

# 'It should be an ordinary thing' – a qualitative study about young people's experiences of taking the HIV-test and receiving the test result

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## 'It should be an ordinary thing' – a qualitative study about young people's experiences of taking the HIV-test and receiving the test result

*Aim:* Increased HIV-testing has public health benefits, but for youth there is a multitude of barriers against the test. The aim of this study is to explore how young women and men in Sweden experience HIV-testing within primary healthcare.

*Method:* Six focus-group interviews were tape recorded, transcribed verbatim and analysed according to qualitative content analysis.

*Results:* Three themes emerged, describing how the informants were met before, during and after testing; '*Obstacles accessing the clinic*' – describes their perceptions on how to overcome different barriers and enter into primary health care. '*Quick and easy testing*' – describes perceptions of the testing procedure and '*Conflicting and unclear information about test results*' – describes inconsistencies concerning

communication of the test result and a concern about 'what would happen' in the event of an HIV-positive finding. Most of these youth preferred the HIV-test 'quick and easy' and preferred a telephone referral of the test result. A minority of them worried about HIV, and they thought that the staff seemed to be unprepared for an HIV-positive test result.

*Conclusion:* According to these youth, a quick and easy testing procedure together with a short pretest discussion may be sufficient and may also help normalising the testing practice. In a Swedish context, it may be common to see heterosexual youth as a risk-free population, and this perception may act as a barrier for HIV-testing and increase missed opportunities for early diagnose of HIV within primary care.

**Keywords:** HIV-test, public health, qualitative content analysis, youth, primary care.

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## Introduction

Globally, three out of five young women and men have insufficient knowledge about HIV (1). There is a growing consensus in Europe that increased HIV-testing will have public health benefits (2). A wider screening of the population can reach groups that today are perceived to be at low risk for infection and therefore at high risk of late diagnosis (3). HIV is a treatable condition today and an early diagnosis will decrease the risk of mortality and transmission (4), while late detection will boost transmission paths. There are gaps in the scientific information

concerning prevention of HIV, but today there is agreement that more testing will have great benefits (1, 4). Recently, a group of researchers used a mathematical model to examine how to reduce the HIV epidemic (5). Their conclusion is that universal voluntary HIV-testing yearly, combined with antiretroviral therapy would be the best step in preventing HIV. However, recent studies reveal that there are a number of barriers towards testing among young people. These barriers are characterised by feelings of vulnerability (6), shame, fear of painful examination, fear of actually having sexually transmitted infections (STIs) (7), fear of having HIV and uncertainty regarding the location of centres, where the test can be provided (8). In a study from US, low perceptions of risk or never having been offered a test are correlated with youth's reasons for not having been tested (9). Teenagers and youth in the US have often poor access to medical care where HIV-testing can be implemented (10). In Sweden, young people have

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easy access to youth clinics in primary care concerning their sexual health. To varying extents, these clinics (over 130) have been opened in most parts of Sweden. Youth clinics promote physical and mental health, prevent unwanted pregnancies and STIs and help young people develop their identity so they can deal with their sexuality. The youth clinics must have at least a midwife with the right to prescribe oral contraceptives, a social worker and/or psychologist and a doctor. These youth clinics provide free, anonymous or confidential testing and counselling services (11). There are also health centres and STI clinics where testing for STIs is free. The Karolinska Hospital Gay Men's Health Clinic, located in the South Stockholm General Hospital, is directed towards men of all ages who have sex with men. The facility offers counselling, testing and treatment for STIs including HIV. In Sweden, in total 8220 cases have been diagnosed with HIV, and very few children and adolescents are diagnosed (12). Approximately, 4500 people of the population are living today in Sweden with HIV. Here, the general strategy has been to focus on risk groups instead of on risk behaviour. Hence, immigrants have been perceived as a risk group, as have homosexual men and drug users. To focus on risk groups can however contribute to a 'cultural racism' (13), which produces flawed results and a self-fulfilling prophecy reproducing the common misconception that HIV does not infect 'normal' heterosexual young women and men. Few qualitative studies have examined the experiences of youth who seek health care with a wish to be tested and how they perceive this procedure. Therefore, this study explores how a selected group of young Swedish people experience taking an HIV-test and receiving their test results.

## Method

The findings in this study are drawn from analysis of six focus-group interviews (FGI). Informants between 18 and 24 years of age were recruited after being tested and found to be HIV negative, by the staff at a youth clinic in Umeå, a university town in northern Sweden. Fourteen women and nine men were recruited and sorted into six groups; three for women, two for men and one mixed.

Out of 52 HIV-tested who were invited to participate, more than half refused ( $n = 29$ ). A first study that explored how young adults constructed the HIV risks is previously published (7). This study is based on the same FGI, where data regarding how they perceived pretest and post-test counselling was analysed.

The interviews followed focus-group research principles (14). The moderator (MC) invited and encouraged everyone in the group to share their experiences of HIV-testing. An observer (EEJ) took notes during the sessions. Afterwards, each informant completed a questionnaire regarding background data (Table 1).

**Table 1** Some characteristics of the informants ( $n = 23$ )

Characteristics	Women ( $n = 14$ )	Men ( $n = 9$ )
Age		
Median years (range)	22 (21–23)	23 (18–24)
Ethnicity		
Born in Sweden	12	7
Born in Sweden (parents mixed ethnicity)	2	0
Born in the middle east	0	2
Education		
University	7	6
Secondary high school	11	9
High school	3	0
Present occupation		
Student	7	7
Employed	3	1
Unemployed	3	1
Sick-leave	1	0
Sexual orientation		
Heterosexual	13	7
Homosexual	0	2
Bisexual	1	0
Number of HIV-tests		
Median (range)	1 (1–3)	1 (1–7)
Sexual debut		
Median years (range)	15 (14–18)	17 (15–18) <sup>a</sup>
Number of sexual partners		
Median (range)	14 (7–30) <sup>b</sup>	8 (0–33) <sup>a,b</sup>
Drug use		
Tobacco regular use	5	0
Tobacco on occasion	2	4
Snuff	10	3 <sup>c</sup>
Alcohol	13	7
Other drugs occasionally	5	0
None	0	1
Present contraceptive use		
Oral contraceptives	7	–
Condom use	1	4
Both condom and oral contraceptives	2	2
None	4	2 <sup>b</sup>

<sup>a</sup>One virgin.

<sup>b</sup>One did not answer.

<sup>c</sup>On occasion.

The tape-recorded conversations lasted 90 minutes, were transcribed verbatim and analysed according to content analysis (15). Two of the researchers (BB and MC) read the transcripts in detail and coded the text independently. The focus-group data were re-examined, and all data that were related to testing and counselling were analysed carefully. The text-parts that concerned the specific situations of HIV-testing and consultation from the staff were extracted, reviewed and coded and sorted according to content and meaning. Meaning units that described events and experiences concerning HIV-testing were reorganised, coded

and grouped to build subcategories. The authors then together evaluated the categorisation, compared codes and subcategories and discussed the similarities and differences to reach a consensus. When the two authors compared their codes and subcategories, they found very few disagreements. To improve the credibility of the study, the codes and subcategories were discussed, compared and revised together with the co-author (EEJ). In the next step, these subcategories were grouped to create the categories. The salient themes that emerged were pieced together to form a comprehensive picture of the experiences of the subject group.

## Ethical considerations

The participants were informed in writing and verbally about the study, and that participation was voluntary. They were assured of confidentiality, and that information gathered would be carefully protected and that the unit of analysis was the group, not the individual. Furthermore, they were informed about the obligation to respect the privacy of the other members by not disclosing any personal information that they shared during the FGI.

The Medical Ethical Research Committee at Umeå University approved the study.

## Results

Three themes describe how these youths were met before, during and after testing. The theme – ‘*Obstacles accessing the clinic*’ – describes their perceptions on how to combat different barriers and enter into primary care. The theme – ‘*Quick and easy testing*’ – describes perceptions of the testing procedure. The theme – ‘*Conflicting and unclear information about test results*’ – describes a vagueness concerning communication of the test result.

### *Obstacles accessing the clinic*

*Administrative barriers.* Several of the informants mentioned that it was complicated to get an appointment, because of inadequate information at the clinic’s home page, busy phone lines and contradictory messages about opening time on the answering machine. One man concluded that all such obstacles could make people give up having a test, as it was time consuming to wait.

‘I bet there are loads of people who’ve become infected or spread the infection to others, because they gave up when they went into the telephone queue.’ There was however some positive feedback. This youth clinic offered ‘drop-in’ appointments which facilitated easy access. This was contrasted with experiences of other clinics. One person tried to become tested at a youth clinic in London, but was directed somewhere else, which complicated the procedure and made her abandon her

intention to be tested. At a student health clinic, another person was told that it was reasonable to test for Chlamydia, but not for HIV.

‘Because last time, I said ‘Hi, I want to check everything’ and when I got the test they didn’t say anything but just tested for Chlamydia’

*Communicative barriers.* Several of these informants thought that they would be asked if they wanted to be HIV-tested, as they were worried that if *they* asked for the test it could be interpreted as rather demanding. Instead, they realised that the staff did not promote HIV-testing, or thought that it was unnecessary. A young woman remembered that the staff did not encourage her to be tested because of her young age:

‘I wanted to be HIV-tested, but then she was all like “you know then you’ll have to get an injection.”

They noted that they had to be resolute, as their wish to be tested was called into question by the staff:

‘Are you sure you want to?’

Some informants had been tested repeatedly at youth clinics. When they had asked for a test they discovered that the staff did not take the concern for HIV seriously:

‘Take it easy, of course you don’t need to have a test!’

‘You almost have to be over explicit or like stern ‘yes, I think this is a problem’ because otherwise you can be like overlooked or not taken seriously’.

They thought that this resistance against testing among the staff was counterproductive, and suggested that young people should be encouraged to be tested, which would normalise testing routines and increase responsibility:

‘I think that HIV-testing should be an ordinary thing, so you can do it now and then, just to be responsible.’

Some women thought that it was easier for women to be tested, because of their regular visits, and their worries about transmitting STIs. One group of women mentioned that it could be embarrassing for men to visit the clinic as the majority in the waiting room are women. One man thought that men are impatient and ‘give up’ if they do not get help at once.

### *Quick and easy testing*

*Welcome to the clinic.* For the majority, the visit to the youth clinic was a positive experience. Informants described it in the following terms; ‘it’s great’, ‘relaxing’, ‘feels so natural’ and ‘it is wonderful’. They perceived the staff to be friendly professional and personal which made them think that they were not troublesome and would be welcomed back. Elsewhere, they had experienced being treated as objects, or being considered a nuisance. They were glad to be spared the judgmental expressions they sometimes received elsewhere.

*Taking a blood sample.* To be tested was frequently described as an easy procedure a ‘no big deal thing’, ‘a nonproblematic issue’, or as ‘rapid testing’. They were impressed by the effectiveness among the staff.

“There were no problems and a merry ‘oh well, okay, let’s take a blood sample’”.

“Just like any other pinprick”

Few mentioned any pretest counselling about their eventual risk or worries. A majority of the informants were satisfied with just being tested. They did not want to talk about their eventual susceptibility for HIV.

“I don’t feel like sitting down and telling my story.”

However, one man declared that the consultation was unsatisfactory, an empty and insufficient conversation. Another man thought that he was on an assembly line, being objectified.

### *Conflicting and unclear information about test results*

*Unsure what we agreed on.* Few of the informants got a reappointment to receive the test result and receive post-test counselling. One person received the test result by letter. For the majority, their test result was given by phone, a routine that most of them thought of as a convenient and rapid way to be informed. Some informants mentioned that it was unclear how the test result was going to be returned. This type of vague communication and lack of professionalism made some of the informants worry about whether the test was analysed, or even lost. One of the women was told that she was to call the clinic to receive her test result, but she never did.

“Call us in 2 weeks’ she said – Shit, I never called”.

A second person stated that the clinic would call her if she was HIV positive while a third person was advised to call if she was worried. A fourth person thought that she would surely hear from the clinic if she was HIV positive.

*Inconsistency in communicating the result.* When the test result was communicated over the phone, the language was perceived to be rather difficult to interpret and understand.

“...and she just ‘yes, your HIV-test is negative...’”

This lack of effective and clear communication left some of the persons ruminating with their interpretations. When words like ‘positive’ or ‘negative’ were used, some of them wondered what negative versus positive test results meant. They mentioned that they were not part of the medical discourse, implying that they were not sure about whether they had HIV or not. Additionally, words were sometimes used to calm them down, but an exact result which they understood was sometimes never provided. The tone and mood of the test communicator influenced what the informants considered the outcome to be. If the care providers sounded happy, depressed or neutral this had an impact on the informants interpretation of what was actually said to them.

“She was somewhat like low-spirited... and then just ‘but hey, it’s cool’”

*What if I was HIV positive?* Very few of these informants worried about having HIV, but some of them discussed *how* they would react if they were infected. They doubted that the staff was prepared for a positive HIV-test result, as the staff never mentioned how a positive test was handled. Some of them claimed that it cannot be taken for granted that the test is negative, just because most young persons in Sweden are HIV negative. The informants would have liked to know what would happen if they had the infection.

“What if I would’ve had it, would they call me and say you have got HIV – come up and we’ll have a chat?”

Some informants suggested different strategies that the staff could use to determine who would benefit from post-test counselling, for example that the staff should ask; “do you believe that you could have HIV?”, or if the staff suspects that the risk for HIV is overt, the person would get a reappointment. Another person thought that the staff could use their earlier experiences, or use their intuition to tell if the patient needed to come back or not.

## Discussion

Most of these youth preferred to be HIV-tested quick and easy, and the majority did not ask for pretest or post-test counselling. Voluntary counselling and testing can be one component in preventing HIV by educating the people about HIV, but a test by itself may not change behaviour and reduce the risks (16). It has also been claimed that where and when the HIV-test is taken, and how well the pretest and post-test conversation goes is important. Hence, new approaches towards HIV-testing give less attention towards time-consuming (i.e. traditional) counselling and instead put more emphasis on very short pretest conversations (4). Traditional counselling may perhaps not be the best opportunity of prevention as it is questionable if it does change sexual behaviour. In this study, many informants doubted the need for pretest and post-test counselling- it was more beneficial to just be tested. Contradictory reflections were also articulated. Some informants thought that they were given too little time to discuss HIV. Hence, our results indicate that it is better to focus on testing that is quick and easy rather than offer extensive counselling to *all* young persons who want testing. Most people in our study do not want this counselling. It is important, however, to be flexible so as to be able to offer counselling to anyone who requests it.

Most of the informants preferred telephone referral of test results. The results show that the test referral is rather indistinct, but also that the language used is unclear. A medical discourse, such as negative or positive, increases

the risk for misinterpretations and should be used with caution when referring the test result.

There is a growing consensus that HIV-testing should be promoted and offered across the population and not only for risk groups. However, these testing practices for HIV/AIDS have been different from other testing procedures—the so-called HIV/AIDS exceptionalism, where it is high time to normalise these practices, i.e. treating HIV like other infection diseases (4, 17). The Centres for Disease Control and Prevention in the US recommend that all patients between ages 13 and 64 years who attend healthcare settings should be screened for HIV (18). In an editorial by Delpierre et al. (3), the message is that to reduce late HIV diagnosis in France, routine testing would be strategic. Making HIV-testing something quick and easy may help normalise the testing practice. Tolou-Shams et al. (19) hypothesises that precedent testing and access to HIV-testing is important when it comes to increasing testing among youth. Some informants in our study concluded that for young people, to be HIV-tested, it should be ‘an ordinary thing’ which would normalise testing routines and increase responsibility among young people for their own sexual health.

Most visitors at youth clinics in Sweden have a heterosexual identity, and because of that reason perhaps are regarded as a risk-free population. An important finding is that many of the youth experienced that they were not encouraged to be HIV-tested and were met with words such as ‘it’s reasonable to test for Chlamydia, but not for HIV’. Possibly, staff does not expect these young women and men to be carriers of HIV because statistically there are few young persons diagnosed with HIV. The Swedish authorities rhetorically note that ‘AIDS is catching us all’ (20), but despite this message, the focus is on certain risk groups instead of risk practices. Risk, however, is not defined only in terms of sexual identities; these identities are ordered hierarchically in terms of risk where for gay or bisexual men, they are defined as high risk and heterosexuals at low risk (21). Heterosexual practice is presented as normal and relatively risk free, despite the rising numbers of Chlamydia within the population. This way of thinking may act as a barrier for HIV-testing and increase missed opportunities for early diagnose of HIV within primary care settings in Sweden.

### *On method*

Preconceptions might make a researcher ‘both blind and seeing at the same time’ (22). This can be a methodological problem in one’s field of practice, and for this reason our preconceptions, expectations and biases have been discussed critically within the group. With different disciplinary backgrounds in the research group; a psychologist, a midwife and a general practitioner with work experiences from youth clinics we strived for various angles in

the analysis. We believe that this diversity of experience and disciplines of the research team affected the coding procedure positively and strengthened the trustworthiness of the findings.

In qualitative research, the term saturation refers to a phase where no new information is identified, and data collection can stop (23). According to Morse, this depends on the nature of the topic and if the topic being studied is obvious and clear. We found that the information was easily obtained in the interviews and that more participants were not needed. In reality, no data are ever truly saturated. Whenever a new interview takes place, new things will always be discovered. Moreover, a FGI is not a ‘natural’ setting, as the knowledge is constructed within the group. With other young persons or other researchers conducting the focus groups in another cultural context the results may differ.

These informants do not represent the whole Swedish population. However, four of them were employed, one was on sick leave, four were unemployed and more than half of them were university students. These students who make use of health clinics could be seen as well informed and well educated. Even so, the experiences these informants have could possibly be shared with more young healthy people. More research is needed to determine whether our results are transferable to similar health care settings.

Focus-group discussion involves sharing the information with other people, a situation that does not protect anonymity (14). Afterwards, we administered a questionnaire with questions concerning sexual behaviour, where each informant had the opportunity to comment the group session. According to Kitzinger (24), this can be beneficial.

### *Implications for practice*

Some informants thought that they were given too little time to discuss HIV. The staff needs more knowledge and necessary skills to provide education about prevention of HIV to youth. Routine HIV-testing may offer an excellent opportunity to give up-to-date information about HIV, safe sex and condom use. It may not be necessary to perform extensive pretest counselling with *all* young persons who ask for an HIV-test. Our findings indicate that it is better to do the testing quickly and easily. To inform young people about their test result, when the test is negative, can be an ideal chance to emphasise the importance of reducing HIV risk behaviour. This can be performed over the phone or preferably at a follow-up appointment. Technologies such as the Internet and the development of a self-test for HIV may provide new ways of test referral.

### **Conclusion**

The findings from this small-scale study, where a selected group of HIV-tested young men and women discussed the

issue of HIV-testing, indicate that providing HIV-testing in a youth-friendly atmosphere is important, but administrative and communicative factors may function as barriers for being tested. A quick and easy testing procedure together with a short pretest discussion may help normalise the testing practice. When referring the test result a medical discourse, such as using the words 'negative' or 'positive', increases the risk for misinterpretations. In a Swedish context, it may be common to see heterosexual youth as a risk-free population. This way of thinking may act as a barrier for HIV-testing and increase missed opportunities for early diagnose of HIV within primary care.

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## Author contributions

Monica Christianson and Eva Elisabeth Johansson created the conception of the design and collected the data. Monica Christianson and Björn Berglin analysed and interpreted the data, wrote the manuscript draft and together with Eva Elisabeth Johansson critically revised it. All three authors gave their final approval of the version to be published.

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