. a contraceptive fitting), or were recruited in environments where they did not necessarily feel free to discuss the infection and options (e.g. school or college), a large share of the interviewees felt they were left without adequate information or guidance.

*"They expected me to know about [chlamydia], it being basic knowledge... I think its important that people know what the disease means. It would be nice for the doctors to tell you more, maybe give you information to take home. It's hard finding out what Chlamydia is."*  
West Midlands, 21

*"They should talk you through it a bit more."*  
East Midlands, 18

*"I did feel like there could be more about the options that might be available after the test I don't know what would happen if it came back positive e.g. the treatment."*  
West Midlands, 20

On the other hand, some of the interviewees felt they received enough information to make them comfortable with the screening process.

*"I got most of the information I need the first time, from my GP... I also got a lot of information from a website I registered on [cannot remember name of website]. I now get updates from my GP every time I get tested, and I get it from the site, too."*  
London, 21

*"I saw a pop-up advertisement online on Facebook. I got sent a home pack and did it at home. The packs were clear about the testing and had leaflets telling me more about the disease."*  
West Midlands, 21

The few male participants in the telephone interviews appeared generally happier with the level of information and guidance they received, and ready to pursue additional information on their own time, if they felt it necessary to know more. This favourable experience may be because the testing was more voluntary than for many of the women who participated. Those women who were most dissatisfied with the lack of information felt that they had little control over the testing process.

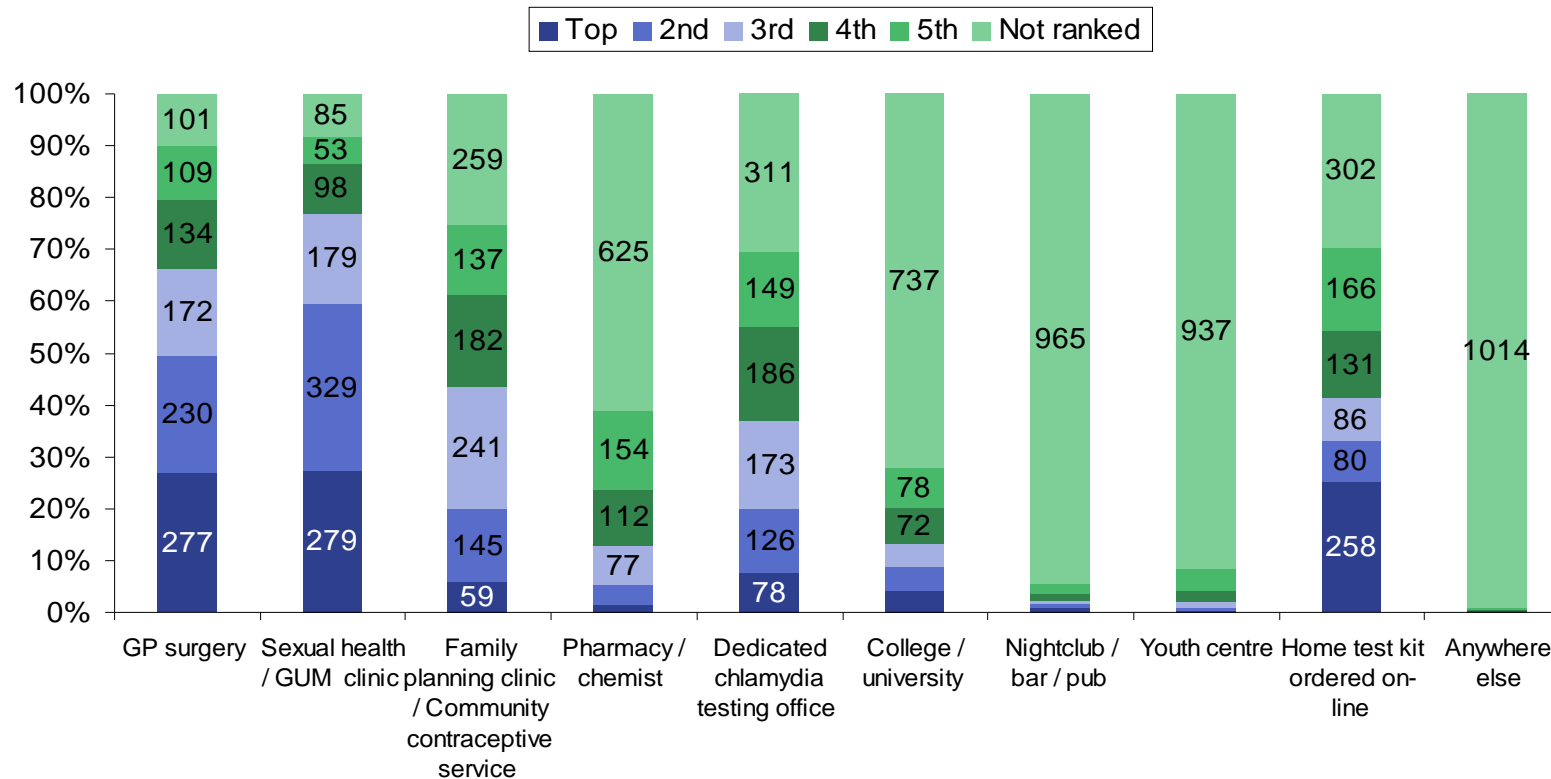
*"I went to family planning clinic to get an IUD fitted. They just said they're going to test for Chlamydia, and that was it really. The doctor didn't say anything else. She wasn't very helpful, to be honest. She told me she had to do it. She didn't give me any information I needed, and was quite rude. I didn't even know what Chlamydia was, so the fact that I was being tested didn't mean much to me."*

London, 22

## 4. Testing itself

### 4.1 Testing settings

Figure 10: These are some settings where you might get tested for chlamydia. Rank your preferred choices from 1 to 5 where 1 is your most preferred option. (Multi-code)



Respondents: 1023 Responses (per setting): 1023

Percentages and totals discussed are the sum of first, second and third ranked responses against the total base of respondents (1023) for each setting

Source: FreshMinds

Respondents' earlier preferences for sources of sexual health information or help (see Figure 7) mirrored their preferences here for testing settings, highlighted in Figure 10 above. These test settings were: firstly sexual health or GUM clinics (which was in the top three choices of 787 people, or 77% of the total sample); secondly GP surgeries (which was in the top three choices of 679 people, or 66% of the total sample) and thirdly family planning/contraceptive services (which was in the top three choices of 445 people, or 43% of the total sample).

It is worth noting that although respondents' first choice source for sexual health information was the internet, this was not a possible test setting per se, only the method by which respondents could order a home test kit. Interestingly, one quarter (258, 25%) of respondents chose the home test kit as their first option for testing. One respondent explained that *"things like this are very personal and I would feel more comfortable doing it myself."*

When asked an open question about which test settings respondents would not use, nearly half (494, 48%) said they would not use services offered in a bar/pub/nightclub. These establishments were deemed inappropriate/untrustworthy/unreliable and unhygienic. Respondents also greatly feared embarrassment. The quotes below reflect some of these sentiments.

*"No way in a club, how embarrassing ... "I'll have a pint of lemonade and a STI test please!"*  
South West England, 22

*"Well I wouldn't really go into a Nightclub/bar/pub and ask for a pint of chlamydia testing kit please.*  
East of England, 18

*"Nightclub - wtf?? What kind of nightclubs have chlamydia tests?!?"*  
Yorkshire and Humberside, 18

*"I would not use college or a bar because I would be with my friends, and I would be worried in case they thought I had chlamydia, because they might not want to be near me anymore."*  
North West England, 18

*"I wouldn't want to get tested in a nightclub or bar or pub. I would feel strange about having a swab in those sorts of places! In somewhere public where other people are it would feel odd"*  
South East England, 23

*"Anywhere where explicit social interaction is involved - makes one feel guilty, embarrassed."*

*"Nightclub/bar/pub - unable to see how this would work... unsanitised environment."*  
West Midlands, 20

In a similar vein, universities/colleges/schools were also less commonly preferred as possible test settings, with only 13% (134) of respondents choosing these places as their first, second or third preferred option. Such venues were disliked primarily because people feared a lack of anonymity as well as being embarrassed.

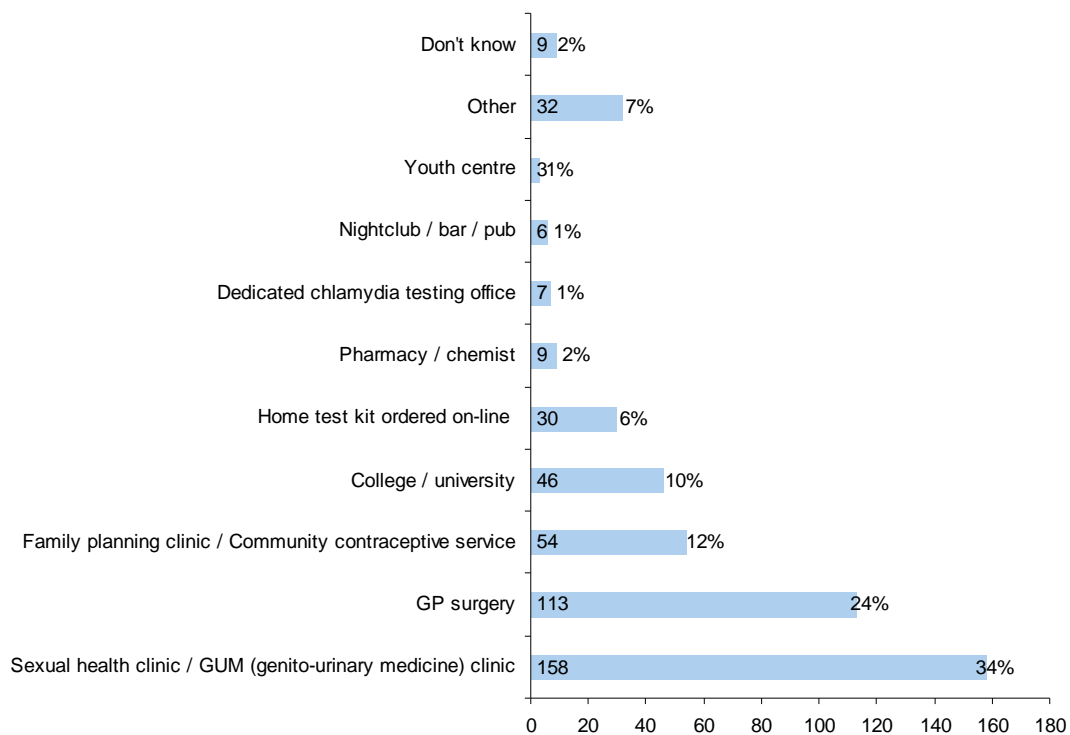


*"University, I would be worried someone I knew would see me take the test."*  
 London, 21

*"University - scared about anonymity."*  
 South East England, 21

*"I wouldn't use my college as it would be too embarrassing."*  
 South West England, 16

**Figure 11: Where did you get your test?**



Respondents: 467

Percentages refer to the total number of respondents.

Source: FreshMinds

As perhaps expected, the three most common settings in which respondents actually took a chlamydia test, (see above), were also the three places respondents most preferred to take a test for chlamydia (see Figure 10 earlier). These were sexual health/GUM clinics, GP surgeries and family planning/contraceptive services. It is of interest to note that the order of preference for test settings also mirrored the order of settings in which respondents actually took the test.

A 'home test kit ordered on-line' was the third most popular first choice (25%) for venue to be tested in (only just less than GP and GUM each at 27%) but where as the actual test settings widely reflect the preferred setting for most of the other venues there is a massive disparity for home test kits, perhaps indicating that this service either isn't being offered enough or isn't being offered in the right way.

It is also interesting that 'college / university' was less commonly preferred as a chlamydia test setting location with only 13% (136) of respondents choosing this as their first, second of third option. Similarly, the above shows that a similar proportion of respondents, that is, 10% (46), were tested for chlamydia in their college or university. Moreover, it is interesting that

while only 10% (33) of females took a test at college/university, 20% (13) of males took a test in the same setting.

Furthermore, it is also worth mentioning that although sexual health/GUM clinics were nearly equally commonly preferred by males and females, 39% (25) and 40% (133), respectively, this was not the case for all the other test settings. GP surgeries were more commonly preferred by females than males, (100, 30% compared to 13, 20%, respectively) as were family planning/contraceptive services (51, 15% compared to 3, 54%).

Age also appears to affect the places in which respondents took their test. 20-24 year olds were more likely to take a test at a GP surgery (80, 33%) compared to 16-19 year olds (33, 21%). Similarly, the former group were also more likely to take a test at a sexual health/GUM clinic compared to the latter, 46% (110) compared to 30% (48) respectively.

### **What telephone interviewees said about nightclubs**

Only one participant in the telephone interviews was tested in a nightclub, and for him it was a uniquely positive experience, which stands in stark contrast to the strong reactions amongst some of the online survey respondents. The dominant reason for this was convenience, the informal setting and the ease of the entire process. Please refer to **Greg: The confident clubber** in the narrative appendix for a detailed case study.

*"It was a nice way of doing it. It was all done for me ... It wasn't invasive. It was easy. I didn't have to go out of my way... If testing stayed in nightclubs and there was another chance to do it, yes, [I'd do it]."*  
South-East, 22

### **What telephone interviewees said about school and college -based testing**

The 5 participants in the telephone interviews who were tested in either a college or school setting were generally fine with the process and happy with its ease and convenience. They also reacted favourably to the friendliness of the staff, the delivery of results by text, and felt that the test was better than they had imagined it would be. One participant even thought the incentive offered by the NCSP to take part in the screening programme was great.

*"It was better than I thought it would be. It was much easier."*  
East England, 16

*"I thought it was pretty good. It wasn't exactly the most comfortable doing it in the toilets at the college. People were around. But it was all very friendly. It wasn't too embarrassing to bring it back. Maybe at a GP's would have been better."*  
London, 19

*"They were handing out free pizza and condoms, so I decided I might as well do it as there's no harm in knowing."*  
East Midlands, 19

However, they qualified their responses with negative sentiments attached to privacy and the depth of the information they could get privately.

*"I just feel there could have been more info given. You just... hand it in etc. It felt too open to ask any personal questions... I would have preferred the handing in area to be more private. It was in the middle of the student union."*  
East Midlands, 19



*"No, I got nothing about approaching partners [if I tested positive]. It was all about the test. I think they were available for questions but there were quite a lot of people so I wanted to get it all done... I would have preferred the handing in area to be more private. It was in the middle of the student union."*

East Midlands, 19

It appears from the telephone interviews that people could see the benefit of testing at schools and colleges, and that they were appreciative of the information they received there, but their concerns about confidentiality and privacy weighed heavily on these benefits. If the self-administered swabs could be taken into toilets attached to NCSP controlled areas, rather than users having to carry test packs across campus, and the tests could be handed in as confidentially as they were in some cases distributed, people may well become more open to testing at these venues.

### **What telephone interviewees said about family planning clinics**

8 of the 34 interviewees screened for chlamydia entered the programme through family planning or sexual health clinics including, amongst others, Hope, Connections, Brook and the Brandon Centre. All of those that were screened by family planning clinics were women diverted into the programme after they presented for contraceptive treatment or gynaecological symptoms. Of the two who went to sexual health clinics, one asked for the test because a friend had recommended it, while the other had an ex partner that tested positive for the infection.

The level of information shared with this group did not vary as much as it did with GPs and GUM clinics, and the general satisfaction with the testing process in this group was relatively high and consistent. Leaflets appeared to have been made available in most cases and the testing and treatment processes were mostly discussed to a level that satisfied participants.

*"In the waiting room there were pamphlets etc. I was told there was a urine sample or a swab. The lady talked me through how I could take it, but I didn't receive additional information. I felt completely comfortable. It was really easy. I liked that there were different options and it was good they offered it routinely as I wouldn't have thought to get it and I'm glad I did. The testing process was so simple that, having done it once, it was easy to get it done again."*

London, 18

*"They talked you through how it would feel, but sometimes it can still be a bit discomforting."*

East England, 24

*"It was quite good. I was well informed. It put your mind at rest. There's just something about it that doesn't make it a nice experience."*

South East, 21

In most cases, participants were also happy with the notification procedures employed by their clinic – whether text or letter – and that they were informed in a reasonable time.

However, one person appeared to have been so ill informed about the process when she was unexpectedly diverted into the testing programme that her response to the process was one of strong dissatisfaction. Please refer to **Jemma: a patient left in the dark** in the narrative appendix to follow her detailed test path. Others also felt there was a lack of information about options.

*"I did feel like there could be more about the options that might be available after the test I don't know what would happen if it came back positive e.g. the treatment."*  
East England, 24

Also, one of the participants in this group felt the notification time took unusually long.

*"I was told I would receive my results in the next few days, but it took 2 to 3 weeks. It was a bit long to wait."*  
London, 18

Another felt that she was not given all the notification options she would have liked, preferring just a text message rather than a telephone call when she tested positive. One might note that it appears notifications by phone call are a common practice that overrides individual preferences.

Those participants in this group that received their results by post were not given the option of a text message and appeared satisfied with the service, in the absence of other options. Comparing their views with those expressed by other participants, it is highly likely that the group who were notified by post would prefer text notifications. This, because post could be intercepted by parents, that it could take longer than expected, and in the event that post did not arrive to notify the person, this could cause distress to someone anxiously waiting for information.

#### **What telephone interviewees said about GPs**

As with family planning and sexual health clinics, GPs appear to play a very active role in diverting people in the 16-25 age group into the NCSP. However, it appears there is a large degree of variance in how GPs approach sharing information about chlamydia and the testing process, which in most cases leads to variance in satisfaction levels amongst patients. Some GPs appear to prefer a hands off approach, informing patients about the various stages of the process on a need to know basis. Some patients respond favourably to this because they want to keep the process as simple as possible. But many others, notably women who have concerns about the infection and its impact on their futures, feel that this hands-off approach leaves them in the dark and dissatisfied with the service.

It was clear that some people preferred seeing a professional for the test rather than attempt to do the test themselves or explore other testing options. Others are very particular about the people they trust with their bodies.

*"I went to my GP because I preferred it...My doctor is a woman, I don't want a man doctor."*  
London, 20

The negative issues that emerged in this group were much the same as those in the family planning group, though one participant, who was fairly young, also felt the service at her local GP could be friendlier. GPs were also very unlikely to discuss with patients how to approach partners, even if they would have liked to have that information upfront. Again, GPs may be attempting to keep the process as simple as possible, but it appears some patients feel more empowered regarding the entire process if they have as much information as they can, from the start.

*"The doctor said I had to go for all these tests but didn't say which. They didn't tell me more until after the test. I wish they informed me before."*  
Yorkshire & Humberside, 22

*"They should talk you through it a bit more. It would've been nice if they were a little less condemning. They talked to me as if I already have it, because I had a similar symptom."*  
East Midlands, 18

*"Don't know whether the doctors would be able to inform on your behalf. If a doctor or nurse could step in that would be good."*  
South East, 22

As with the group tested by family planning and sexual health clinics, the majority of interviewees were happy with how they were notified regarding their test results. One person felt the waiting period was too long, even if, in her case, it was within a week. Interestingly a large number of participants from this group felt that the service could be improved by introducing home-based or postal testing, which indicates that there is either a lack of awareness when it comes to postal testing or it is not available as an option.

### **What telephone interviewees said about GUM clinics**

Many of the issues raised by participants in other clinical groups were also raised by the respondents that used GUM clinics. Though some users rated the services they received through GUM as highly professional, friendly and supportive, others felt that because chlamydia was lumped into broader screens they were left in the dark about the infection, its ramifications and advice on how to approach partners, if they tested positive.

*"I'd give both [GP and GUM testing] a 10 out of 10. I got both my initial and follow up results back within two days of being tested. I didn't wait long at all. The staff made me feel comfortable and they had a bit of a laugh with you."*  
North-East, 23

*"It was a bit nerve-wrecking sitting in the waiting room with ten others."*  
South West, 22

One participant, who tested positive and went through the entire treatment process, noted that she still was not sure what chlamydia was and what it could do to her in the long-term. Two respondents noted, however, that they were very happy with a testing process where the results were made available immediately.

*"The staff need to be a bit more understanding. They're not very sympathetic. I asked questions afterward, especially about the long-term implications [of testing positive]. But they couldn't answer me. It was like 'I don't know'. They just told me to use protection."*  
South West, 22

The major complaint with GUM clinics is its drop-in nature. Most interviewees in this group had an aversion to waiting in an exposed area where they might be identified. Also, one participant noted that the GUM clinic in her city is relatively inaccessible, especially because she works unusual hours. Most of those that were tested in a GUM setting were unhappy with the fact that swab tests were still administered by a GP or nurse, though those who highly rated GUM clinics generally had experiences with self-administered swabs.

Three respondents had their first chlamydia tests within the framework of a GUM clinic and progressed to other testing centres – one moved on to a GP, one to a family planning clinic and the last to postal testing. All of these noted an improvement in how they felt about the

process, especially when it came to privacy and convenience, but one felt that she did enjoy the GUM clinic's annual reminder to return for a test, and saw no reason why GPs cannot offer the same reminder service for chlamydia testing.

*"[Difference between GUM and family planning clinic?] There's a lot more people around at a GUM clinic and the family planning centre is more discreet. It's a different atmosphere, really. But the service at both is professional. The information is the same as well. The GUM keeps track of your records and they contact you with reminders. It's not like that at the family planning clinic. It makes it easier to see when you've last been."*  
East Midlands, 20

When it came to contacting partners on the patient's behalf it appeared as though people prefer to have choices.

*"They talked to me about partners but they didn't offer to call them on my behalf. I'm happy to do it on my own, but if there's a difficult case, I'd prefer them to do it for me."*  
East Midlands, 20

#### **What telephone interviewees said about home-based/postal testing**

Though home-based testing proved a very commonly preferred option amongst online survey respondents, and many telephone interviewees stated they would improve the testing process by introducing testing at home, there appears to be a distinct lack of awareness about this option. It is not always clear from the interviews, whether postal testing is not an option in that area or if people are just not aware of it as an option. Either way, more advertising on this front could see a strong shift in customer satisfaction and willingness to get tested.

4 of the 34 telephone interviewees used some form of the home-based service, whether offered by the NCSP, local council, an internet order, or a unique home visit from healthcare professionals (Please see **Olivia: Home-based testing with a difference** in the narrative appendix for a detailed case study). There was uniform agreement amongst interviewees that home-based testing is easy, simple and confidential. Suggestions on how to improve the service were sparse compared to other groups, with two admitting they have no idea how to improve it further.

*"I'd put more information into the pack, like a booklet. The leaflet is rather simple."*  
Yorkshire & Humberside, 22

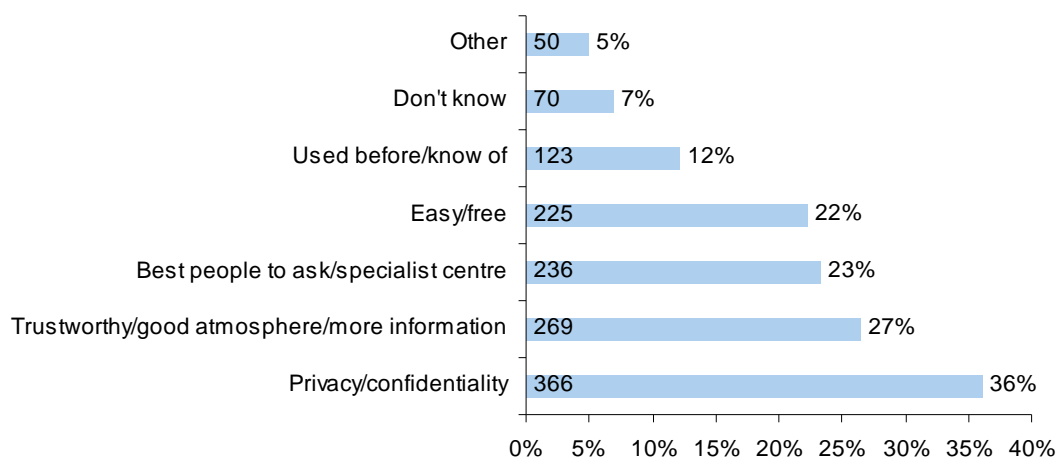
Criticism was centred on the lack of information about the infection, though most users felt there was enough in the leaflets to inform them why the screening was being done, and exactly how the test should be used. One respondent was not happy with the waiting period.

*"Yes, my expectations were met. But the waiting period is three weeks. It's too long. I've so far been waiting just under three weeks."*  
South-East, 19

In general, it appears that the greatest potential for expansion of the NCSP's services exist in rolling out home-based testing on a larger scale.

## 4.2 Features of different testing settings

**Figure 12: Can you briefly explain why you are most likely to use your selected venue for a chlamydia test? (Multi-code)**



Respondents: 1014 Responses: 1339

Source: FreshMinds

Multi-code means that respondents were given the option of providing more than one answer.

Percentages refer to the total number of respondents rather than responses.

The reasons for respondents' preferred sources of sexual health information or help (see Figure 12 above) are also the reasons they would opt for their preferred chlamydia test settings. Figure 12 above confirms respondents would choose their preferred chlamydia test settings because they believe such settings: offer privacy/confidentiality (366, 36%); are trustworthy and can provide more information (269, 27%); are specialist centres (236, 23%) and are easy to access/free (225, 22%).

It is worth mentioning that the Define Report also stressed the importance of confidentiality in the provision of chlamydia testing services, required from the initial contact with the target audience, through to results, medical records and partner notification. The Report also supports the findings from our online survey, which reveal that simplicity/ease of the test are very important too.

The following quotations from respondents, in which they highlight the grounds for their preferred test setting, are similarly revealing, especially when details of their preferred testing venue from the online survey are included.

*"It's reliable and they would treat your case with understanding and hopefully offer/advise other STD testing - if you've been vulnerable to an STD you're vulnerable to all."*

South West England, 21

Preferred venue: Dedicated chlamydia testing office

*"More privacy. Reduces embarrassment."*

South East England, 23

Preferred venue: Sexual health clinic / GUM clinic



*“These types of people are used to things like this and I wouldn't feel embarrassed as I would not be the only one with this problem.”*

East of England, 19  
Preferred venue: Sexual health clinic / GUM clinic

*“Because they test you for all the STDs and they can help afterwards.”*

South East England, 22  
Preferred venue: Sexual health clinic / GUM clinic

*“I also don't like the fact that people could judge you for walking into a sexual health clinic for being dirty or a "slut" whereas really you're being responsible. When you walk into a GP surgery it could be for a variety of things and people don't judge you.”*

West Midlands, 18  
Preferred venue: GP surgery

The tag cloud below provides a visual confirmation to illustrate the reasons respondents opted for their preferred test settings. The larger the word, the more often it appeared as the basis for respondents' preferred chlamydia test setting. As can be seen from Figure 12 above and Figure 13 below, the tag cloud reinforces the importance of privacy, knowledge, comfort and ease.

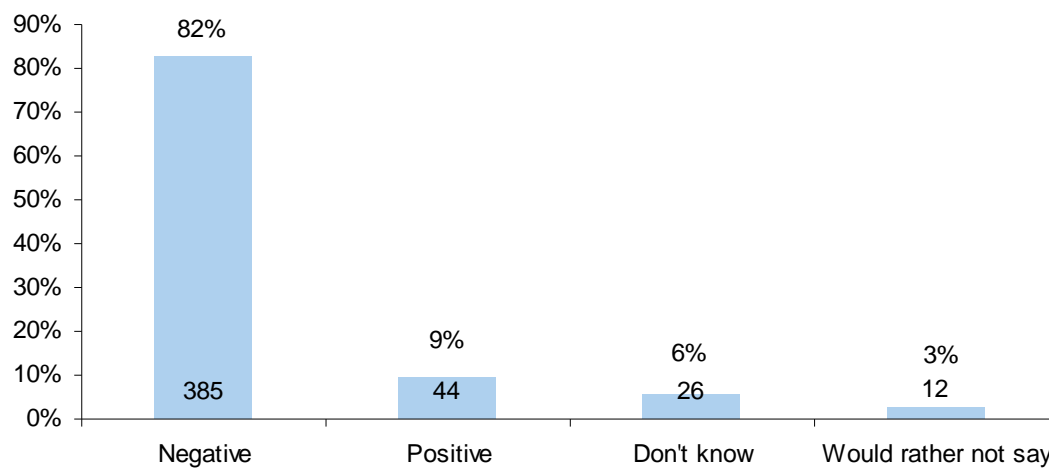
**Figure 13: Can you briefly explain why you are most likely to use your selected venue for a chlamydia test?**



Source: FreshMinds

### 4.3 The testing experience

Figure 14: Please tell us the results of your test?

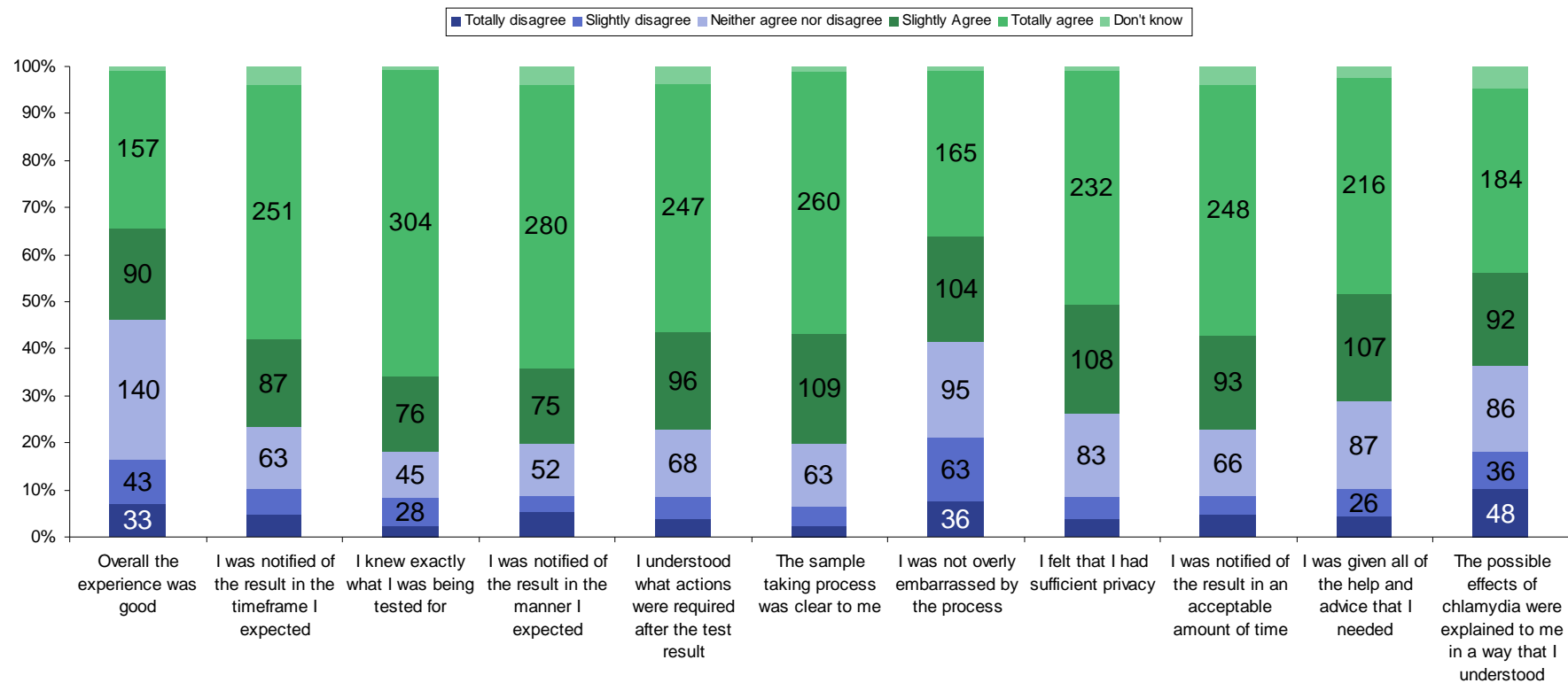


Respondents: 467

Source: FreshMinds

Of the 1023 respondents who completed the online survey, fewer than half (467, 46%) said that they had been tested for chlamydia. Of those tested, 82% (385) were female and the remaining 18% (82) were male. 9% (44) of these respondents tested positive for Chlamydia and it is interesting to note the differences in gender. While there were approximately five times more females than males, a higher percentage of males (6, 10%) told us they tested positive than females (38, 8%).

**Figure 15: To what extent do you agree with the following about your experiences of being tested? (Multi-code)**



Respondents: 467 Responses: 467 per statement

Source: FreshMinds

Percentages and totals discussed are the sum of first, second and third ranked responses against the total base of respondents (1023) for each setting



It would appear from Figure 15 above that respondents broadly had a positive experience when they took a chlamydia test as more than half of all respondents either '*slightly agreed*' or '*totally agreed*' with all of the statements above, which gauge their satisfaction levels with their testing experiences.

Looking at respondents experiences more closely, 81% (380) either '*slightly agreed*' or '*totally agreed*' that they knew what they were being tested for, 76% (355) totally agreed or slightly agreed that they were notified of results in a manner they expected and 79% (369) felt the sample taking process was clear.

Despite this, there are still areas of possible improvement when screening for chlamydia. Interestingly, 18% (84) of respondents '*slightly disagreed*' or '*totally disagreed*' that the person who tested them for chlamydia explained the possible effects of the STI in a way they understood, while a further 18% (86) felt ambivalent, or 'so so' about this. Similarly, 10% (47) of respondents '*slightly disagreed*' or '*totally disagreed*' that they were given all the help / advice they needed, with another 19% of respondents (87) feeling 'so so' about this statement.

In addition, just over half (247, 53%) of respondents '*slightly agreed*' or '*totally agreed*' that overall the experience was good.

Furthermore, only 58% (269) '*slightly agreed*' or '*totally agreed*' that they were not overly embarrassed by the process. This is of interest because as seen in Figure 8 a lack of embarrassment/privacy (40%, 407) was the most important factor for respondents when choosing a source of information or assistance for sexual health problems.

It is also vital to note that age was an important factor affecting satisfaction levels of respondents' testing experiences. Generally, younger respondents aged 16-19 years were less satisfied with their testing experience than older respondents aged 20-24 years. On average, younger respondents were 14% less likely than older respondents to '*slightly agree*' or '*totally agree*' with all of the statements in Figure 15 measuring satisfaction levels for the testing experience.

Of the 109 respondents who thought they were tested under the NCSP, a significantly higher proportion (70%, 76) '*slightly agreed*' or '*totally agreed*' with the statement that 'overall the experience was good' than among the 231 who thought they were not tested as part of NCSP (42%, 98). 88% (96) of the NCSP-tested respondents '*slightly agreed*' or '*totally agreed*' with the statement 'I knew exactly what I was being tested for' and 83% (90) '*slightly agreed*' or '*totally agreed*' with the statement 'I was notified of the result in the manner I expected'. The two joint-lowest areas of satisfaction for this group were the 73% (79) who '*slightly agreed*' or '*totally agreed*' with both the statement 'I was not overly embarrassed by the process and with 'The possible effects of chlamydia were explained to me in a way that I understood'.

If analysing satisfaction by setting, using the highest and lowest scores, you get the following results. Of the 113 respondents tested in GP surgeries, 76% (86) '*slightly agreed*' or '*totally agreed*' with the statements 'I was notified of the result in an acceptable amount of time' and 'The sample taking process was clear to me'. However only 47% (53) '*slightly agreed*' or '*totally agreed*' that 'overall the experience was good'. Of the 158 tested in GUM clinics, 83% (131) '*slightly agreed*' or '*totally agreed*' that 'I knew exactly what I was being tested for' while only 47% (74) '*slightly agreed*' or '*totally agreed*' that 'overall the experience was good'. Of the 54 people who were tested through a Family planning clinic/Community contraceptive service, 91% (49) '*slightly agreed*' or '*totally agreed*' with the statement 'I knew exactly what I was being tested for'. Only 57% (31) '*slightly agreed*' or '*totally agreed*' that 'the possible effects of chlamydia were explained to me in a way that I understood'. Only 9 people were tested at a pharmacy or chemist making it difficult to build a more nuanced picture of their experiences. Similarly only 7 people were tested at a 'dedicated chlamydia testing office'. 46 respondents were tested at college/university and 91% (42) of them '*slightly agreed*' or '*totally agreed*' that 'I knew exactly what I was being tested for'. Only 59% (27) of this group slightly or totally agreed with the statement 'the possible effects of chlamydia were explained to me in a way

that I understood'. 6 people were tested in a night club, bar or pub and only 3 in a youth centre, again precluding any more detailed analysis.

#### 4.4 Information, advice and guidance

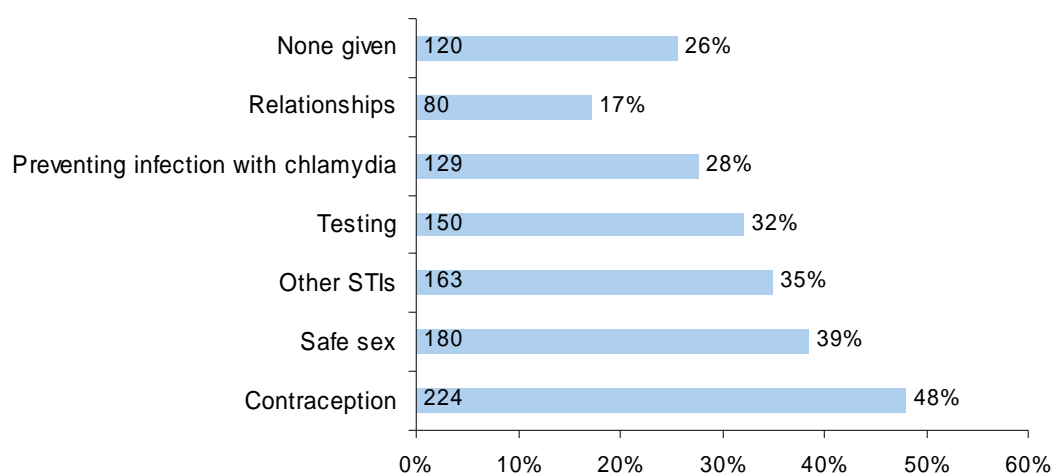
When respondents were tested, they received advice on a number of topics.

Figure 16 below reveals that contraception was the most common topic on which they received advice, with 48% (224) of those tested choosing this option, closely followed by advice about; safe sex (180, 39%), other STIs (163, 35%), testing (150, 32%) and prevention of chlamydia infection (129, 28%). Interestingly, males and females received similar advice.

Disappointingly though, 26% (120) of respondents claimed to have not received any form of advice during the testing process itself. Interestingly, this seems to be affected by age, as 32% (90) of 20-24 years reported not receiving any advice compared to only 16% (30) of 16-19 year olds. Furthermore, of the 44 people who tested positive, 16% (7) did not receive any advice, and only 59% (26) received advice on contraception, 55% (24) received advice about other STIs as well as safe sex, 43% (19) received advice on preventing infection with chlamydia, 39% (17) received advice on testing and 23% (10) received advice on relationships. Those who thought they had been tested as part of the NCSP were almost half as likely to receive no advice, with 17% (19 of 109) versus 30% (70 of 231).

These findings reveal that people who take chlamydia tests, and more worryingly, people who are testing positive are **not receiving sufficient information** about chlamydia.

**Figure 16: When you were tested, what advice did you receive about sexual health? (Multi-code)**



Respondents: 467 Responses: 1046

Source: FreshMinds

Multi-code means that respondents were given the option of providing more than one answer.

Percentages refer to the total number of respondents rather than responses.

In light of the above findings, it is necessary to understand from where respondents received advice. Of the 306 respondents to this question, nurses were the most commonly selected source of advice (56%, 172), followed by GPs (21%, 65) and then college or university staff (7%, 21). Again, it is worth noting that males were more likely to receive advice from university staff than females, 16% (9) compared to 5% (12), respectively. This may be in part due to the fact that a higher percentage of males (13, 16%) were tested on university/college campus compared to females (33, 9%).

All respondents were also asked what the best way of notifying their partner(s) would be if they tested positive for chlamydia. 48% (491) said they would like to notify their partner(s)

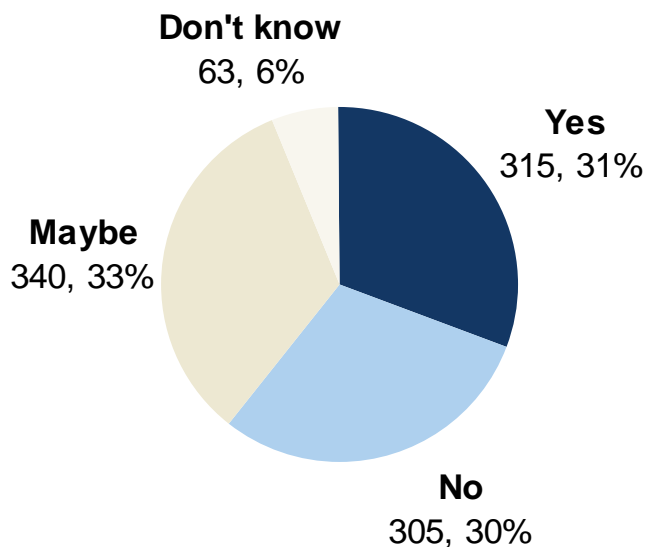
themselves and 40% (405) preferred to have the option of notifying their partners or having the test centre do it on their behalf. More women than men chose this option, 43% (348) compared to 26% (57), respectively. 8% of respondents (83) opted for the testing centre to inform their partner(s) and invite them for a test.

## 5. After testing

### 5.1 Future testing behaviour

As is evident from Figure 17 below, approximately one third of all respondents would take a chlamydia test in the next year (315, 31%), approximately one third would not take a test (305, 30%) and one third was unsure if they would do so (340, 33%). It is worth noting that only half (22) of the respondents who tested positive said they would take a test in the next year and 27% (12) said they would not.

**Figure 17: Do you think you will get a chlamydia test in the next year?**



Respondents: 1023

Source: FreshMinds

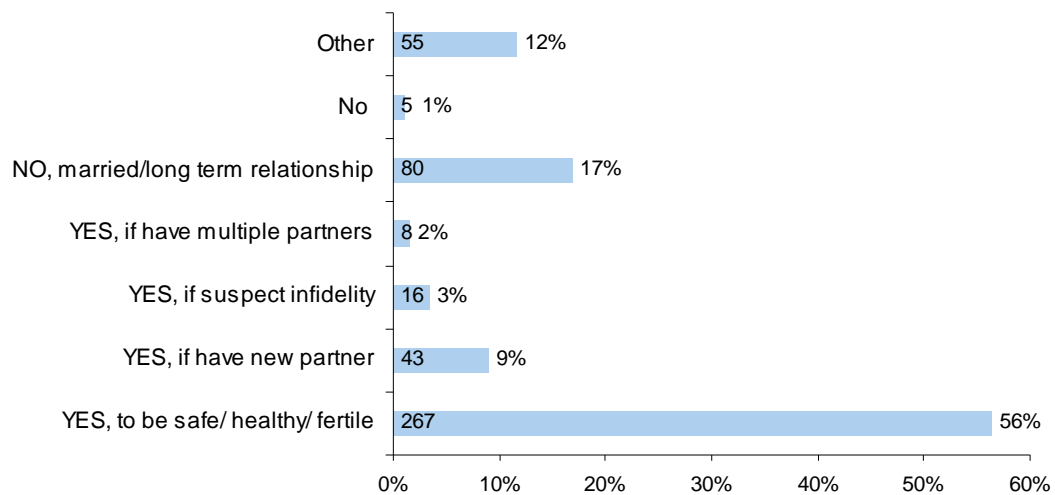
As mentioned above, it seems the proportion of all respondents who were confident they would take a test in the next twelve months was not particularly high (315, 31%). When those 467 respondents that had been tested were asked whether they would take a chlamydia test in the next one to five years, the percentage who replied affirmatively was comparatively quite high (74%, 345). Responses for males and females were virtually identical.

Respondents who had been tested were also asked whether they would like to receive a reminder for future tests. Again, only approximately one third (159, 34%) wanted a reminder while two thirds (308, 66%) did not. It is worth mentioning that while approximately one third of women (139, 36%) opted to receive a reminder, only approximately one quarter (20, 24%) of men chose this option. Furthermore, whilst 39% (108) of 20-24 year olds wanted to receive a reminder, only 27% (51) of 16-19 year olds wanted this.

Figure 18 below highlights reasons why respondents that have been tested would take another chlamydia test. More than half of the respondents (56%, 267) said they would take chlamydia tests in order to remain fertile, healthy and safe. Again, gender affected respondents' reasons for future testing with only 54% (216) of women choosing this as a reason for a future tests compared to higher proportion of men (72%, 51).

Other reasons for future testing included having a new partner (43, 9%) and suspecting infidelity (16, 3%). Interestingly, 17% (80) of respondents stated they would not take a test again as they were married or in long term relationships and trusted their sexual partners.

**Figure 18: Would you get tested for chlamydia again? Why do you say that?**



Respondents: 474

Source: FreshMinds

Multi-code means that respondents were given the option of providing more than one answer.

Percentages refer to the total number of respondents rather than responses.

Respondents were also specifically asked what would encourage them to take chlamydia tests. Although the base for this question was too small to reach any conclusive findings, a few patterns emerged. It seems a small number of respondents would be encouraged to get tested for the following reasons:

### 1. Easier access, including home tests

*"If I receive some test at home I will do it".*  
North East England, 23

*"If I actually remembered to ask next time I was at the doctors for my pill check!"*  
South East England, 20

*"Free, quick and easy."*  
London, 21

*"If it was part of a routine test like cervical smear - you didn't have to ask for it."*  
Scotland, 24

*"Advertisement if it's free, easier access with little embarrassment."*  
London, 19

### 2. Requests from medical authority

*"A letter from the NHS or a GP."*  
London, 19

*"An invitation to get tested."*  
London, 16

*"More information or an appointment automatically sent to everyone my age from GPs."*  
South West England, 20

### 3. More information/Advertising

*"Advertising and educating me more on the dangers."*  
East Midlands, 24

*"Adverts on TV showing the risk, more info at GP surgery."*  
South East England, 22

### 4. Suspecting a partner or knowing a friend who is positive

*"Partner having chlamydia."*  
South West England, 18

*"It sounds awful but if I knew someone had it I definitely would get tested!"*  
South East England, 23

*"If someone I knew got it."*  
North West England, 19

*"Finding out she had it."*  
North West England, 18

## 5.2 Future sexual behaviour generally

When probed about future sexual behaviour, 60% (291) of respondents did not change their behaviour in any way after having a chlamydia test, while 16% (77) were more careful and practised safer sex.

The following comments from respondents broken up into four categories are noteworthy.

### 1. Respondents who did not change their behaviour after taking a chlamydia test

*"Not really, only done it to get the free pregnancy test."*  
East of England, 18

*"No, I don't feel it has, it was a day out of many where I got tested for cervical cancer and other things like that so it wasn't a specific event, but I do now understand the risks of STDs and feel that I am more aware when getting a new partner."*  
South West England, 19

*"No. I was tested as a general check up as I had just started seeing someone new. It was just for piece of mind. It wouldn't change my behaviour because I am careful anyway."*  
South East England, 22

## 2. Respondents who now realise the testing process can be quick and painless

*"The first time I got tested I was at the GP and it was a swab test, after I had been tested I NEVER wanted to be tested again. The second time was a couple of days ago at college and they allowed the girls to do a urine test as we were uncomfortable with the swab test and now I'm happy to go back and be tested whenever I feel I have to. I feel more confident and less worried when coming to be tested and more open about conversations with experts of a sexual nature."*  
West Midlands, 18

*"Well it's made me think its not as hard as I thought it was to get tested, and its not painful either, because there is all that talk of doctors shoving a rod down your penis which I'm not too keen on. But aside from that, I wouldn't say I've become more careful with who I sleep with, but I tend not to sleep with girls that have slept with a lot of guys."*  
East of England, 18

## 3. Respondents who now understand the importance of condoms to protect against STIs as well as other forms of contraception to prevent pregnancy

*"Having a full test has made me think about carrying contraception (to protect against STIs - I have the implant)."*  
South East England, 21

*"Made me practice safe sex, knowing that I need to use a condom to keep me safe from STDs as well as taking the pill to stop pregnancy."*  
North East England, 22

*"Always make sure I use protection, the contraceptive pill and condoms."*  
West Midlands, 21

## 4. Respondents who learnt something from the testing process and or changed their behaviour in some form.

*"It made me be more aware at the time... but as time passes after the event you forget and I have had chlamydia twice so I was quite stupid! **I think the effect like PID and infertility should be clearer and made more dramatic to stop men and women forgetting or feeling embarrassed to use a condom. In the advert it should say.... 'I can't have children now. I have long term effects.'** That is what's scary."*  
North West England, 23

The above quote from an online respondent reinforces findings from the Define Report which highlighted the need for some 'shock value' in chlamydia related campaigns. As stated both in the Report and the above quote, campaigns need to show that chlamydia is insidious and that



it is not possible for people to control the risk of contracting the STI without using condoms. Additionally, as mentioned again in the Define Report and the above quote, the threat of contracting chlamydia need to be bolstered by evidence of the real damage it can do.

*"Made me more aware that there are services out there to be used and they should be used by us without feeling embarrassed or feeling too under informed about what will happen."*  
West Midlands, 20

*"It's made me more aware of STIs so if me and my partner break up and I have a new partner I'd make us both get checked before having unprotected sex."*  
North East England, 23

*"Yes, to always wear a condom until you are in a long term relationship, and only then when your partner has been tested and is clear can you engage in unprotected sex."*  
London, 22

*"Made me realise it's more common than you think, and you can have it without realising!"*  
South East England, 22

*"Yeah I'm a lot more careful about having safe sex as one of my old partners told my friends he had chlamydia and it really worried me as I was in a new relationship at the time, but I had to go for a smear test due to something else so asked them to check for chlamydia as well."*  
South West England, 20

## 6. Narrative case studies

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34 people were interviewed by telephone over three days as part of a broader research programme evaluating perceptions and experiences of chlamydia screening. The study also compared experiences of users within different NCSP settings as well as at GUM clinics, which fall outside of the NCSP's remit.

The 34 phone interview participants were drawn from an online survey of 1023 sexually active individuals. 467 of these people had been screened for chlamydia, and came from various regions and ethnic groups with experiences of a wide variety of testing locations and circumstances. A broad spread of age groups was also achieved, with the majority of respondents falling in the early twenties. The emphasis was on interviewing people who had tested positive for chlamydia because it was felt they could provide the most information on the entire customer journey through the NCSP programme. As with most sexual health research, there were a much greater number of women who participated in the online study, a trend repeated among those that opted-in to the telephone interviews.

Following are a selection of case study narratives which illustrate the journeys of six participants through the testing process. These participants were selected on the basis for their high exposure to the testing process, unique experiences and for being tested in settings of particular interest to the broader study.

*Please note that the names in these narratives have been changed to protect respondent anonymity, in line with the Market Research Society (MRS) Code of Conduct.*

### 6.1 Rosie: Advocating more information for young people (GP)

Rosie is a twenty year old student in London and describes herself as British Black. She comes from a low-income home where the main earner of the household makes less than £10,000 per annum.

She is reasonably aware of STIs in general, and frequently gets tested for these and for chlamydia, although on different occasions. She has never tested positive for chlamydia.

Rosie first came across chlamydia screening at college, in the form of leaflets and tests which were handed out. However, she did not want to be tested there, preferring to approach her GP for a test.

*"I went to my GP because I preferred it. Sometimes you're not really comfortable. I didn't know that my doctor did it. Brooke is really uncomfortable. I didn't want anyone knowing my business."*

Rosie heard horror stories about the testing process, and so it is essential to her to get tested by someone she can trust.

*"My doctor is a woman, I don't want a man doctor."*

She made an appointment and her doctor walked her through the test and treatment process. They also discussed safer sex and speaking to sexual partners if she came back positive. It is interesting to note that her doctor offered a good deal of information, but did not volunteer to phone previous sexual partners on Rosie's behalf; instead, the practitioner urged her to contact them herself.

Rosie was told it would take about a week to process the results, which sounded good to her because she knew that Brooke clinics could take up to three weeks. In fact, it took less time than that, but still, this caused her apprehension:

*"The service is good, but I don't want to wait that long."*

Her biggest complaint is with the lack of information for young people.

*"You just don't get any information. My mom never told me about it, either. I wish I had the information at school. I had to piece it all together after I had unprotected sex."*

For this reason, Rosie, who is getting regular testing now, actively educates younger siblings and friends about the infection. She has made a point of collecting leaflets from her GP and distributes them to friends and family.

Key points:

- Information dissemination in schools would be helpful.
- The privacy and reassurance offered by a health professional in a clinical setting can be more appealing than testing in schools or colleges and could be more widely advertised.
- The testing process can serve as an educational platform which spurs youngsters into advocacy.

## 6.2 Jemma: A patient left in the dark (family planning)

Twenty-two year old Jemma is a full-time student based in London and from a home where the primary earner has an income between £20,000 and £30,000. She believes she knew about the NCSP because of the Jade Goody campaign, even though this effort focused on cervical cancer screening rather than chlamydia. Jemma went to a family planning clinic for a contraceptive fitting and was diverted into what she thought was mandatory chlamydia testing. Though she tested negative, her short but unsatisfactory customer journey underlines how important it is to keep patients informed about the screening process.

*"I went to a family planning clinic to get an IUD fitted. They just said they were going to test for chlamydia and that was it really. The doctor didn't say anything else. She wasn't very helpful, to be honest. She told me she had to do it. She didn't give me any information I needed, and was quite rude. I didn't even know what chlamydia was, so the fact that I was being tested didn't mean much to me."*

Her experience illustrates how much apprehension can be caused if a patient is not made fully aware of what is happening and why. Perhaps more importantly, it can lead to resentment.

*"I personally thought the test was only done for people with more than one sexual partner. I thought she [the GP] assumed that I was sleeping with different people, even though I'm married. That wasn't nice."*

Jemma went on to research chlamydia after this negative experience, but still feels there are gaps in her knowledge.

*"I still don't know what causes it."*

She wants to do more research herself before committing to future testing.

*"I would need to look into what kind of people need to be tested and why."*

Of all the participants in this study, Jemma offered the lowest satisfaction score with the service she received and felt she knew little, even after completing the testing and repeat encounters with her clinician. Asked how she would improve the service, her answer appeared straightforward.

*"Tell me why I'm being tested. Tell me what the test is going to be like. I would have preferred to have some kind of notification afterwards if I was positive or negative."*

## Key points:

- Considering that “horror stories” are a major barrier to more women getting tested, it is vitally important that the customer experience is as positive as it can be under the circumstances.
- Information about the condition, the test and why it is being done is essential to putting patients at ease. Our research has clearly indicated that people who have had a positive experience are likely to repeat testing and encourage others to get tested.
- Sensitivity training for test providers, or home-based testing with ample information, could temper negative reactions to an unfamiliar, embarrassing and stressful situation.

### 6.3 Greg: The confident clubber (nightclub testing)

Greg, 21, and one of the few men to agree to an interview, is a full-time student from the South-East. He is from an urban environment, and comes from a home where the major earner is a professional, with an income of between £40,000 to £50,000. He tested once for chlamydia and came up negative.

He sounds confident and outgoing, which could be one reason why he favoured getting tested in a nightclub. Then again it could also have been the ease of the test and casual setting which were important to him.

*“To be honest I like the fact that it was in a nightclub. It was easy and informal. If it stays in the nightclubs and there was another chance I definitely would [get tested again] as it’s so easy.”*

Greg received most of his information on chlamydia screening from TV and local newspapers and knew about home-based testing. Still, it took recruitment at a nightclub to pull him into the process, because he never thought he needed to get tested before.

*“To be honest I’ve only been with one person and she’d only been with me, so I saw no need.”*

The goodie bags they were handing out in the nightclub were attractive to Greg, but what most appealed to him was that the testing was not invasive and he did not have to go out of his way to have it done.

*“They were offering a bag of goodies in return for doing a chlamydia test. Just a question of taking a urine test and filling in some details. They sent a text message saying your results were negative. It’s a nice way of doing it. Quite easy. It was all done for me.”*

Where others might have expressed concern about the lack of information, Greg appeared to be quite happy with the service he received. He was “talked through it” and given a “one on one chat” about why the testing is being done, but told little else, yet he still gave the service ten out of ten.

Asked how the screening might have changed him, Greg said,

*“It’s more that [chlamydia] is out there and people are thinking about it now. It’s in the public domain and it’s advertised. It doesn’t affect me that much but I do think about it.”*

On the surface it appears a carefree response. But Greg is in a stable long-term relationship in which he feels secure. Asked if he talks about chlamydia with others, he gave this unusual response:

*“Yeah, definitely. Because it was in the nightclub there were a lot of interested people. A lot of people being tested at the same time. It was the talk of the town for a few days.”*

Key points:

- Greg's case suggests that clinical testing settings are not for everyone and offering variety can help reach a wider group of people.
- It underlines how different people may prefer different levels of information at various stages in the process. Options and choices therefore seem key to attracting a variety of participants.
- Nightclub testing, if not necessarily leading to high levels of repeat testing, could still be a powerful marketing tool in breaking down stigma, raising awareness amongst a high number of young people in a relatively short space of time, and getting them tested.

#### 6.4 Susanne: The clinic that had no answers (GUM)

Susanne, twenty-two and from the South-West, comes from a home where the breadwinner earns less than £10,000. She is also currently unemployed. Susanne originally thought she did not need to get tested because she was married, and so only got screened when her current partner tested positive.

*"I wasn't exactly comfortable talking to my partner about getting tested. It was actually him that got tested first and came back positive, which is why I went."*

She made an appointment and was tested by one of the nurses. Susanne was not told anything about chlamydia because it was part of a broader screening process, but she was asked how she would prefer to be informed about the results. When the results came back positive, she was told to come in and pick up the antibiotics; she was also told to practice safer sex. After she took the pills, she adds nonchalantly, *"it was like, 'go on, enjoy your life'."*

This suggests there was little connection between her and the staff, and the importance of the infection may have been lost, even after she was tested positive and treated.

*"The staff need to be a bit more understanding. They're not very sympathetic. I asked questions afterward, especially about the long-term implications [of chlamydia]. But they couldn't answer me. It was like, 'I don't know'. They just told me to use protection."*

In terms of notifying a partner about her status, Susanne did not feel the usual pressures that others might have felt, as it had been her partner who warned her about his positive status.

Susanne now goes for regular testing even though she is in a stable relationship. She also knows that chlamydia can lead to infertility and tells others they should rather get tested than risk not having children later. But she probably will not be one to soothe others' fears about the testing process.

*"They're all as bad as each other, the tests. It's not a pleasant experience and it never will be. No one would give it a ten and say 'I had a fantastic time'."*

She was so disappointed in the process that the interviewer volunteered information about GPs and home-based testing. Her response to this was, *"They would be more convenient. It's just, you don't hear about that."*

## Key points:

- Susanne and other respondents have made it clear that home-based and GP testing options would be more appreciated than GUM testing. Aggressive advertising for these options may improve screening numbers and testing experiences.
- To mitigate negative reactions to invasive testing, staff in all clinics could offer less invasive swab tests, and should be adequately trained to answer any questions resulting from the process.
- Testing positive is likely to motivate people to start regular testing and to encourage others to get tested. But a negative experience can lead patients to speak negatively about the process, which may ultimately discourage others from going.

## 6.5 Anne: Moving from one good service to another (GUM to NCSP postal)

Anne lives in a suburban environment in the North-West, is twenty four years old, and is in a full-time clerical position, with a salary of between £20,000 and £30,000. She tested positive for chlamydia the first time she went to a GUM clinic some years back. What kept her from going for a test before then?

*“The main thing for me was privacy. It’s very intrusive... the reason why I did it was because of my health...when a friend of mine came back positive I thought I should go.”*

Anne knew something of chlamydia testing from television adverts and her friend, but even then she did not know what to expect from her first visit to a GUM clinic.

*“I didn’t know what to expect. I had friends who gave me an idea, so it was pretty straight forward. It was all fine but I still wasn’t keen on the intrusive idea. I sat with a nurse. I got a lot more information. They asked you lots of questions. They put you at ease.”*

Anne opted to be informed about her test results via text, rather than a phone call, because, *“I didn’t want my parents to take the call, and with work, I didn’t want to take a call there, either. I also didn’t want to miss a call, and if the number came up withheld, I couldn’t ring back.”*

The clinic called her back a few days later with a positive result. She went back in and received the pills from a nurse, and described the process as *“it was all fine”*.

The clinic offered to approach any sexual partners on her behalf, notifying them by text, but she preferred to pick up a flier and take it home to him.

When Anne found out about home-based testing, she switched over for a variety of reasons. *“Since then I’ve gotten the postal test. You don’t have to go around to drop-in clinics. I also work strange shifts, which makes it difficult for me to get to a place that’s open. So it’s been a lot easier, because you can do it in your own home.”*

She feels she knows a great deal about the issues linked to chlamydia, from testing, treatment and consequences, to the variety of options on offer. She was also happy that the GUM clinic offered to phone her partner on her behalf when she tested positive, but took a leaflet for him instead. Regarding the notification options, Anne preferred a text message rather than a call.

*“I didn’t want my parents to take the call. And with work, I didn’t want to take a call there. I also didn’t want to miss a call, and with a withheld number I couldn’t ring back.”*

Anne continues to get tested once a year.

*"I do it just to be on the safe side. I have a fear of becoming infertile. I'd be devastated if I couldn't have children because of something that happened when I was younger."*

When she discusses chlamydia testing now, it appears to be an open and frank discussion with significant others.

*"I'm very open with my mom and dad and we speak about it on a regular basis. I'd be honest with friends. It's not the best experience in the world, but I'd advise them to go with the postal test. I wouldn't try to put them off. I'd even go along with them to put them at ease."*

Comparing her first GUM testing experience with postal testing, she would rate the first relatively high, apart from the discomfort, and give the postal testing a full ten out of ten, because of the ease and comfort of the experience.

Key points:

- Even if a clinical experience is very positive, candidates for testing will most likely still prefer home-based testing.
- Home-based testing is considered more favourably for a variety of reasons: it's less intrusive, easy, comfortable and preferred by people who cannot necessarily reach clinics during regular hours.

## **6.6 Olivia: Home-based testing with a difference (home-based/professional visit)**

Twenty year old Olivia is from an urban environment in the West Midlands. She is a full-time student, and the family's main earner is a manager, though she does not know what that person earns. Olivia did not know the result of her chlamydia test at the time of her interview, but her unique experience with NCSP screening, and her high level of satisfaction, could indicate a new direction for testing locations. NCSP staff canvassed the neighbourhood and paid her a visit at home with a self-administered test.

*"I didn't think I needed it at the time. I didn't have many partners so I didn't think I was at risk. The only reason why I got tested was because someone came to the door. They asked me if I'd heard about the test and gave me information."*

Though she tested negative, her experience illustrates what might be a particularly effective combination of private and professional testing which might appeal to a greater number of people.

*"The NCSP came to our door and offered to give us information. They gave us a bit of time to read through the information, then we [returned] our samples. They also told us more about how the results work, and how we can get the result sent to us. The test was quite all right. It makes you aware how important it is if people come to your door. If the information is just lying around at the doctor's you don't feel it's got anything to do with you. You feel you have to hide it. If they come to your door, it becomes something you can talk about."*

The NCSP staff did not at this stage volunteer information about how to approach partners if she tested positive, but they did offer to contact partners on her behalf. Olivia was given the choice, but she would have preferred to contact partners herself.

Though she does not see herself getting tested again in the foreseeable future, this has nothing to do with a lack of interest. Rather, she is single now and normally "quite cautious" if she has sexual contact. If she was to be sexually active again, she would get tested again.

*"If I didn't know his history I would also do it."*

Her satisfaction with the process could point to a way forward for other councils and trusts.



*“I would recommend it to people if they were worried about it. I’d tell them it’s easy and nothing to worry about and the results come back quite quickly. [The disease] can be dealt with quickly afterwards. It’s very easy and very relaxed. There’s nothing invasive. It’s quick.”*

Key points:

- Home-based testing can reassure participants and make them more open to re-testing. Moreover, they could become champions of the testing process and spread awareness of that particular offer.
- If a professional accompanies the home-based test and is on-hand to answer any questions, this could mitigate any sense of being left uninformed by an impersonal test pack.
- The need for privacy is one of the key messages that have come out of the interviews. All home-based testing scored very high on customer satisfaction, whereas clinical settings tended to vary.

## 6.7 Amina: Using the web and a GP to keep up to date (GP testing)

Amina is a full-time student from London, who describes herself as Asian British. The main earner in her family is a professional with an income of between £30,000 and £40,000. She is one of the few interviewees who proactively initiated testing with her GP, after she and her partner agreed to get tested before getting married. The only thing that kept her from getting tested beforehand was that she did not know about the infection.

*“The first time I did the test I had no information about chlamydia. I was at my GP’s for something else and saw information about the screening on his door and decided to get it when he said it was a free kit.”*

She feels she got most of the information she needed about the infection that first time around, and continues to get regular updates about the infection from her doctor when she visits for a test.

*“I got most of [the information] the first time. Now I get regular updates from my doctor, and if I got the symptoms I’d know what they are and I could get tested again. It’s just to be safe.”*

Recently, she and her partner found a website which has information about chlamydia screening and registered on it. Though she could not remember the name of the site at the time of the interview, she now receives regular updates about developments.

Amina is happy to continue testing with her GP every six months, but feels free home-based testing which can be ordered online could be marketed better for people that are shy, like her friends.

*“I’ve told my friends about it. They’re pretty shy. Many of them think they can get it and live with it. But I got some friends to do it and they’re happy with it.”*

Key points:

- Advertising in a doctor's waiting room, in the form of leaflets or posters, is used by potential screening clients when deciding to opt into the program.
- Information is important, even to people that initiate a screening. Amina kept highlighting how confident she is about the process and her knowledge of the infection, and underlined that she liked getting updates from various sources.
- Online marketing is reaching people who are sensitized to the screening program and the infection, but could perhaps be even more aggressively pursued as an attractive option for less confident people.

## 6.8 Helen: A scholar gives a ten out of ten to testing at school (NCSP school test)

Helen, 16, resides in a rural part of East England and is still at school. She describes her father as a semi-skilled worker who earns somewhere between £10,000 and £20,000. She was recently tested at school, the result of which came back negative.

She feels she did not know anything about chlamydia until the NCSP visited her school.  
*"It was really good. I think she was a nurse. She told us about how widespread chlamydia is, and handed out cards afterwards with more stuff on it. I think it was pretty effective."*

The nurse brought testing kits to school and took up a classroom. The students were given leaflets on what the test was and how to do it. Then they took it to the bathroom and did it themselves. The nurse who gave out the packs was also there to offer more information about the process in person. *"We went to the bathroom and gave it back to them. It was fine as an experience. It was very private, and much better than I thought it would be. Much easier."*

Despite the fact that test results were not available at that time, the scholars were still informed that the NCSP could approach partners on their behalf. This contrasts with the experiences of many other interviewees, who were not told anything about approaching partners before tests results came back.

*"I'd still rather do it myself, because it's something that you need to do yourself; it's personal."*

Helen feels confident that she now knows how chlamydia is contracted and what she needs to do to prevent it. She believes the test has made her more careful and is sure she would get tested again.

*"Yes for reassurance."*

Asked if she would recommend it to others, she said,  
*"Yes, people don't know how easy it is. It gives you peace of mind. I'd give it a ten out of ten, because it's so easy and quite private."*

Key points:

- The online survey and interviews suggested that school and college testing can be unpopular, especially if any aspect of the process is too public, like having to walk to the toilets with a pack. However, if handled privately, scholars and students might be more open to the process.
- If enough information is shared with the students and someone is there to quickly supply information (as opposed to students having to wait or crowd for information) that could be a much more positive experience.
- Helen's case suggests that simple and easy self-administered testing could open students to repeat testing and word of mouth marketing.

## 6.9 Daniela and the Facebook download (self-administered home-based test)

Daniela, 21, is a student who lives in a suburban environment in the West Midlands. She describes the main earner in her home as a supervisor, who earns between £40,000 and £50,000. She has only had one test, which she ordered from Facebook, the result of which was positive.

She appears to have been quite aware of chlamydia and the NCSP before she was tested. *"There were posters about chlamydia in a nightclub and in the doctor's surgery. There was also someone in the toilets offering the test."*

Asked if there were any barriers to her getting tested, she felt there were none. And how did she receive the test?

*"I saw a pop-up advertisement online on Facebook. I clicked on it and registered. I got sent a home pack and did it at home. The packs were clear about the testing and had leaflets telling me more about the disease. Everything was what I thought it would be."*

She felt the information pack and leaflets were clear about the testing and infection.

Two weeks after the test, Daniela was called in because she had tested positive. She received her pills and was told she needed to get in touch with any partners; the clinic did not offer to do it on her behalf.

*"I told them [my partners]. I knew I should, but the lady that got back to me also said I should."*

Doing the test, and testing positive, did not appear to have the cautionary effect on Daniela as it did on others. She neither indicated that she was interested in more information about the infection nor that it had a strong effect on her behaviour, in terms of repeat testing – an unusual attitude in the group of interviewees that tested positive.

*"I'd just be more careful having unprotected sex. I would only get another test if I felt I needed to."*

Key points:

- It is not clear whether the relatively depersonalised nature of ordering a test online and doing it in private might have led to some disengagement from the infection and its repercussions. But it does appear as if people in this age group might consider the infection not a serious threat, if there is little engagement with a professional.
- Daniela was satisfied with the service she received and would not know how to improve the testing process. What makes her opinion especially relevant is that she had gone through both testing and treatment, unlike other interviewees who had positively rated postal testing.