LATE PRESENTERS
– FOR HIV IN DENMARK

hiv DANMARK 2011
ABOUT THE REPORT

All percentage figures in the tables have been rounded up or down to whole numbers, which is why some total percentages may be above or below 100.

Six respondents reported that they had been diagnosed with HIV before 2003, while six other respondents reported that they had been diagnosed with CD4-counts greater than 200. The list provided by the Danish HIV Cohort (DHC) of persons to whom it would be relevant to supply questionnaires included only people who were admitted for monitoring or treatment after January 1st 2003 with CD4-counts of less than 200. These twelve people may therefore either have filled in the form incorrectly, the questionnaire may have been given to late persons who should not have been included, or they may have tested positive without commencing monitoring or treatment. As we have not been able to determine why the questionnaires were completed in the way that they were, and these responses do not otherwise distinguish themselves from the other responses, and as this is an explorative study which is not intended to provide definitive answers but to identify possible explanations for late testing, we have chosen to include these twelve completed questionnaires in our analyses.

ABBREVIATIONS USED

- DHC: The Danish HIV Cohort
- MSM: Men who have sex with men
- PLHIV: People living with HIV
- SSI: State Serum Institute
- STI: Sexually transmitted infections

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i. The Danish HIV Cohort is an open prospective population based cohort initiated in 1998 in collaboration between all HIV treatment centres in Denmark.

ii. However, four of the six who reported an HIV diagnosis earlier than 2003 also stated a CD4-count which makes it likely that the latter possibility is the explanation.
FOREWORD
The idea for this study was conceived one late afternoon in autumn 2008 in the secretariat of HIV-Danmark. At that time it had been evident for several years that many people were being diagnosed as HIV positive with low CD4-counts – so low that they were immediately admitted for treatment. If these people had taken an HIV test sooner, they could have been offered treatment at an earlier stage.

A number of initiatives were set in motion at that time, both to reduce the number of PLHIV who were unaware of their infection, and the number of persons diagnosed with HIV with low CD4-counts. As so often before, we discussed why nobody had ever asked the persons diagnosed with low CD4-counts why they had not chosen to test earlier – and this was what led us to sit down and formulate a concrete project description, which has now resulted in this report.

There are many people who deserve our thanks for their help during this project, which we could not have completed without help ‘from outside’. First and foremost, we owe our thanks to the doctors and nurses at the eight HIV treatment centres. We know how difficult it can be, especially in large departments, to organise the logistics of questionnaires, but all eight centres immediately supported the idea of handing out questionnaires dealing with ‘explanations for late HIV testing’, and felt that this was an important subject that needed to be studied.

To locate the medical records belonging to the people who were to be given the questionnaire would have been laborious and costly without the willing co-operation of DHC under the leadership of Dr. Niels Obel, who undertook the work of finding the DHC serial numbers of the relevant persons in the DHC database and sending these numbers directly to the departments. This meant that it was not necessary to examine all of the medical records, as we could simply use the list to identify the records of people for whom questionnaires should be included.

We also owe our thanks to the professionals who shared their knowledge with us during the initial phase of the project, and to the counsellors of HIV-Danmark’s Counselling Unit in Copenhagen, who were helpful in finding relevant interviewees for the initial qualitative interviews.

During the project we also benefited greatly from the assistance of two anthropologists, Katrine Villadsen and Nina Finch, who helped us to find literature and to study and discuss the tables and statistics, and who challenged the ways in which we interpreted our figures and stories.

Our thanks are also due to Astrid Kiil MSc, PhD student at IST, the Research Unit for Health Economics at the University of Southern Denmark, for her help in providing us with guidance on P-values, minimum counts, and everything else that belongs to the world of statistics!

Neither should we forget Staff Specialist Susan Cowan of the State Serum Institute (SSI), who made the HIV surveillance data available to us, thereby providing us with a suitable background population for comparison, and who discussed many details large and small with us in the course of the project.

And finally, the Tryg Foundation, the AIDS Foundation and the pharmaceutical companies Bristol-Myers Squibb and Gilead deserve our warm thanks for their financial support towards the implementation of the project.

But most of all, we thank the people who took the time to talk to us during the initial phase of the project, and those who subsequently filled in questionnaires and returned them to us – without their help, this report could not have been written.

Anders Dahl & Morten Rye Eiersted
English version, September 2011
The Danish version of this report, which was published November 2010, had a list of recommendations. These recommendations, however, are very country specific and was therefore substituted with an abstract to give people outside Denmark an introduction to HIV in Denmark.

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ABSTRACT

This report is a slightly revised version of the Danish report on late presenting for HIV which was published in November 2010.

Around 150,000 HIV tests are performed in Denmark each year. Approximately 250 individuals test positive for HIV in a population of 5.5 million inhabitants. In Denmark HIV testing can be performed anonymously. If people test positive to HIV they are protected from disclosure because they need to give their consent to let outsiders know about their HIV status. Furthermore HIV treatment is free of charge and managed at highly specialised units at certain hospitals.

About half of all persons diagnosed with HIV are diagnosed with a CD4 count of less than 350 which is the official Danish indication to initiate HIV treatment. People diagnosed below this indication are hence denominated as late presenters.

This report about late HIV presentation is the first of its kind in Denmark. Our research has been conducted by interviewing and handing out surveys to recent discovered late presenters. The report is explorative and the questions that we have asked our respondents in the survey have been inspired from questions posed in other research from abroad and from the interviews conducted prior to the survey.

The survey was handed out to every PLHIV who has been diagnosed at a Danish HIV outpatient clinic between January 1st 2003 and June 30th 2009 with a CD4-count less than 200. 97 surveys has been accepted for analysis which constitutes a response rate of 25.5%.

Since this research is based on arbitrary returned responses from a cohort it is not representative on every aspect to late HIV presentation, but this report will give the reader insights into some of the obstacles that might cause people to test late.

In this report the challenge with late presenting has been viewed from two perspectives: The encounter with the health care system and the personal barriers for PLHIV to test earlier for HIV. Earlier research has pointed to the fact that no concept of risk, being afraid to find out about HIV and the fear of negative responses from friends and family all play a part in why PLHIV present late. In the present research the lack of knowledge about symptoms for HIV has also played a part in delaying the time for detection of HIV. More than half of the respondents ascribe some or a great deal of importance for late testing to these four reasons mentioned above.

In this research it seems that the MSM, a group who is often perceived to be well exposed to HIV information, express some reluctance towards testing for HIV. More so than other groups. This is an interesting point, and it seems to be related to denial of HIV or fear of stigma.

Being afraid to find out about HIV and the fear of negative responses from family and friends point to the fact, that stigma still exists and is a barrier for testing earlier for HIV.

Though this report cannot be conclusive about the need for campaigns some new work still is needed to combat stigma and people’s fear of HIV to make them test earlier to minimize the risk for further morbidity and mortality due to late testing.

Some work still is needed to help people make a connection between their symptoms, thoughts of HIV and the possibility of testing for HIV.

It might also be reasonable if people testing negative for HIV are encouraged to consider their own future strategy for HIV testing. For most Danes this will not have any relevance, but among late presenters with risk behaviour HIV testing more frequently would likely have lead to earlier detection.

Overall late testing among the respondents seems to be more due to personal barriers than problems with in the health care system to encourage testing for HIV.

The National Board of Health has during this research issued new guidelines for HIV testing which might lead to more targeted testing.
1. PROJECT DESCRIPTION
The significant improvements in recent years of the treatment of HIV infection, and the good prognosis for people on treatment, has increased the focus on providing treatment for PLHIV before their CD4-counts become too low. Late presenting PLHIV receive treatment at a late stage of their infection, with a consequent increased risk of illness or death.

In 2009, the National Board of Health launched a series of initiatives aimed at reducing the grey zone (HIV-infected persons who have not taken an HIV test). In November 2009, the Board issued new guidelines regarding persons to whom health care professionals should in future actively offer HIV tests. These are characterised as individuals at particular risk of infection, see box 1.1. The grey zone for PLHIV in Denmark is estimated to be between 500 and 1,000.

The benefits of earlier testing include the health effects for the individual when provided with appropriate treatment, as well as the preventive effect of offering advice that can support a change in the individual’s behaviour in the direction of more consistent safer sex practices. Early testing can also help trace relevant contacts, who can be offered counselling and testing. Finally, PLHIV who are on treatment are less likely to transmit their infection to others, due to lower viral load. Overall, early HIV testing of individuals practising risky behaviour is of benefit both to the individual (less risk of illness and death) and to society (reduction in the number of new infections).

There may also be socio-economic benefits from PLHIV being diagnosed with their HIV status before their CD4-count becomes too low. A Canadian study (Krentz et al., 2004) has shown that people who are diagnosed HIV positive with CD4-counts below 200 cost the health service more than twice as much in the first year of treatment as those who are diagnosed with higher CD4-counts.

There is at present no knowledge in Denmark about the background and rationales that can cause some people to choose not to take an HIV test; is this due to lack of knowledge of the good treatments, fear of knowing the HIV status, or because they choose to live in ‘blissful ignorance’, or because they do not believe they have been at risk, or have denied that risk? Or perhaps it is due to some other factor entirely?

The aim of this project is to investigate the background for the fact that approximately one-third of all HIV-infected persons are diagnosed as infected at a time at which they are immediately offered treatment, in order to better focus efforts to encourage earlier testing. This project therefore takes the form of an exploratory study, i.e. it is intended to explore lesser-known phenomena, and is aimed more at developing ideas and concepts than at testing hypotheses.

BOX 1.1.
Groups who should actively be offered an HIV test

1. Men who have sex with men, and do not consistently practise safer sex, should be tested at least annually.
2. Patients who are tested for gonorrhoea and syphilis (and other STI’s, where relevant) should at the same time be HIV tested.
3. People from Africa, Asia, South America and Eastern Europe should be HIV tested at their first contact with health services, irrespective of the reason for the contact.
4. Partners of people who are HIV positive.
5. Former and current intravenous drug users.
6. All patients with tuberculosis.
7. Anyone who has had sex with people from high-risk regions, or who has been stationed abroad in such regions.
8. Patients with symptoms that are not readily diagnosable should be HIV tested, even in the absence of known HIV exposure.

STUDY POPULATION
The project focuses on people who had been diagnosed with HIV with low CD4-counts, and who did not have an acute HIV infection.

In Denmark, about half of all persons diagnosed
with HIV are diagnosed with a CD4 count of less than 350 (which is an indication of treatment commencement), and more than one fourths are diagnosed with a CD4 count of less than 200.

These figures, however, are not an isolated Danish phenomenon – the rest of Europe also shows the same tendency for many PLHIV to be identified late in their disease trajectory.

It was decided to limit the survey to PLHIV diagnosed with CD4-counts below 200, in order to avoid including too many people with acute HIV infections (and consequent low CD4-counts). It was also decided to conduct the survey among people who had been diagnosed with HIV during the period from January 1st 2003 to approximately June 30th 2009. January 1st 2003 was chosen as the cut-off date for two reasons: firstly, it was desired that the respondents should be aware of the good treatment possibilities that have been available since 1996 (and which could provide a decisive argument for being tested), and secondly, a medical record study of late presenters was carried out in the same period by Aarhus University Hospital, Skejby, which utilises the same cut-off date – see box 1.2.

The survey moreover includes only persons aged 18 years or more.

**LITERATURE**

The following databases were examined with a view to find literature dealing with late presenters: *The Danish State and University Library* (search terms: *late testing* HIV; *life situation*, HIV test; *late testing*, cancer; *late presenter HIV*); *PubMed* (search terms: HIV test; *HIV testing*; *HIV screening*); *Google* (search terms: *late testers*; *late testers HIV*; *late testers AIDS*).

Since 1996, a number of studies have been carried out on the psychosocial explanations for being tested, or not being tested, for HIV. In this study, these factors are termed the ‘personal barriers’ of the respondents which have resulted in them being tested at a late stage.

In general, however, these studies have the common characteristic that they contain data that is difficult to compare, and focus mainly on minority groups and vulnerable groups who are at risk. Overall clarity has not been aided by the fact that it was not until late 2009 that consensus was achieved in Europe on the definition of a late presenter.

Most of the studies have been carried out in the USA or in other English speaking countries, and have a socio-demographic character or take

**BOX 1.2.**

In 2010, the Research Centre for Sexually Transmitted Infections and Reproductive Health (Forskningscenter for Seksuelt Overførte Infektioner og Reproduktiv Sundhed: CESOIRS) at Aarhus University Hospital, Skejby, conducted a study which is to some degree related to this project. The CESOIRS study reviewed medical records for patients who were diagnosed with HIV during the period 2003-2009, examining differences between late presenters (CD4-counts <200) and non-late presenters. Correspondingly, the medical history of late presenters was examined to determine whether these infected people could have been identified at an earlier stage, if for example there had been contact with the health service due to symptoms related to HIV infection, but without a HIV test being offered.

The difference between the two studies is that this survey uses self-reported data and examines the period up to and including the first contact with the health service. The CESOIRS study, on the other hand, focused on the medical records created upon contact with the hospital, and subsequently. The two studies thus illuminate the same problem in different ways.

In connection with the drafting of the questionnaire, it was ensured that the questions included in the survey would be comparable with the data collected by CESOIRS from medical records.
the form of checklists on the basis of an assumed rationale of why people fail to be tested. The present survey attempts to combine both of these approaches.

In recent years, four central reviews have been published:


**INTERVIEWS**

Following the initial review of the literature, a number of professionals were interviewed. The term ‘professionals’ in this context refer to people who work professionally with PLHIV, and whose work may have permitted them to acquire a special knowledge of the reasons why some people are tested late. A total of 16 professionals were interviewed.

On the basis of the literature review and our interviews with the professionals, an interview guide was compiled and semi-structured qualitative interviews were conducted with seven persons who had been diagnosed with HIV with low CD4-counts.

The interviewees were selected in co-operation with the HIV-Danmark’s Counselling Unit in Copenhagen. The purpose of the interviews was to gain insight into as many different kinds of explanations as possible. The interviewee group should ideally be as varied as possible, i.e. including people from both rural and urban areas, and heterosexual, bisexual and homosexual men and heterosexual women, drug users, young people and older people, people born in Denmark and abroad, etc.

A group interview was also held with approximately thirteen persons with non-Danish backgrounds (‘approximately’ because people both came and went during the interview!). This was established in collaboration with Cross-Over^3.

On the basis of these interviews, a questionnaire was drawn up for distribution among people aged 18 years or more who, after January 1st 2003, had begun monitoring or treatment for HIV with a CD4-count of less than 200.

**QUESTIONNAIRES**

All of the questionnaires were distributed along with postage pre-paid envelopes (addressed to an anonymous PO box) in connection with monitoring visits to the HIV treatment centres from mid-September 2009 to the end of March 2010, and the completed questionnaires received were entered on an ongoing basis into an SPSS database^4.

According to SSI^5, a total of 335 persons were diagnosed with HIV in Denmark with a CD4-count of less than 200 in the period from January 1st 2003 until June 30th 2009. However, the CD4-count is stated in only 60% of the reports to the SSI (HIV reporting system).

The DHC provided kind assistance in allowing the use of their database to identify those persons who had begun monitoring or treatment for HIV during the survey period with a CD4 count of less than 200. The DHC sent the anonymised cohort numbers directly to the HIV treatment centres; HIV-Danmark was not involved in this procedure, but forwarded the questionnaires to the HIV treatment centres to be handed out. The DHC identified a total of 392 persons to whom a questionnaire should be given. However, it was found in follow-up conversations with the HIV treatment centres in the autumn of 2009 that some of these individuals had either died or had been transferred to another centre, so the questionnaire was in fact only made available to a maximum of 375 persons.
In the spring of 2010 we once again made contact with all of the HIV treatment centres, in an attempt to gain an impression of how many questionnaires had actually been handed out. This information was not available at all of the departments, but a conservative estimate, based on the available information, suggests that between fifty and sixty percent of the questionnaires were handed out.

Two problems were typically mentioned in connection with the handing out of questionnaires: language difficulties (i.e. some respondents did not understand sufficient Danish or English to be able to fill in the questionnaire) and the question of anonymity (i.e. doubts about how the survey could be anonymous when you were personally given a questionnaire which had been selected on the criterion of a low CD4-count). However, it was also felt that most of the potential respondents were reassured on this point when given an explanation.

Ninety-seven valid and three blank questionnaires were received, which means that we have received responses from just over a quarter of all late-tested persons from January 2003 to June 2009.

A response rate of 25.5% (100/397) may be considered to be satisfactory. All experience indicates that it is difficult to achieve high response rates in surveys conducted among PLHIV. In this context we could mention that the first Norwegian survey ‘Levekår og livskvalitet blant hivpositive’ (‘Living conditions and quality of life among people living with HIV’) (2002) achieved a response rate of approximately 20%, and that the latest Norwegian living conditions survey ‘Fra Holdninger til Levekår’ (‘From Attitudes to Living Conditions’) (2009) actually had a slightly lower response rate. A similar survey conducted in New Zealand achieved a response rate of approximately 21% (Grierson et al., 2008), while an Australian study achieved a response rate of 6.4% (Grierson et al., 2006). Only the Living Conditions Survey of Hiv-Danmark6 (Carstensen et al., 2007) achieved a significantly higher response rate, at 38%.

The permission of the Danish Data Protection Agency was obtained. It was not necessary to register the project with the Biomedical Research Ethics Committee.

1. The data was collected at the DHC in August 2009, but there can be some delay in reporting to the DHC.
2. More than 20 different definitions were previously used for late presenters. In October-November 2009, however, two meetings initiated by ‘HIV in Europe’ agreed to recommend the following two definitions of late presentation (Antinori et al., 2010):
   • Late presentation: Persons presenting for care with a CD4-count below 350 cells/µL or presenting with an AIDS-defining event, regardless of the CD4-count.
   • Presentation with advanced HIV disease: Persons presenting for care with a CD4-count below 200 cells/µL or presenting with an AIDS-defining event, regardless of the CD4-count.
3. Organisation working with HIV/AIDS and sexual health for ethnic minorities living in Denmark.
4. P-values are indicated in the cross-tabulations. P-values indicate whether the observed correlations are statistically significant or simply due to chance. The significance level has been set to 5%, which is normal for this type of survey. In the tables, this is indicated as P = 0.05 or less. For cross-tabulations with lower P-values, it is more likely that the observed relationship is actually valid.
5. Information from Staff Specialist Susan Cowan, SSI.
6. The living conditions survey conducted by Hiv-Danmark will henceforth be referred to simply as the Living Conditions Survey.
2. FACTS ABOUT RESPONDENTS
This chapter provides a description of the group of respondents and its generalisability. Retrospective-ly we examine if the respondents previously had been tested, and details of when the respondents were infected. This is done in an attempt to clarify the circumstances under which infection occurred, and to examine whether there is anything in these situations that either distinguishes them from other PLHIV, or could guide general efforts to promote prevention and motivate earlier testing. The chapter is based on a number of questions from the questionnaire – see box 2.1.

THE RESPONDENTS
71 men completed the questionnaire, of whom 34 identified themselves as homosexual, 10 as bisexual, 24 as heterosexual and three could not specify a sexual identity.

25 women completed the questionnaire, of whom 19 were heterosexual, four could not specify a sexual identity, and two did not state their sexual identity.

One respondent did not specify gender.

The average age of the respondents at the time of HIV diagnosis was between 42 and 43 years of age, and the median age was 40.

72 of the respondents were Danish-born and 25 were non-Danish-born. The latter had on average lived in Denmark for more than eight years at the time of HIV diagnosis. Nine of the non-Danish-born respondents came from Asia, eight from Africa, three from Europe, three from America and two from the Middle East.

50 respondents reported that they were living in established couple relationships at the time of diagnosis; of these, 26 were heterosexual (15 women and 11 men), 16 were homosexual men, five were bisexual men, two did not reply to the question of their sexual identity, and one person was unable to specify a sexual identity.

GENERALISABILITY
This survey cannot be regarded as representative, as it is not based on a random sample. It cannot therefore indicate anything about the group of late presenters as a whole in Denmark in the period under review, but only about the 97 people who chose to fill in the questionnaire.

However, although the survey is not representa-tive, it may still be useful to compare the respondents with data obtained from SSI for the same period, which can convey a sense of the extent to which the respondents are ‘similar’ or ‘different’ to the background population (i.e. PLHIV with CD4-counts below 200 and reported to the SSI) – see table 2.1.

The figures from the SSI represent only an approximate description of the background population of PLHIV diagnosed with CD4-counts of less than 200, but the comparison nonetheless provides a good impression of the degree to which the respondents resemble the background population.

With respect to gender and age, there is a very strong correlation between the survey data and that of the HIV surveillance system, with only 35-44 year olds apparently under-represented in the survey.

On the other hand, it is clear that PLHIV from other European countries and Africa are under-

BOX 2.1. FROM THE QUESTIONNAIRE
Are you male or female? (Q.1)
In which year were you born? (Q.3)
Where were you born? (Q.4)
Which of the following statements of sexual identity describes you at best? (Q.7)
Did you have a permanent partner, when you where diagnosed with HIV? (Q.11)
Do you know in which specific situation you became infected with HIV? (Q.12)
Did you know that this was a situation that involved a special risk of infection? (Q.13)
Where do you think it is most likely that you became infected with HIV? (Q.14)
Is it most likely that you became infected through purchase or sale of sexual services? (Q.15.5)
Have you earlier had a negative HIV-test? (Q.17)
represented, and only a single respondent has stated that the infection arose through intravenous drug use. This under-representation is not, however, surprising. Many members of the group of drug users may have few resources, while in the case of a large number of the non-Danish-born respondents, there can be both language difficulties and a lack of resources. African-born persons and drug users were also under-represented in the Living Conditions Survey. On the other hand, it is noteworthy that HIV-positive persons from both Asian and American backgrounds appear to be well represented (although the numbers are small).

As can be seen from the table, 45% of the respondents in this study were infected through homosexual contact (MSM), while only 35% indicated this pathway in the HIV surveillance system. Men infected through homosexual contact are thus over-represented in the survey.

It should be noted that the questionnaire offered the possibility of checking several boxes under ‘Probable mode of transmission’, whereas the HIV surveillance system only records one most likely mode of transmission, and that the questionnaire also included the categories ‘Purchase or sale of sexual services’ and ‘Other/Not sure’, which are not included in the HIV surveillance system.

We also note that proportionately more respondents (five persons: four Danish-born and one non-Danish-born) indicated blood transfusion as a probable mode of transmission than is the case in the background population. Two of these, however, indicated that heterosexual contact could also have been a possible infection pathway, while two others, in addition to the possibility of being infected through blood transfusion, also checked “Other/Not sure”. Given the relatively small number of people infected with HIV through blood transfusion, it seems most likely that those who also specified a second likely pathway were infected by means other than transfusion.

In relation to age and gender, the data from this survey quite closely matches that of the HIV surveillance system. There is however an under-representation of heterosexual late presenters. This under-representation of heterosexuals was also apparent in the Living Conditions Survey. There is also an under-representation of late presenters from Europe and Africa, while drug users are largely absent from the survey. The under-representation of drug users and respondents from Africa was also apparent in the Living Conditions Survey, and is probably due to a combination of language difficulties (for the African-born respondents) and a lack of resources.

Due to the under-representation of heterosexuals, drug users and persons born in the rest of Europe and Africa, caution should be exercised in generalising data from the survey to apply to the group of late presenters as a whole.
PREVIOUSLY HIV TESTED

Just over one-third of the respondents (37%) had previously been tested negative for HIV. These are thus persons for whom it is likely that, at any rate in the past, they had a suspicion of being exposed to the risk of HIV infection.

Not surprisingly, proportionately more homosexuals had previously taken an HIV test – see table 2.2. The prevalence of HIV among men who have sex with men is much higher than among heterosexuals, as most of these men were probably aware, and frequent HIV prevention campaigns are also targeted at MSM.

Just over half of the homosexual respondents had previously taken a test for HIV, while less than one-third of the heterosexuals had done so.

No major difference was observed between Danish-born respondents (38%) and non-Danish-born respondents (32%) in relation to whether they had previously had an HIV test (not shown in table). However, a big difference could be observed in relation to place of origin. Of the six people who were born in the Americas or in Europe, four had previously been tested, while only four people of the nineteen respondents who came from Africa, Asia and the Middle East had previously been tested. The three respondents from Europe were all heterosexual men, while the three from the Americas were all homosexual men.

The 2009 Sex Life Survey also asked respondents whether they had previously been tested for HIV. In this survey, 79% responded that they had previously been tested, with 55% tested within the previous 16 months. In the present survey, when responses from the group of bisexual men are added to the group of homosexual men (=MSM) (in order to obtain the correct figures for comparison with the data from the Sex Life Survey), we find that 51% had previously taken an HIV test.

This strongly suggests that there had been less previous test activity among MSM who were diagnosed as late presenters – which distinguishes them from the respondents in the Sex Life Survey.

In an article on HIV test behaviour in the Danish population (Lemcke et al., 2007), which was based on data from the National Health Institute Surveys of 2000 (NHIS), it is stated that 44% of MSM had at some time taken an HIV test. Among heterosexual men and women, the NHIS figures state that 28% and 32%, respectively, had been tested for HIV at some point.

The NHIS figures – the representative figures for the Danish population – are thus in quite close agreement with those of this survey. Late presenters are not, therefore, people who have been tested more or less than the Danish population in general.

The questionnaire also asked when respondents had taken their last negative HIV test, to which about one-third of the respondents (37%) reported that it had been within the previous five years – see table 2.3. This is perhaps somewhat surprising, as one might otherwise suppose that those encompassed by the term ‘late presenters’ would be people who had been infected for some years before being tested positive.

It is possible that some of these people actually had an acute HIV infection, and were therefore not ‘real’ late presenters, but merely had a CD4 count which by definition led to them being designated late presenters. However, this is unlikely to have been the case for many of them. The cut-off point of a CD4-count of less than 200 was chosen precisely to eliminate people with an acute HIV infection from the respondents.

It is also possible that some of the respondents remembered incorrectly, and entered the wrong year for their last negative HIV test.

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**TABLE 2.2. HAVE YOU EARLIER HAD A NEGATIVE HIV-TEST? (Q17) N=94**

<table>
<thead>
<tr>
<th></th>
<th>HETEROSEXUAL MEN AND WOMEN</th>
<th>HOMOSEXUAL MEN</th>
<th>OTHER IDENTITY</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>13 (31%)</td>
<td>18 (55%)</td>
<td>4 (21%)</td>
<td>35 (37%)</td>
</tr>
<tr>
<td>No</td>
<td>29 (69%)</td>
<td>15 (45%)</td>
<td>15 (79%)</td>
<td>59 (63%)</td>
</tr>
</tbody>
</table>

P=0.029
Finally, it is possible that this group encompassed some people whose immune system had become weakened at a faster rate than the average, and who were therefore diagnosed as positive with a low CD4-count.

There was no observed difference between the groups of heterosexuals and homosexuals in relation to the length of time that had elapsed since the last negative HIV test\textsuperscript{11}.

TABLE 2.3. DURATION BETWEEN NEGATIVE TEST AND DIAGNOSIS WITH HIV (Q8 AND Q18) N=35

<table>
<thead>
<tr>
<th>Duration</th>
<th>N</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 5 years</td>
<td>13</td>
<td>(37%)</td>
</tr>
<tr>
<td>Between 6 and 10 years</td>
<td>8</td>
<td>(23%)</td>
</tr>
<tr>
<td>Between 11 and 15 years</td>
<td>8</td>
<td>(23%)</td>
</tr>
<tr>
<td>More than 15 years</td>
<td>3</td>
<td>(9%)</td>
</tr>
<tr>
<td>Not reported</td>
<td>3</td>
<td>(9%)</td>
</tr>
</tbody>
</table>

that it had involved a special risk. The figures are small, so caution is required in interpreting them, but they suggest that some late presenters had refrained from being tested, even though they knew they had been exposed to a risk.

One might otherwise imagine that people who knew they had undertaken risky behaviour would be more likely to choose to be tested than people who did not feel they had undertaken risky behaviour. This assumption, however, does not hold true for the group of men who have sex with men. The Sex Life Survey states that:

*“It is perhaps particularly interesting to ask whether a correlation exists between testing and unsafe sex. None has been observed. Those who have practised unsafe sex had not been tested more frequently than those who had not had unsafe sex. The same result was observed in 2006.”*

The relationship between unsafe sex and frequency of testing among heterosexual men and women is not known.

KNOWLEDGE OF THE SITUATION IN WHICH INFECTION OCCURRED

Twenty of the survey’s respondents (21%) stated that they were aware of the specific situation in which they had become infected. In the Living Conditions Survey, almost twice as many (39%) replied “Yes” to this question.

The difference is striking – why are there so many more among the group of all PLHIV who knew when and how they had become infected? Is it because they had in general been infected for a shorter period of time, and could therefore either remember or have had an opportunity to find out in which situation they had become infected? The survey cannot provide an answer to this question.

Equally remarkable is the fact that of these twenty people, twelve (60%) also indicated that they knew it was a situation that involved a special risk of infection. In the Living Conditions Survey, only 33% stated that they knew that they had been exposed to a special risk.

While, on the one hand, fewer people in the present survey were aware of the situation in which they had become infected, more of those who were aware of the infection situation knew

MOST LIKELY TO HAVE BEEN INFECTED IN DENMARK OR NOT?

The survey also included questions about where the individual believed he or she had become infected: in Denmark or abroad. HIV surveillance data indicates that approximately one-third of Danish-born heterosexual PLHIV were infected abroad, while the rate for MSM is around 12\textsuperscript{12}. The large number of heterosexuals who are infected abroad is probably explained both by the greater risk of meeting an HIV-infected sexual partner, due to the higher prevalence of HIV in most places abroad, and because many people find it easier to ‘bend’ the safer sex rules once they are removed from their familiar environment:

*“Another example of an ‘acceptable’ situation [when the safer sex rules are ‘bent’] is when a person is outside of their normal surroundings and with strangers, such as [...] on vacation” (Sandin et al., 2008).*
Periods spent abroad thus increase the risk of practising unsafe sexual behaviour – perhaps even without the person concerned regarding it as unsafe sex – or of repressing the greater risk in this connection. And if you do not consider your behaviour to be risky, you will not necessarily feel the need to be tested.

The question of where the individuals believed they had been infected was included in the survey to investigate whether there was a greater proportion of Danish-born late presenters, compared to the group of HIV-positive persons as a whole, who believed they had been infected abroad, and who may not have regarded their behaviour as risky, or repressed the thought that it could have been. There is however no evidence to suggest that more Danish-born late presenters were infected abroad than Danish-born PLHIV in general.

As mentioned, around one-third of all Danish-born heterosexual PLHIV believed they had been infected abroad. In this survey, twenty Danish-born heterosexuals (77%) believed they had been infected in Denmark, while five (19%) believed they had been infected abroad. One did not know where he had been infected. Although these figures are small, they seem to strongly suggest that late presenters – at least in the group of heterosexually-infected, Danish-born men and women – are more likely to have been infected in Denmark than is the case among the group of HIV-positive people as a whole.

Among all Danish-born MSM, less than 10% believed that they had been infected abroad. In this survey, twenty-eight MSM (70%) stated that they had been infected in Denmark, five (13%) that they had been infected abroad, and seven (18%) did not know where they had been infected. The number of MSM who did not know where they had been infected is therefore quite large, and it is consequently difficult to draw any conclusions from these figures.

As shown in table 2.4, 40% of the non-Danish-born respondents believed that they had been infected in Denmark.

This might a priori appear surprising, but is less so when the responses are examined more closely. The ten non-Danish-born persons who believed they had been infected in Denmark had lived in Denmark for an average of more than eleven years at the time they were diagnosed with HIV.

The length of time all non-Danish-born late presenters had lived in Denmark at the time they were diagnosed as HIV positive is shown in table 2.5.

The table shows that only a single non-Danish-born person was diagnosed with HIV before coming to Denmark, while three were diagnosed within the first year of residence in Denmark. In addition, five persons were diagnosed with HIV within their first five years of residence in Denmark.

Half (12 out of 25) of the non-Danish-born respondents had resided in Denmark for six years or more before being diagnosed with HIV.

One must assume that respondents who were diagnosed with HIV within one year of arrival in Denmark had been infected abroad, hence cannot comprise a potential group for preventive efforts. However, they naturally represent a potential group to be offered HIV testing at the earliest possible opportunity, with the consequent benefits to their health as stated by the National Board of Health (see box 1.1).

Of the six non-Danish-born persons who believed they had been infected abroad, four had lived in Denmark for two years or less before being diagnosed with HIV, one had lived in the country for 35 years, and the final one had lived in Denmark all his life.

This might imply either that not many foreign
‘new arrivals’ who are diagnosed as PLHIV are late presenters, or that these individuals did not complete the questionnaire. The latter is probably the most likely explanation, as one could imagine that language difficulties may have prevented them from doing so.

It is also noteworthy that the majority of the African and Asian late presenters were women – of the eight respondents from Africa, only one was a man, while of the nine respondents from Asia, only two were men.

UNCERTAINTY CONCERNING HOW THE MODE OF INFECTION

In response to the question on how the infection took place, 18% of the respondents checked the answer ‘Other/Not sure’ – a figure which does not differ significantly from the Living Conditions Survey, in which 14% indicated ‘Other’ or ‘Not sure’. More non-Danish-born than Danish-born respondents checked ‘Other/Not sure’ concerning the mode of infection, and this tendency is also present in the Living Conditions Survey. The group of late presenters thus does not appear to contain more people who are unaware of how they became infected with HIV than the group of HIV-positive persons as a whole.\(^{15}\)

PURCHASE OR SALE OF SEXUAL SERVICES

The survey included a question on whether the individual believed he or she had become infected via the sale or purchase of sexual services. This question was included in order to investigate if there might be a larger proportion of late presenters who believed they had become infected in this way – as the buying and selling of sex is often associated with taboo behaviour, and perhaps therefore constituted a risk which might be mentally repressed.

Eight people stated that they believed they had become infected through the purchase or sale of sexual services, of whom five were Danish-born and three non-Danish-born. All of the Danish-born respondents were men; four of them were heterosexual, and one was bisexual. Three of them believed they had been infected in Denmark, one abroad, and the last one did not know the place of infection.

Among the non-Danish-born respondents infected through the purchase or sale of sexual services, one was a woman who had become infected abroad, and the final two were men. Of these, one did not know where he had become infected, while the other was infected abroad.

These figures are too small to allow any conclusions to be drawn.

SUMMARY

In relation to age and gender, the data from the present survey quite closely matches that of the HIV surveillance system. Heterosexuals, drug users and persons born in the remainder of Europe and in Africa are however under-represented. Caution should therefore be exercised in generalising data from this survey to apply to the group of late presenters as a whole.

Approximately one-third of all late presenters had previously been tested for HIV, while among the group of MSM respondents, half had previously been tested. Far fewer MSM respondents in this survey had previously been tested than the respondents to the Sex Life Survey, which suggests the lack of a testing strategy among late-presenting MSM.

Late presenters are thus not people who have been tested more or less than the rest of the Danish population.
Just over one-third of those who had previously been tested for HIV stated that they had had their last negative test within the previous five years. This is probably either due to some respondents remembering incorrectly when their last test had been taken, or to some late presenters having only been infected for a few years before being diagnosed HIV-positive as late presenters. 41% stated that the negative test was taken at least eleven years previously.

By comparison with the Living Conditions Survey, fewer of the late presenters were aware of the situation in which they had been infected, but more of those who were aware of the infection situation knew that it involved a special risk.

One-third of all the Danish-born, heterosexual HIV-positive men and women were infected abroad, but there is nothing to suggest that the late presenters in this group are more likely to have been infected abroad – quite the contrary. It is difficult to draw any conclusions about the group of Danish-born MSM from the survey data with regard to the place of infection, as more than one-third stated that they did not know where they had been infected.

7. There is considerable variation in the figures, from one person who was diagnosed HIV positive a year before arrival in Denmark, to one who had lived in the country for the past 30 years.
8. In table 2.1, the late presenter data is compared with reports to the SSI notification system from 2005 until 2009. Since 2005, a new coding system (SOUNDEX) has been used for reports which eliminates any double reporting. In addition, the SSI figures from 2005 onwards offer a more complete account of CD4-counts in reports to the SSI that those from 2003 and previously.
9. The woman in question was however apparently unsure of the mode of infection, and indicated likely routes of infection as both heterosexual contact, homosexual contact and intravenous drug use.
10. The 2009 Sex Life Survey (Sexlivsundersøgelsen 2009) will hereafter be referred to simply as the Sex Life Survey.
11. Only eight non-Danish-born respondents had previously been tested.
12. This data covers the period from 2005 onwards. Information from Staff Specialist Susan Cowan, SSI.
13. It is assumed here that the number of years respondents stated they had lived in Denmark was contiguous with the period before they were diagnosed HIV positive.
14. The person in question probably arrived in Denmark as an infant, but is too old to have been infected via mother to child transmission.
15. In the HIV surveillance system, only 3% are stated to have been infected by ‘unknown mode of infection’. There is thus a somewhat greater degree of uncertainty concerning the mode of infection in self-reported data than in data reported by doctors.
3. THE HEALTH CARE ENCOUNTER

This chapter looks at the contact between the late presenters and the national health service at the time when they were diagnosed with HIV, and during the period prior to this contact, to investigate whether the respondents had had symptoms of HIV, where they had been diagnosed, who took the initiative to take the HIV test, whether long waiting times for a test response contributed to the delay in being tested, etc.

The aim was to discover whether there had been any problems, difficulties, or special challenges associated with the respondents’ contact with the health service which may have contributed to the lateness of the HIV test.

The chapter is based on a number of questions from the questionnaire, see box 3.1, in which the respondents were asked to describe their contact with the health service at and prior to the time of being diagnosed HIV positive.

WHERE THE RESPONDENTS WERE DIAGNOSED

Initially, we will examine where the individual late presenters were diagnosed with HIV. 30% were diagnosed with HIV by their own GPs, and as shown in table 3.1, almost half of the respondents were hospitalized when found with HIV. There were no significant differences with respect to gender, sexual identity or place of birth.

These figures suggest that a number of the late presenters must have been quite ill with their HIV infection at the time when they were diagnosed with HIV. This is hardly surprising, since the weaker the condition of the immune system, the greater the risk of increased morbidity.

In the HIV surveillance system for the period 2005-2009, 30% of new cases of HIV infection were registered as being diagnosed by GPs, 37% at an infectious diseases clinic, 16% at “another hospital department” and 13% at an STI clinic.

The HIV surveillance system does not record whether individuals were diagnosed with HIV during hospitalization, and it is not therefore possible to compare the data from the present survey with the HIV surveillance data: the 37% who were diagnosed with HIV at an infectious diseases clinic includes both those who had been hospitalised, and those who visited the clinic at their own initiative to be tested for HIV.

It is nonetheless worth considering whether any of the 46% of respondents to the present survey who were diagnosed with HIV in hospital could have been diagnosed before they became so ill that hospitalization was necessary. This survey cannot however immediately answer the question of whether the group of late presenters who were diagnosed during hospitalization had been in contact with the health service at an earlier time due to their symptoms.

On the other hand, the survey can provide information on the length of time that elapsed from the first consultation due to symptoms (for those who actually had symptoms) until the HIV diagnosis. As will be shown later in table 3.6, three out of four respondents were diagnosed with HIV within a year of the first consultation.

If we look at the locations where individuals of particular sexual identities were diagnosed with HIV, an interesting picture emerges. As shown in table 3.2, significantly fewer homosexual men were diagnosed with HIV in hospital, compared to
other places (own GP, clinic or elsewhere)\textsuperscript{18}. This is probably because homosexual men are more likely than others to be encouraged to take an HIV test in connection with visits to their GP, or when visiting a clinic to be tested for other sexually transmitted diseases. There was however no difference between the Danish-born and non-Danish-born respondents.

Turning to the reasons why the respondents were tested, it is clear from table 3.3 that in most cases (nearly two out of three), it was a doctor who suggested the HIV test – and here there were no significant differences between gender, sexual identity or place of birth. This means that homosexual men are encouraged just as much as others to take the test – but they also tend to take the test before they are hospitalised due to symptoms of a weakened immune system.

One in four had independently taken the initiative to be tested, while partner notification and a partner being diagnosed with HIV accounted for just 7% – see table 3.3.

As many late presenters are diagnosed in hospital, it is perhaps not surprising that many of the tests were taken at the suggestion of a doctor. In fact, for 78% of those diagnosed with HIV during a hospital admission, the test was taken at the initiative of a doctor (not shown in table).

A large proportion of the late presenters had in their own opinion not practised risky behaviour (for two out of three, this had some or a great deal of influence on the fact that they had not been tested earlier), and therefore may not even have considered the possibility of being infected with HIV – or if they had in fact considered this possibility, they had, for one reason or another, not mentioned this to their doctor (more on this in Chapter 4).

The figures for late presenters diagnosed as HIV positive at a clinic are small, but it is worth noting that of the sixteen people who were tested at a clinic for HIV, six (40%) did so at the suggestion of a doctor. This suggests that these individuals visited the clinic to be tested for other STI, and that the doctor then encouraged them to take an HIV test. The respondents in question were three heterosexual men, two homosexual men and one bisexual man.

It cannot be inferred from the survey data if these persons could have been asked to take a test at an earlier date in connection with contact with the health service, but closer attention on the part of health professionals to the risk of HIV would probably result in some late presenters being diagnosed at an earlier stage. In the initial interviews prior to designing the questionnaire, several accounts revealed instances in which the individuals concerned could in fact have been offered a test at an earlier stage. One homosexual man in his thirties, who was diagnosed with HIV in 2008 with a CD4-count of 0, said for example:

“I remember that some years ago, I began to get some enlarged lymph nodes on my neck ... I visited my doctor and said: ‘I don’t understand this ... it’s strange.’ I was there to get a broken nose treated, so I asked him to take a look at those glands in my neck as well ... and he said it was quite normal, they were just a bit enlarged. In retrospect, there are obviously many things that fall into place.”

This man is fairly sure that the doctor knows he is gay, as his boyfriend has the same doctor.

Another interviewee, also a homosexual man
who was diagnosed with HIV in 2004, when he was
in his late thirties, spoke about his contact with
his GP prior to the HIV diagnosis. He said that he
had experienced a variety of symptoms, including
shingles and fungal infections. He had thought
about being tested for HIV, as he was constantly on
antibiotics. The doctor treated these symptoms,
but never suggested an HIV test, although he was
quite aware that the patient was homosexual. The
patient had previously spoken to the doctor about
his problems about disclosing his gay identity
during a period of depression.

He was not diagnosed HIV positive until a hospi-
tal admission, when a friend—who suspected HIV
—urged the staff to ask him if they could test him
for HIV. He agreed to this because, as he put it, he
was so sick by then that he would have agreed to
anything.

Both respondents are homosexual: the first is
fairly sure that his doctor knows this, and the other
is certain of it. Both had symptoms that could
indicate an HIV infection (enlarged lymph glands,
shingles and fungal infections), but without their
doctors suggesting an HIV test. In hindsight, they
could both have been asked to take an HIV test at
an earlier stage.

With regard to their reasons for not taking an
HIV test, this was in the case of the first person
because he did not feel he had practised risky
behaviour since taking his last negative test during
the nineties. He was also “too busy to get it done”,
but says that he would have been glad if he had
been asked to take an HIV test at an earlier stage.

The other interviewee says that he would prob-
ably not have been tested if he had not been ill. He
says he actually contemplated asking his doctor
during the 3–4 years from the onset of his first
symptoms until he was actually tested, but, as he
says, this would also have had consequences. If he
was negative, then he would probably be suffering
from something else, and if the test was positive,
he would have to deal with that. The thought
frightened him, because nobody in his family knew
he was gay, and he was afraid they would disown
him.

Most of the interviews conducted prior to draft-
ing the questionnaire, however, left the impression
that the persons concerned had not considered
that they could be at risk of HIV infection and had
not consulted their GP.

**SYMPTOMS AND TEST PROCEDURE**

In the questionnaire, respondents were asked
whether they could remember having had
symptoms of HIV before they tested positive. By
examining these answers and comparing them
with how the respondents reacted to the symp-
toms (whether they had considered a test, and
whether they were in fact tested), we can examine
how many were tested, and the length of time that
elapsed before this occurred.

Among the respondents to this survey, more
than half recall having symptoms of HIV (table 3.4).
This is an interesting point, because symptoms of
illness might cause people to contact their doctor.

Table 3.4 shows that more homosexual men
could remember having HIV-related symptoms, by
comparison with heterosexual men and women,
bisexual men and people who could not specify a
sexual identity.

This difference is probably due to the fact that
homosexual men, thanks to information cam-

---

**TABLE 3.3. WHY THE RESPONDENTS
TESTED FOR HIV (Q16) N=89**

<table>
<thead>
<tr>
<th>Reason</th>
<th>Yes</th>
<th>No</th>
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</thead>
<tbody>
<tr>
<td>Doctor-encouraged test</td>
<td>54</td>
<td>8</td>
<td>62</td>
</tr>
<tr>
<td>Friend-encouraged test</td>
<td>4</td>
<td>25</td>
<td>29</td>
</tr>
<tr>
<td>Partner found with HIV</td>
<td>4</td>
<td>14</td>
<td>18</td>
</tr>
<tr>
<td>Partner notification</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Own initiative</td>
<td>21</td>
<td>71</td>
<td>92</td>
</tr>
</tbody>
</table>

**TABLE 3.4. RECALLING HIV SYMPTOMS (Q20)
N=95**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual men and women</td>
<td>19</td>
<td>24</td>
<td>43</td>
</tr>
<tr>
<td>Homosexual men</td>
<td>24</td>
<td>9</td>
<td>33</td>
</tr>
<tr>
<td>Another identity</td>
<td>11</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>54</td>
<td>41</td>
<td>95</td>
</tr>
</tbody>
</table>

P=0.045

---

**Table 3.4**

**Heterosexual Men and Women**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>19</td>
<td>24</td>
<td>43</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>9</td>
<td>33</td>
</tr>
</tbody>
</table>

**Homosexual Men**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>24</td>
<td>9</td>
<td>33</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>7</td>
<td>16</td>
</tr>
</tbody>
</table>

**Another Identity**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>11</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

**Total**

<table>
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<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td>Yes</td>
<td>54</td>
<td>41</td>
<td>95</td>
</tr>
<tr>
<td>No</td>
<td>41</td>
<td>41</td>
<td>82</td>
</tr>
</tbody>
</table>

P=0.045

---

**Table 3.4**

**Heterosexual Men and Women**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>19</td>
<td>24</td>
<td>43</td>
</tr>
<tr>
<td>No</td>
<td>24</td>
<td>9</td>
<td>33</td>
</tr>
</tbody>
</table>

**Homosexual Men**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>24</td>
<td>9</td>
<td>33</td>
</tr>
<tr>
<td>No</td>
<td>9</td>
<td>7</td>
<td>16</td>
</tr>
</tbody>
</table>

**Another Identity**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>11</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>No</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

**Total**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>54</td>
<td>41</td>
<td>95</td>
</tr>
<tr>
<td>No</td>
<td>41</td>
<td>41</td>
<td>82</td>
</tr>
</tbody>
</table>

P=0.045
campaigns, are generally more informed about HIV and are perhaps more aware of HIV-related symptoms, as the risk of infection for MSM is much greater than for heterosexual men or women, if unsafe sex is practised. But we can also see that the homosexual men did not apparently take the initiative to be HIV tested more often than others, and despite their (presumably) greater knowledge and awareness of HIV, they required as much encouragement as others to take an HIV test.

If we take a closer look at the symptoms that respondents remember (table 3.5), only acute HIV infection indicates an early symptom of HIV. However, less than 10% of the respondents can recall having an acute HIV infection.

On the other hand, quite a few (just over half) remember having weight loss, or suffering from fatigue and fungal infections (just under half).

Fatigue can be a rather vague symptom, but (unexplained) weight loss and fungal infections should cause people to consider consulting their doctor.

Under ‘Other’ in the questionnaires, shingles are noted three times, as well as tuberculosis, marks on the body, frequent colds, mouth ulcers, excessive acne, coatings on the tongue, gum problems, feeling cold and glandular fever.

The survey also contained questions intended to clarify how the individual and/or health care professionals responded to these symptoms. To clarify the individual respondent’s reaction, the question “Did these symptoms cause you to consider taking an HIV test?” was asked.

As shown in table 3.6, far fewer of the homosexual men (8/24) did not consider taking an HIV test, compared to the other respondents. At the same time, however, many more homosexual men than other respondents stated that they had considered taking an HIV test, but had not in fact been tested (8/24).

As mentioned earlier, the fact that so many more homosexual men considered taking an HIV test is presumably because these men were more aware of the risk of HIV than the other respondents. It may be possible to utilise this extra attention to symptoms as a means of making this group of men aware of the health benefits of having an HIV test as early as possible.

However, four of these sixteen homosexual men (those who either did not consider an HIV test, or considered an HIV test but were not tested) replied in another question that they had actually been tested, at the suggestion of a nurse or doctor.

Among the non-homosexual respondents, 71% indicated that they had not considered an HIV test, even though they could subsequently remember actually having had symptoms of HIV. It will probably be much more difficult to reach this group of predominantly heterosexual men and women with information about the benefits of an HIV test, as most of them did not believe that they had practised risky behaviour, and therefore did not think about HIV in relation to their symptoms. In relation to this group, it is the health care professionals who will have to consider the possibility of an HIV test if these individuals report symptoms.

It should however be noted that eleven of the twenty non-homosexual respondents who did not consider an HIV test, and the one respondent who did consider one, but was not tested, also reported that they actually were tested at the suggestion of a doctor (recall note 19 for an explanation of this).

In order to clarify the reaction of health care

<table>
<thead>
<tr>
<th>TABLE 3.5. SYMPTOMS OF HIV (Q21)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=54</td>
</tr>
<tr>
<td><strong>Primary infection</strong> 5 (9%)</td>
</tr>
<tr>
<td><strong>Fatigue</strong> 23 (43%)</td>
</tr>
<tr>
<td><strong>Weight loss</strong> 29 (54%)</td>
</tr>
<tr>
<td><strong>Diarrhoea</strong> 15 (28%)</td>
</tr>
<tr>
<td><strong>Respiratory tract infections</strong> 23 (43%)</td>
</tr>
<tr>
<td><strong>Stomach or intestinal infection</strong> 15 (29%)</td>
</tr>
<tr>
<td><strong>NB: NOT MUTUAL EXCLUDING SYMPTOMS</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TABLE 3.6. DID THESE SYMPTOMS MAKE YOU CONSIDER AN HIV-TEST? (Q22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=52</td>
</tr>
<tr>
<td><strong>HOMOSEXUAL MEN</strong></td>
</tr>
<tr>
<td><strong>ALL OTHER</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
</tr>
<tr>
<td><strong>No</strong> 8 (33%)</td>
</tr>
<tr>
<td><strong>Considered, but no test</strong> 8 (33%)</td>
</tr>
<tr>
<td><strong>Yes, tested b/c of symptoms</strong> 8 (33%)</td>
</tr>
<tr>
<td><strong>P=0.006</strong></td>
</tr>
</tbody>
</table>


professionals to the symptoms, the question “Did these symptoms cause a nurse/doctor to suggest that you take an HIV test?” was also asked.

There appears to have been some uncertainty among the respondents as to how this question should be answered. Some respondents, for example, both replied that they had refused a test, and that they had been tested due to their symptoms. It may however be noted that 52 persons answered the two questions “Did these symptoms make you consider an HIV test?” and “Did these symptoms make a nurse/doctor suggest that you should take an HIV test?”, and of these, a total of 31 (60%) responded, to one or the other of the questions, “Yes, that was why I took a test for HIV”. In the group of homosexual men, 10 out of 24 (42%) replied a similar ‘Yes’ to one of these questions.

Due to the apparent uncertainty in relation to how to answer the question, no further interpretation will be placed on the responses.

The respondents were also asked to state how long a period of time had elapsed from their first consultation due to symptoms until they were diagnosed with HIV – see table 3.7.

It is interesting to see the answers concerning the length of time that was required to detect HIV among those respondents who remembered having symptoms of HIV and consulting a doctor in this connection. This is another way of asking when taking the test was suggested (either by the doctor or by the respondent). 35 of the 54 respondents who stated that they could remember having symptoms also replied to this question. Nearly three out of four were diagnosed with HIV within a year.

Nine of the 35 who answered this question said it had taken more than a year for the diagnosis to be made, while four (11%) stated that it had taken more than five years to obtain the HIV diagnosis. It is not possible to know whether these individuals could have been diagnosed with HIV earlier, in the absence of knowledge of the specific disease progression.

**WAITING TIME AND THE DISTANCE TO ANONYMOUS TESTING**

Since 2006, ‘STOP AIDS – Bøssernes hiv-organisation’ (‘STOP AIDS – the gay men’s HIV organisation’) has offered a quick test (CheckPoint) to MSM, in which people can drop in and take an HIV test and obtain an answer twenty minutes later. Since 2009, Cross-Over has also offered this service to the group of non-Danish-born citizens. The service has been established, amongst other reasons, in an attempt to make HIV testing more easily accessible to these groups (amongst whom the risk of being infected with HIV is greater than in the general population), and thereby contribute towards reducing the grey zone. For the general population in the Copenhagen area (i.e. those who are not MSM or non-Danish-born) a similar offer will be introduced this year at the STI clinic at Bispebjerg Hospital in Copenhagen Municipality.

It was therefore considered relevant in the survey to ask the late presenters how significant the waiting time for test results had been to them. As can be seen from table 3.8, however, the waiting time for the test results does not appear to have been of any decisive significance for most of the late presenters; only 5% stated that waiting time for the test results was of great importance. Overall, however, more than one in five stated that it had been of some degree of importance.

**TABLE 3.7. DURATION FROM FIRST CONTACT TO DIAGNOSIS (Q24) N=35**

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 1 year</td>
<td>26 (74%)</td>
</tr>
<tr>
<td>Between 1 and 5 years</td>
<td>5 (14%)</td>
</tr>
<tr>
<td>More than 5 years</td>
<td>4 (11%)</td>
</tr>
</tbody>
</table>

**TABLE 3.8. WAITING TIME FOR TEST (Q27.11) N=77**

<table>
<thead>
<tr>
<th>Importance Level</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance</td>
<td>60 (78%)</td>
</tr>
<tr>
<td>Some importance</td>
<td>13 (17%)</td>
</tr>
<tr>
<td>Great importance</td>
<td>4 (5%)</td>
</tr>
</tbody>
</table>

**TABLE 3.9. DISTANCE TO TEST (Q27.12) N=77**

<table>
<thead>
<tr>
<th>Importance Level</th>
<th>Number (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance</td>
<td>61 (79%)</td>
</tr>
<tr>
<td>Some importance</td>
<td>9 (12%)</td>
</tr>
<tr>
<td>Great importance</td>
<td>7 (9%)</td>
</tr>
</tbody>
</table>
There was no difference between the importance assigned to the difficult waiting period by Danish-born MSM and non-Danish-born late presenters in the above figures. This survey cannot confirm that establishing more CheckPoints would cause a significant number of late presenters to be tested earlier.

Respondents were also asked whether long distances to a location at which it was possible to obtain an anonymous test had had any influence on the late presentation, but this does not seem to have been of major importance either, although slightly more people (9%) felt that this was a factor of great importance to the lateness of the HIV test – see table 3.9.

**SUMMARY**

Almost half of the respondents were diagnosed with HIV during a hospital stay, suggesting that these individuals had become quite ill from their HIV infection before being diagnosed as infected. However, far fewer homosexual men than others were diagnosed with HIV during hospitalisation, which suggests that many of these men were encouraged to take a test by a doctor before they became ill. In all, nearly two out of three late presenters were tested for HIV at the suggestion of a doctor.

More than half of the respondents could recall having had symptoms of HIV, and about 60% of these were subsequently tested at the suggestion of a doctor. However, it is unclear how much time elapsed between the onset of the symptoms and the test. Three out of four were tested for HIV within a year of first consulting a doctor due to symptoms of HIV.

In summary, it can therefore be said that there are signs that health care professionals are attentive to the risk of HIV infection in these patients.

The fact that fewer homosexual men were diagnosed with HIV in hospital, but – to just as great an extent as the other groups – were encouraged to take the test by doctors, provides further confirmation that health care professionals are particularly aware of the risk of HIV infection among this group.

Neither the waiting time for test results nor the distance to a location where an anonymous test could be obtained appear to have been factors of major importance, and this survey cannot confirm that establishing more CheckPoints would result in a substantial number of late presenters being tested earlier.

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16. Information from Staff Specialist Susan Cowan, SSI.
17. ‘Other sexual identity’ includes bisexuals and those who indicated that they could not locate themselves in any of the listed sexual identities.
18. Those who checked ‘Elsewhere’ on the questionnaire had an opportunity to specify the location. Of the eight who checked ‘Elsewhere’, six stated that they were diagnosed HIV positive at an outpatient clinic, one answer could be interpreted as a home test, and the last wrote ‘ophthalmologist’.
19. The time of the test, in relation to the symptoms that respondents could recall, is not known. There seems to be two possible ways in which to interpret responses from respondents who said they did not consider an HIV test (two persons): either they went immediately to the doctor due to symptoms that they did not themselves associate with HIV, and the doctor then suggested taking an HIV test, or there is a temporal ‘lag’ in the answers – i.e. a period of time elapsed between the onset of symptoms and the time at which the person concerned consulted a doctor. In the case of the two respondents who answered that they had been considering an HIV test but were not tested, but who also say that they were tested at the suggestion of a doctor, there must presumably have been a temporal ‘lag’ between the symptoms and the test – otherwise the responses do not make sense! 20. After reviewing the answers to these two questions, an inconsistency has been revealed in the responses. Twelve people for example responded that they did not consider taking a test, but also stated that a nurse/doctor had suggested a test, and that they had therefore been tested. Three persons indicated that they had been encouraged to take a test, but refused – but also responded that they had been tested due to their symptoms. These discrepancies in the responses are probably due to a temporal ‘lag’ for the individuals in the answers (i.e. they had not initially considered taking a test, but were later encouraged to do so).
4. PERSONAL BARRIERS

In this chapter we will examine the more personal ‘barriers’ or ‘explanations’ that individuals have mentioned as factors which influenced the delay in being tested for HIV – or to put it another way: the individual’s considerations regarding the pros and cons of taking a test. The chapter is based on a number of questions from the questionnaire – see box 4.1.

Since the introduction of combination therapy in 1996, a series of studies has been undertaken of possible personal barriers to being tested for HIV, as mentioned in Chapter 1. In an article published in 2008, de Wit and Adams review 50 articles on what they term the ‘psychosocial barriers’ to HIV testing in high-income countries, and remark: “Studies that actually address barriers and facilitators of HIV testing in relatively well-adjusted individuals and communities in high-income countries are sparse.”

Although the various studies are difficult to compare, there are a number of explanations or barriers which are repeatedly mentioned as significant in most studies of ‘personal explanations’ or ‘psychosocial barriers’ to taking HIV tests:
- The individuals concerned did not regard themselves as being at risk
- Fear of discrimination and stigmatisation
- Fear of being HIV-positive

In the survey questionnaire, a number of questions were asked concerning barriers that might have influenced the individual against taking a test at an earlier stage. The inspiration for these questions was drawn from the literature, as well as from the qualitative interviews that were conducted before the questionnaire was drafted, and the Sex Life Survey.

It appears clear from the following that the experience of other countries with regard to personal barriers to HIV tests also applies to this survey. For 66% of the respondents, it was of some importance, or great importance, that they did not consider themselves at risk of being infected, 58% wished to avoid negative reactions if other people heard they were infected, and 50% responded that they were afraid to find out that they were infected.

Only two factors in the questions about barriers were rated in importance equal to or greater than the above: that you only visit the doctor if you are ill (83%), and lack of knowledge about the physical symptoms of HIV infection (59%).

BOX 4.1. FROM THE QUESTIONNAIRE
I was afraid to find out, that I had HIV (Q27.1)
I did not think, that I was at risk of getting HIV (Q27.2)
I did not want my friends or family to know that I had HIV (Q27.4)
I was in a steady relationship and did not think that I was at risk of getting HIV (Q27.5)
I wanted to avoid negative responses, if people got to know that I had HIV (Q27.6)
I did not know the physical symptoms of HIV (Q27.8)
I did not know that there is good treatment (combination therapy) for people with HIV (Q27.9)
I did not know, that I could get an anonymous test for HIV (Q27.10)
I did not know, that HIV-medication was free (Q27.14)
(To persons born outside Denmark):
I was afraid, that I could be expelled from Denmark, if I was diagnosed with HIV (Q27.15)
(To men, who have sex with men):
I was not open about my sexuality (Q27.16)
between Danish heterosexual men and women, Danish MSM and non-Danish-born respondents. It will be a challenge to get any person who do not believe himself or herself at risk of HIV infection to consider taking a test. It is not possible to reach this group of people through traditional campaigns, since a large proportion of the general population should in that case be encouraged to be tested for HIV.

In relation to encourage HIV test, it should also be noted that the number of late presenters among Danish-born heterosexual men and women is small compared to the total population of heterosexual men and women. If the guidelines of the National Board of Health from 2009 are adhered (= which groups should actively be offered a test), it could however be assumed that a number of the late presenters would be found earlier. In particular, anyone who has had sex with people in high-risk regions (or who has been posted abroad to such regions), and anyone with symptoms that are not immediately diagnosable, should be offered an HIV test.

With regard to people in the MSM group, the recommendation of the National Board of Health is that unless they consistently practise safer sex, they should be offered a test at least once annually.

In relation to the group of non-Danish-born persons, the National Board of Health recommends that people from Africa, Asia, South America and Eastern Europe should be offered an HIV test at their first contact with the health service, regardless of the reason for the contact. However, this recommendation would not necessarily reach the group of non-Danish-born persons who have lived in Denmark for many years before becoming infected with HIV (see Chapter 2), and who in this survey represented 40% of all non-Danish-born respondents22.

At the initial interviews, two categories of persons were identified who did not feel they had practised risky behaviour: those who had not practised a ‘defined’ risk behaviour (and had thus become infected through sex with a person who was not considered to have been at particular risk of being HIV infected), and those who downplayed or denied their risky behaviour.

The first group included a 49-year-old woman who was diagnosed with HIV in 2008 when her GP sent her for further tests because she had had a large number of unexplained abdominal infections. She said that she was not in a couple relationship at that time, but through partner notification was able to draw up a list of 18-20 sexual partners dating back to 1988. She thus had an average of around one sexual partner per year over the previous 20 years, and had almost always, according to her own account, used condoms. She had only agreed to have sex without a condom with a boyfriend she had back in 2006. They had used a condom for the first six months of their relationship, at which point her boyfriend had suggested that they stop using condoms. For the next six months that they were together they had sex without condoms, until the relationship ended. Her boyfriend was a ‘perfectly ordinary Danish man’, and the woman still believes it is unlikely that he was the person who infected her.

It would be difficult, on the basis of an objective assessment of this story, to claim that this woman practised behaviour that exposed her to a special risk.
The second group included a heterosexual man in his late fifties who was diagnosed with HIV in early 2009 during hospitalization. The person concerned did not himself believe that he had practised risky behaviour, but admits that he had had unprotected sex with three foreign women in a country where the prevalence of HIV among women who have sex with foreign men is relatively high. His own assessment was that they were not infected, and did not come from a ‘sexual environment’ (i.e. prostitution), as he had met them in completely different contexts.

In this case it would be easier to claim that this man practised behaviour that exposed him to a special risk.

Common to both of these individuals is that they were both diagnosed with HIV in connection with illness, neither of them believed they had practised risky behaviour – for which reason they did not feel the need to take an HIV test – and both were tested for HIV at the suggestion of a doctor.

The difference between them is that the woman did not practise sexual behaviour that could be characterised as risky, while the man, on the basis of an objective assessment, could be said to have done so. Today, in accordance with the guidelines of the National Board of Health, he would have been offered an HIV test – providing that he informed a doctor about his sexual behaviour.

Among Danish MSM 22% said the fact that they did not believe themselves to be at risk of becoming infected with HIV – see table 4.2. Of the 50 people who were in steady relationships at the time they were diagnosed with HIV, 38 responded to this question. The responses from these 38 people did not distinguish themselves from the group who were not in relationships. It is not possible on the basis of the information collected in the questionnaire responses to determine whether, of these 38, it was the respondents who infected their permanent partners, or the partners who infected the respondents, which may be considered to be a factor of significance to risk perception.

FEAR OF NEGATIVE REACTIONS

In surveys conducted in other countries, the fear of other people’s reactions if you are diagnosed with HIV has been found to be a recurring and significant factor which discourages some people from taking an HIV test, for which reason questions on this subject were also included in this survey.

As can be seen from table 4.3 and 4.4, almost 60% stated that the desire to avoid negative reactions if others found out that they were infected with HIV was of some importance, or great importance, in relation to their late presentation. The same high percentage responded that they did not wish their family or friends to know they were infected with HIV.

<table>
<thead>
<tr>
<th>TABLE 4.4. AFRAID OF NEGATIVE RESPONSES (Q27.6) N=82</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance 34 (41%)</td>
</tr>
<tr>
<td>Some importance 14 (17%)</td>
</tr>
<tr>
<td>Great importance 34 (41%)</td>
</tr>
</tbody>
</table>

had never been tested, 48% replied ‘I have not been at risk’, while among those who had not been tested recently, 63% gave the same answer.

Although the data are not directly comparable, it nonetheless appears that more late presenters than Sex Life Survey respondents assessed that they had in fact practised risky behaviour, but that other factors had discouraged them from taking a test. However, as mentioned in Chapter 2, there is no correlation among the MSM group between unsafe sex behaviour and HIV testing – those who practised unsafe sex were not tested more frequently than those who did not have unsafe sex.

Respondents were also asked whether they had been in a steady relationship, and therefore did not believe themselves to be at risk of becoming infected with HIV – see Table 4.2. Of the 50 people who were in steady relationships at the time they were diagnosed with HIV, 38 responded to this question. The responses from these 38 people did not distinguish themselves from the group who were not in relationships. It is not possible on the basis of the information collected in the questionnaire responses to determine whether, of these 38, it was the respondents who infected their permanent partners, or the partners who infected the respondents, which may be considered to be a factor of significance to risk perception.
There were no significant differences in the responses from Danish-born heterosexual men and women, Danish-born MSM and non-Danish-born respondents.

Despite many years of information campaigns on HIV/AIDS, as well as the absence of a risk of infection through normal social contact, and the fact that HIV is no longer regarded as a fatal disease, a major taboo still attaches being HIV infected. In the conclusion of a survey conducted by the AIDS Foundation in 2009 on Danish attitudes to PLHIV, it is stated:

“Despite the fact that all of the respondents would hope to be met with tolerance and openness if they were themselves infected with HIV, the vast majority fears social isolation and the prejudices of other people. Most would tell only a few other people about their illness.”

Most people thus regard HIV as “a special disease”.

The stigmatisation of PLHIV since the mid-1980s (see for example Jonathan Mann 1987) has been described as one of the biggest obstacles to the prevention of HIV. This stigmatisation prevents PLHIV being open about their HIV status, it discourages people from being tested, it causes discrimination against PLHIV, and finally, it causes psychological stress to those who are HIV-positive.

This survey can confirm that the stigmatisation of PLHIV remains a highly significant factor in discouraging individuals from seeking an HIV test.

Most remarkable is perhaps the fact that among Danish-born MSM, no less than 67% indicated that avoiding the negative reactions of other people to their HIV positive status was a factor of some importance, or great importance, while only 33% said it was of no importance (not shown in table).

The Sex Life Survey asked a similarly phrased question concerning the reasons for not getting a test, to which one of the response options was: ‘I wish to avoid negative reactions if people learn I am HIV positive’. 8% of those who had never had a test checked this response option.

The difference in the responses in the two surveys is remarkable, and strongly indicates that fear of other people’s reactions was an important factor for the MSM late presenters.

Breaking down the stigma of HIV infection will require long-term, multi-pronged efforts. The stigmatisation of PLHIV is associated with the idea that HIV is ‘a special disease’ linked to taboo sexual behaviours, as well as with the fact that it is contagious, and that only very few PLHIV are open about their HIV status. If more PLHIV were open about their HIV status, it would not in itself remove the stigma, but would help to diminish its effect. As the HIV and Living Conditions Survey puts it:

“... a situation in which more people have the courage to be open about their HIV status without fearing the reactions of the people around them will not come about by itself. The reactions of other people are probably due to an exaggerated fear of the risk of becoming infected in contexts other than sex, but also to the fact that HIV is still regarded as “a special disease”, associated with taboo sexual behaviour, death and contagious infection – a perception which causes many people, and even some health care professionals who are not accustomed to working with HIV-positive people, to react inappropriately. It is therefore recommended that broad campaigns should be conducted, focusing on these two elements: the exaggerated fear of transmission, and the stigma of HIV.”

In the autumn of 2008, at the instigation of the Living Conditions Survey, the National Board of Health carried out an anti-stigma campaign entitled ‘Bliv fri for fordomme’ (‘Drop the prejudices’).

**AFRAID OF FINDING OUT THAT YOU ARE HIV POSITIVE**

The statement ‘I was afraid of finding out that I was HIV positive’ probably covers a multitude of different feelings and concerns: fear of facing up to reality (better to live in ‘blissful ignorance’); concern about who to tell, or not to tell; concern about how your life is likely to change; worry about
to get a partner if you are not in a relationship, or if you are, that your partner may leave you; concern about whether you will be able to keep your job; fear of how others will see you, etc. But being afraid to find out that you may be HIV positive also implies that there must have been an awareness of the risk of infection.

It is striking that this type of question still receives such a strong reaction both in the foreign surveys and in this one, in which half of the respondents indicated that it was a factor of some importance, or great importance, in explaining why they had not previously been tested (see table 4.5). In the MSM group, 63% responded that this fear was a factor of some importance, or great importance, in discouraging them from seeking an earlier test (although the difference between the groups is not significant), and here again it is interesting to compare this figure with the Sex Life Survey, which asked a similar question, namely whether “I am afraid of getting an HIV positive result” was among the reasons why the respondent did not get tested.

Among the MSM individuals in the Sex Life Survey who had never been tested, 13% stated that they were afraid the result might be positive. Although, as mentioned earlier, the surveys cannot be directly compared, we once again find a remarkable difference between the responses to this survey and those in the Sex Life Survey, which suggests that the fear of finding out that you might be HIV positive could be a major contributory factor in explaining why many MSM are late presenters.

LACK OF KNOWLEDGE OF THE PHYSICAL SYMPTOMS

The questionnaire asked whether lack of knowledge of the symptoms of HIV had influenced the respondents not to get tested earlier (see table 4.6). 59% indicated that this was a factor of some importance, or great importance. There were no significant differences when the respondents were broken down by sexual identity or place of birth.

It is perhaps not surprising that heterosexual men and women do not possess special knowledge of the symptoms of HIV, but it seems more surprising that this also applied to a large group of Danish-born MSM. Over half of these indicated that a lack of knowledge of the symptoms was a factor of some importance, or great importance, in explaining why they had not previously taken a test. One might otherwise suppose that the MSM group, among whom HIV is more frequent than among heterosexual men and women, and who are exposed to ongoing, targeted information campaigns, would be more familiar with the symptoms of HIV.

There were no significant differences between the groups when asked whether knowledge of the symptoms affected whether they recalled or did not recall having symptoms.

It is not possible to say whether a better understanding of the symptoms of HIV might have influenced those for whom this was a factor of importance to take a test earlier, but as described in Chapter 3, just over 60% of those who recalled having symptoms of HIV were in fact tested at the suggestion of a nurse or doctor – although it is unclear how long a period of time elapsed between the onset of symptoms and the test.

<table>
<thead>
<tr>
<th>TABLE 4.5. AFRAID OF FINDING OUT (Q27.1) N=83</th>
<th>TABLE 4.6. DID NOT KNOW HIV SYMPTOMS (Q27.8) N=80</th>
<th>TABLE 4.7. DID NOT KNOW ABOUT GOOD TREATMENT (Q27.9) N=78</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance</td>
<td>No importance</td>
<td>No importance</td>
</tr>
<tr>
<td>Some importance</td>
<td>Some importance</td>
<td>Some importance</td>
</tr>
<tr>
<td>Great importance</td>
<td>Great importance</td>
<td>Great importance</td>
</tr>
<tr>
<td>42 (51%)</td>
<td>33 (41%)</td>
<td>42 (54%)</td>
</tr>
<tr>
<td>17 (21%)</td>
<td>18 (23%)</td>
<td>12 (15%)</td>
</tr>
<tr>
<td>24 (29%)</td>
<td>29 (36%)</td>
<td>24 (31%)</td>
</tr>
</tbody>
</table>
LACK OF KNOWLEDGE OF THE GOOD TREATMENT AVAILABLE

Until 1996, HIV was by definition a fatal disease, but since the introduction of the combination treatment in that year, the medical treatment of HIV has enjoyed considerable success. HIV is thus no longer considered a fatal disease if you receive treatment before your immune response has been weakened.

The questionnaire asked whether lack of knowledge of the good treatment options available (combination therapy) was among the reasons explaining why the respondents had not been tested earlier. Somewhat surprisingly – considering the substantial amount of publicity given to the success of the treatments – almost half of the respondents indicated that lack of knowledge of the treatments available had been a factor of some importance in explaining why they had not been tested earlier, while one-third indicated that it had been of great importance – see table 4.7.

There were no significant differences in this area between the responses of the groups of Danish-born heterosexual men and women, Danish-born MSM and non-Danish-born respondents.

It is remarkable that knowledge of the good treatments available is not more common among MSM, where the prevalence of HIV is high, and where one might assume that knowledge of HIV and of the treatment of HIV was much greater than among ‘ordinary’ Danish heterosexual men and women.

The questionnaire also offered the response option: ‘I did not think that knowing my HIV status would be of any benefit to me’. 77 respondents both checked this response and indicated that they were aware of the good treatment possibilities. In 27% of these responses, the respondents selected ‘some importance’ or ‘great importance’ to both questions. It may be that these respondents, if they had known of the good treatment possibilities available, would have been more likely to have seen some benefit in knowing their HIV status.

DID NOT KNOW THAT TREATMENT WAS FREE

For the majority of the Danish-born respondents, the question of possible payment for treatment had no influence – although one cannot help noticing that 21% of the Danish-born heterosexual men and women indicated that this factor was important (and all five in this response category indicated that it was of ‘great importance’) – see table 4.8 and 4.9.

But the most remarkable result is the large proportion of the group of non-Danish-born respondents who indicated that not knowing that treatment was free was an important factor in explaining why they did not seek to take a test earlier. Almost 60% responded that this factor was important, and the vast majority indicated that it was of great importance.

The numbers are small, but it was clear from the focus group interviews held at ‘Cross-Over’, before the questionnaire was drafted, that many people here also shared the view that non-Danish-born people did not realise that treatment for HIV was free in Denmark. One of the professionals initially interviewed, who works with ethnic minorities in Denmark, also took the same view.

<table>
<thead>
<tr>
<th>TABLE 4.8. DID NOT KNOW TREATMENT WAS FREE (Q27.14) N=75</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance</td>
</tr>
<tr>
<td>Some importance</td>
</tr>
<tr>
<td>Great importance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TABEL 4.9. DID NOT KNOW TREATMENT WAS FREE (Q27.14) N=75</th>
</tr>
</thead>
<tbody>
<tr>
<td>----- BORN IN DENMARK ----- HETEROSEXUAL MEN AND WOMEN ----- HOMOSEXUAL MSM BORN OUTSIDE DENMARK</td>
</tr>
<tr>
<td>No importance</td>
</tr>
<tr>
<td>Some or great importance</td>
</tr>
<tr>
<td>P=0.003</td>
</tr>
</tbody>
</table>
DID NOT KNOW THE TEST COULD BE ANONYMOUS

Ever since it became possible to test for HIV (1985), it has been part of Danish AIDS policy to allow anyone to be tested anonymously. The reason for this was the desire to ensure that as many people as possible (of those at risk of being infected) would choose to be tested in spite of the stigma to which the individual might be exposed in the event of a positive test result.

As shown in table 4.10, just over one-quarter of respondents indicated that lack of knowledge of the anonymous test option was among the reasons why they did not take an earlier test. But as can be seen from table 4.11, there were significant differences between Danish-born and non-Danish-born late presenters in this area. Almost six out of ten of the latter indicated that lack of knowledge of the anonymous test option had been an important factor in their late presentation, and the majority of these indicated that it had been of great importance. As mentioned, this issue was identified as crucial during the focus group interviews at ‘Cross-Over’.

Although the figures are small, they provide reason to consider enhanced information efforts towards the group of ethnic minorities in Denmark.

FEAR OF BEING DEPORTED FROM DENMARK

No restrictions apply to residence permits in Denmark on the basis of whether or not the applicant is an HIV-positive. However, this was mentioned both by participants in the focus group interviews at Cross-Over and by the interviewed professional who works with ethnic minorities in Denmark as an issue of central importance to many non-Danish-born people when the possibility of taking an HIV test is being considered. The questionnaire therefore included a question for late presenters who were not born in Denmark, asking whether concern at the possibility of being deported from Denmark had been a factor of importance in the reasons why they did not take an earlier test.

Only half (12 out of 25) of the non-Danish-born respondents answered the question. There does not appear to be any correlation between the length of time the respondents had been in Denmark and whether or not they chose to answer the question. Of the thirteen who did not answer the question, five had been in Denmark for seven years or less, while eight had been in the country for ten years or more.

Of the twelve who answered this question, eight indicated that fear of deportation had not been among the reasons why they were not tested earlier, and only four indicated that it had been of importance (one stated that it had been of some importance, and three that it had been of great importance). The four who stated that it was a factor of importance had resided in Denmark for between seven and sixteen years. The survey cannot thus confirm the fear of deportation which was mentioned as a factor during the initial interviews.

But as this was mentioned so often in the initial interviews with professionals and people affected by HIV it is worth considering taking action on this topic.

LACK OF OPENNESS ABOUT HOMOSEXUALITY OR BISEXUALITY

When you belong to a sexual minority that has

<table>
<thead>
<tr>
<th>TABLE 4.10. DID NOT KNOW ABOUT ANONYMOUS TEST (Q27.10) N=77</th>
<th>TABLE 4.11. DID NOT KNOW ABOUT ANONYMOUS TEST (Q27.10) N=77</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance 56 (73%)</td>
<td>----- BORN IN DENMARK -----</td>
</tr>
<tr>
<td>Some importance 8 (10%)</td>
<td>HETEROSEXUAL MEN AND WOMEN</td>
</tr>
<tr>
<td>Great importance 13 (17%)</td>
<td>HOMOSEXUAL MSM</td>
</tr>
<tr>
<td></td>
<td>BORN OUTSIDE DENMARK</td>
</tr>
<tr>
<td>No importance 19 (79%)</td>
<td>7 (41%)</td>
</tr>
<tr>
<td>Some or great importance 5 (21%)</td>
<td>6 (17%)</td>
</tr>
<tr>
<td></td>
<td>10 (59%)</td>
</tr>
<tr>
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<td>P=0.004</td>
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been subject to taboo and secrecy, questions of openness play a major role, and the group of MSM were therefore asked whether a lack of openness about sexuality had influenced them against being tested earlier.

In 2009, the Danish National Association for Gays and Lesbians\(^4\) (LBL) published a living conditions survey (Gransell & Hansen, 2009) which amongst other things examined the question of openness among homosexual and bisexual men. The LBL survey found that 7% of homosexual men had never spoken to anyone about their sexual orientation, and that the same was true of 21% of bisexual men. The question of openness towards one’s family was also explored, and 57%-86% of homosexual men said they were open about their sexual orientation towards their families, while only 43%-51% of bisexual men in the LBL survey were open in this context. Homosexuality and bisexuality are thus subjects which remain shrouded in silence to a certain degree.

In the present survey, 31 men identifying themselves as homosexual answered the question about whether a lack of openness had contributed to the late test, and of these, 27 (87%) indicated that it had no influence — see table 4.11.

Nine men identifying themselves as bisexual answered the question, only one of whom responded that openness about sexuality had no influence on the lateness of the HIV test. The eight remaining bisexual men were equally divided between indicating that the lack of openness was of some importance or great importance.

This distribution is not surprising. As shown in the survey of the Danish National Association for Gays and Lesbians, there are three times as many bisexual men as gay men not living openly with their sexual identity — and many bisexual men fear that a positive test could reveal this life.

### SUMMARY

There are four themes that stand out when we examine the ‘personal barriers’ which have had the greatest effect in influencing the respondents not to take an earlier test:

- **Not believing oneself to be at risk of infection**
- **Fear of negative reactions from other people**
- **Fear of being HIV-positive**
- **Lack of knowledge of the physical symptoms of HIV infection**

These themes were important to all groups of respondents — no significant differences were observed between Danish heterosexual men and women, Danish MSM and non-Danish-born respondents.

If we compare the data from late presenting MSM with data from the Sex Life Survey (non-infected MSM), three trends clearly emerge: it appears that more late presenters than non-infected MSM assessed that they had in fact practised risky behaviour, but that other factors had discouraged them from being tested; that the fear of facing negative reactions is greater among late presenters; and that late presenters are more likely to be afraid of discovering that they are HIV positive.

The non-Danish-born late presenters distinguished themselves significantly from the Danish-born respondents in relation to two themes which had an influence on their late presentation: not knowing that treatment was free, and not knowing that you could be tested anonymously. Here it should be noted that the non-Danish-born respondents in this survey had on average lived in Denmark for more than eleven years, and that there must therefore be an under-representation of non-Danish-born late presenters who have lived in Denmark for a shorter period of time – among whom, presumably, there is even less awareness of

### TABLE 4.11. NOT OPEN ABOUT SEXUALITY (Q27.16) N=40

<table>
<thead>
<tr>
<th></th>
<th>HOMOSEXUAL MEN</th>
<th>BISEXUAL MEN</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>No importance</td>
<td>27 (87%)</td>
<td>1 (11%)</td>
<td>28 (70%)</td>
</tr>
<tr>
<td>Some importance</td>
<td>0 (0%)</td>
<td>4 (44%)</td>
<td>4 (10%)</td>
</tr>
<tr>
<td>Great importance</td>
<td>4 (12%)</td>
<td>4 (44%)</td>
<td>8 (20%)</td>
</tr>
<tr>
<td><strong>P=0.000</strong></td>
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</table>
the possibility of obtaining anonymous testing and free treatment. In the initial interviews it was indicated that fear of being deported from Denmark was also a factor of great importance to many people in this group, but the questionnaire survey could not confirm this.

It is also worth noting that 46% of respondents indicated that the fact they did not know that good treatments for HIV were available was a factor of some or great importance in discouraging them from taking the test at an earlier stage. Here, too, no significant differences were observed between Danish heterosexual men and women, Danish MSM and non-Danish-born respondents.

21. Terms are employed such as: fear of being diagnosed; fear of the disease itself; fear of learning that one is HIV positive; fear of being HIV-positive.

22. This figure is however hardly representative of all non-Danish-born late presenters. The respondents in this survey had lived in Denmark for quite a number of years, and there is apparently an under-representation of persons who had lived in Denmark for a shorter period of time.

23. Both the questions and the possible answers are phrased differently. In the Sex Life Survey, respondents were ‘only’ asked to check an answer if they did not believe they had been at risk – in this survey, respondents could qualify their response according to whether this factor was of ‘some’ or ‘great’ importance. Moreover, the premise for answering was different for the two groups. The responses in the Sex Life Survey were provided by men who did not believe themselves to be HIV positive (and who may not have practised risky behaviour), while the data in this survey has been supplied by men who knew they were HIV positive. Despite these caveats, the difference between the responses is so great that there are grounds to consider whether this fear of finding out that you are HIV positive may be much greater among late presenters than among MSM in general.

24. The Danish National Association for Gays and Lesbians has now become the Danish National Organisation for Gay Men, Lesbians, Bisexuals and Transgendered Persons (LGBT Danmark).
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