

HIV- Quality of Life Survey





***The co-operative body of the Nordic umbrella-
organisations for HIV-positive people***

Quality of life survey

Quality of life survey is a questionnaire assessing quality of life of HIV-positive people in the Nordic countries. The objective of the study was to get an overall picture of how people living with HIV in the Nordic countries look upon their lives.

The study has been made possible by support from Bristol-Myers Squibb. The company has no rights to the results data and has not influenced the content of the study. NordPol, co-operative body of the Nordic umbrella organizations for HIV-positive people, owns the rights to the results of the survey.

This is a non-scientific survey. The aim was, for the first time, to find out more about the living conditions for people living with HIV in the Nordic countries. The questionnaire consisted of 49 questions which took approximately 20 minutes to answer. This report is just a sample of the final report where NordPol will compare the results with data from other surveys done in Denmark and Norway. The final report will be published in time for the World Aids Conference in Mexico in July 2008.

The Quality of life survey was carried out between September 2006 and May 2007 in Finland, Iceland and Sweden. The survey was conducted both on-line (www.hivhealthsurvey.com) and as a paper questionnaire.

There were banners with a link from websites for example from the self-help groups in Sweden, Finland and Iceland. In Finland the paper questionnaires were sent for further distribution to some HIV-out-patient clinics and Aids Councils. The questionnaires were distributed at Positiiviset ry's drop-in centre and peer support courses. In Sweden the survey was sent to all members in the Swedish self-help groups that the organization have a postal address to. It was also possible to find the forms at the office of Noaks Ark/Redcross in Stockholm. In Iceland the form was distributed on a meeting for HIV-positive people and on www.aids.is.

The survey was answered by 823 of the approximately 6000 living HIV-positive people in these three countries.

Helsinki, Reykjavik and Stockholm, November 2007
The working-committee for NordPol

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About this report

This report is a smaller version of the comprehensive report which will be published later and is intended to give a first glimpse on the overall picture of how people living with HIV/Aids in Finland, Iceland and Sweden. The complete report will be available and presented in late spring 2008.

In this survey we have pointed out what we refer to be the most important questions on the agenda in our work to get better living conditions for people living with HIV/Aids in the Nordic countries.

The report will give a background on the socio-demographic data of the respondents, then follows an analyze that includes 20 of the 49 questions in the survey. If you are interested in reading the full survey, please don't hesitate to contact NordPol.

We have focused on four targets:

- Telling people about your HIV-status
- The respondents own health
- What they think about their contact with health service and the nature of this contact
- Sex life and sexual issues

We have chosen to make some changes, not in the data, but in the presentation of the data. The reason for that is that we want to compare some of the questions more thoroughly and merge data from several questions in one figure. No data has been cut out or changed in the original data file.

General questions

Socio-demographic

The survey was answered by 823 people with this socio-demographic spread

	Frequency
Total	823
Country	
Sweden	572
Finland	174
Iceland	24
Age	
Younger than 25 years	36
25 years – 34 years	124
35 years - 44 years	287
45 years - 54 years	223
55 years or older	139
Sex	
Male	646
Female	172
Sexual identity	
Heterosexual	216
Homo- or bisexual	512
Year of receiving diagnosis of HIV-positive	
1987 or earlier	135
Between 1988 and 1997	258
Between 1998 and 2002	177
Between 2003 and 2005	146
Later than 2005	78

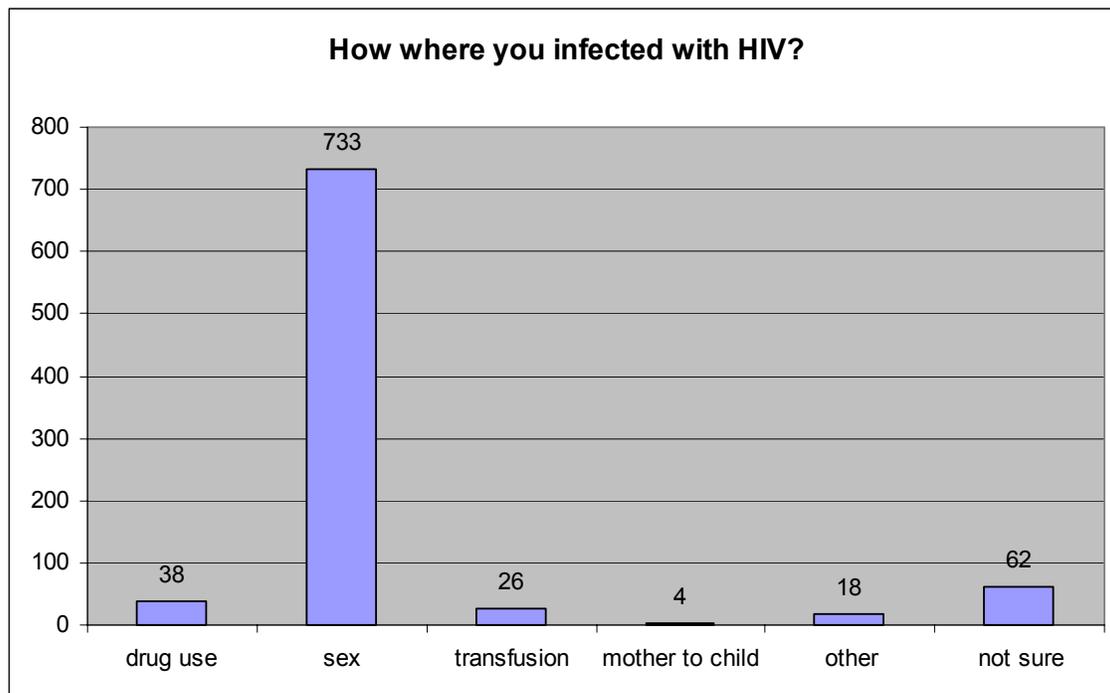
The total number of people living and infected with HIV:

Sweden	4 500
Finland	1 800
Iceland	270

The majority of the respondents in this study are men from Sweden. Half of the respondents are in the middle age (between 35 and 45) with work and partners. Only a few have children. The women in this study identify themselves as heterosexual.

- The main group in this survey is homosexual men (62%)
- In Finland a third of the respondents (36%) identify themselves as heterosexual. In Sweden and Iceland the corresponding number is 25%
- 14 % of the respondents, younger than 35 years of age, identify themselves as bisexual
- Most of the respondents became infected through homosexual contact

See the numbers in the chart below

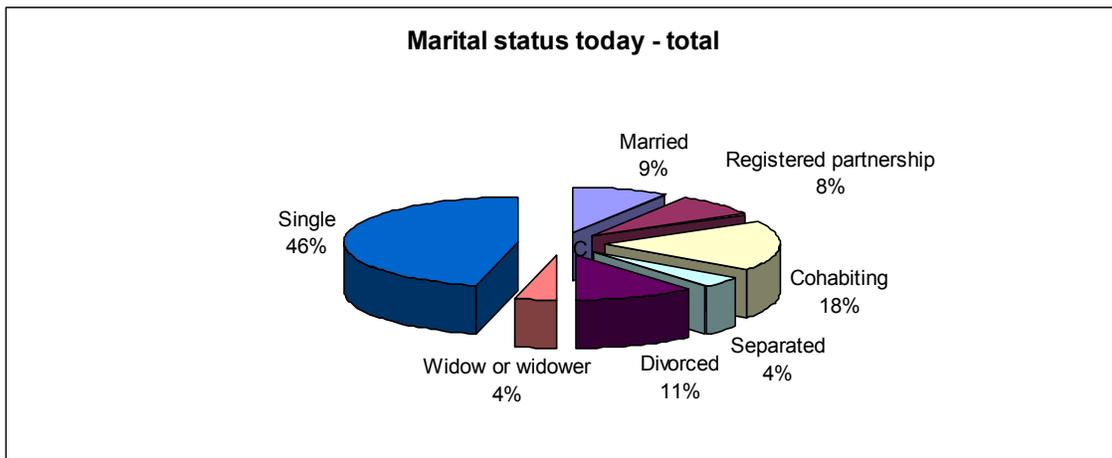


Permanent partner and marital status

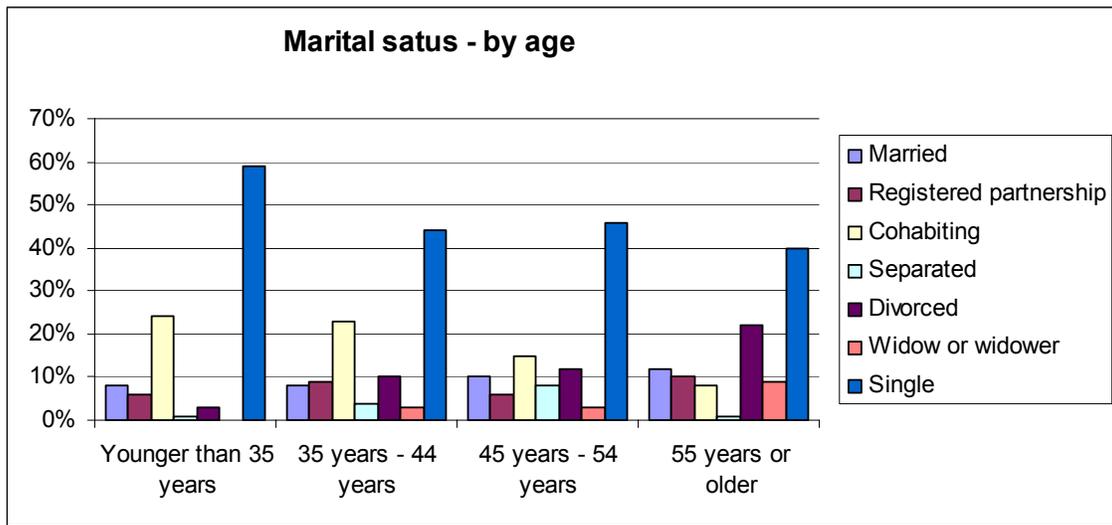
In all three countries half of the respondents have or have had a permanent partner. As you can see in the diagram below, individuals under 44 years of age have more permanent relationships than individuals over 45 years of age.



If you compare the figures from the diagram above to those below you can see that many of the respondents are single but still answer that they have a permanent partner. The reason might be that the respondents who call themselves single perhaps have a permanent partner but they are not married or cohabiting.



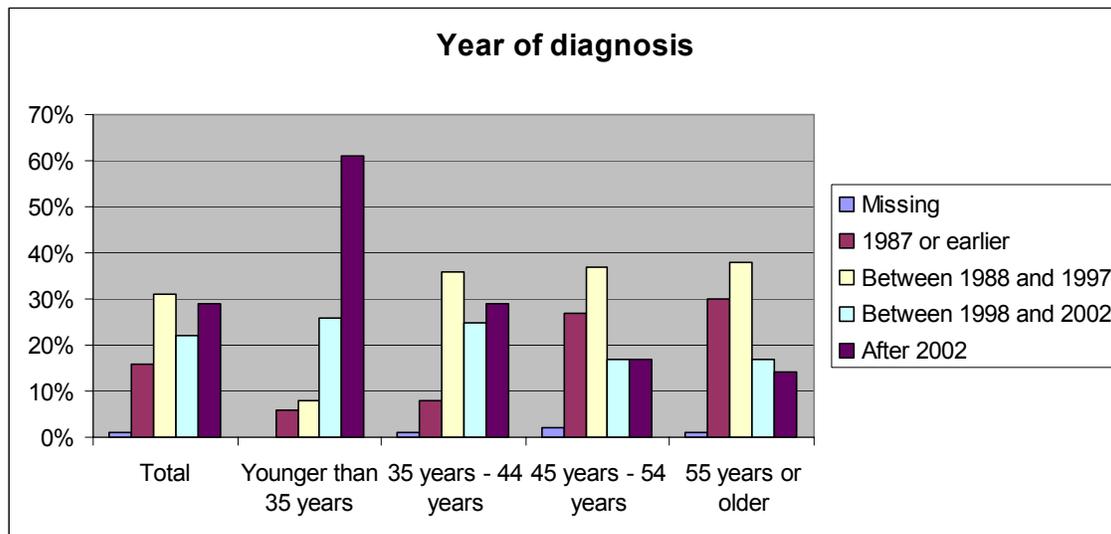
The most common marital status is to be single, irrespective of the age of the respondents. One can also see that it is usually younger people who live together.



The diagnosis

When one look at what year the respondents received their diagnose of HIV, one can see that it is quite uniformly distributed. The smallest group being “diagnosed 1987 or earlier” is only 16 percent. The reason why this group is so small might be because the individuals diagnosed before 1990 might have died in AIDS.

It is no surprise that those who are “younger than 35 years” have got their diagnosis after 1998 but still 6 percent of people younger than 35 years old have received the diagnosis in 1987 or earlier. Altogether 14 percent of the younger respondents got the diagnosis before the new combined medication was introduced to the Nordic countries in 1996.



Education, employment and financial situation

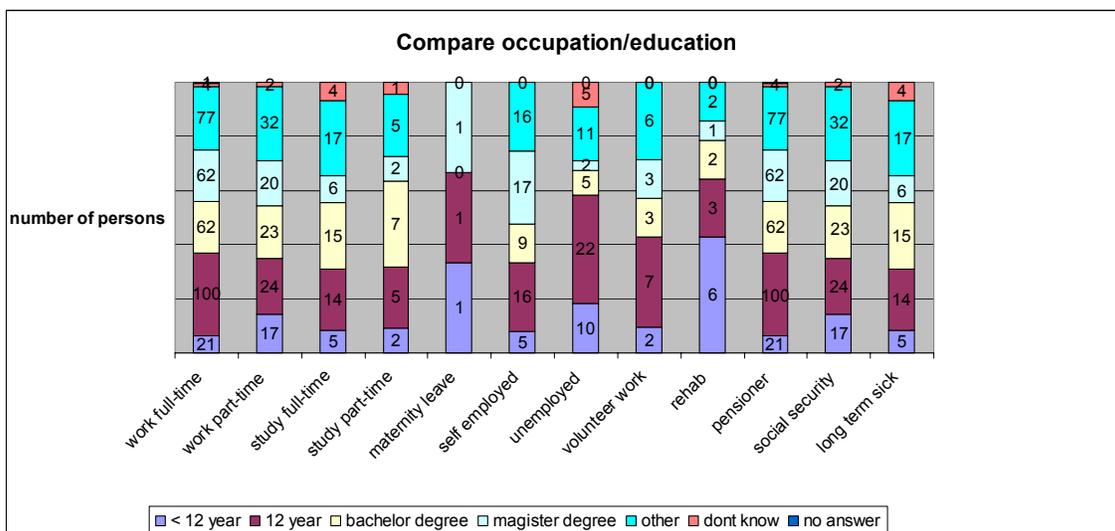
The respondents seem to have achieved good level of financial situation and formal education. Half of the respondents assess their financial situation as good or very good. The level of formal education is high and many of the respondents have higher levels of education.

Every second respondent is employed, the majority of the respondent work full- or half-time including 40 percent who work full-time.

Comparison occupation/education

<i>occupation at the moment</i>	<i>< 12 year</i>	<i>12 year</i>	<i>bachelor degree</i>	<i>master degree</i>	<i>other</i>	<i>don't know</i>	<i>no answer</i>
work full-time	21	100	62	62	77	4	1
work part-time	17	24	23	20	32	2	0
study full-time	5	14	15	6	17	4	0
study part-time	2	5	7	2	5	1	0
maternity leave	1	1	0	1	0	0	0
self employed	5	16	9	17	16	0	0
unemployed	10	22	5	2	11	5	0
volunteer work	2	7	3	3	6	0	0
rehab	6	3	2	1	2	0	0
pensioner	21	100	62	62	77	4	1
social security	17	24	23	20	32	2	0
long term sick	5	14	15	6	17	4	0

Below are the differences more visually



If one analyze and compare the socio-demographic figures one will see that the male respondents have better financial situation than the females. Only 34 percent of female assess their financial situation as good or very good compared to 52 percent of the male respondents. Homosexual assess their financial situation to be a little bit better than heterosexuals.

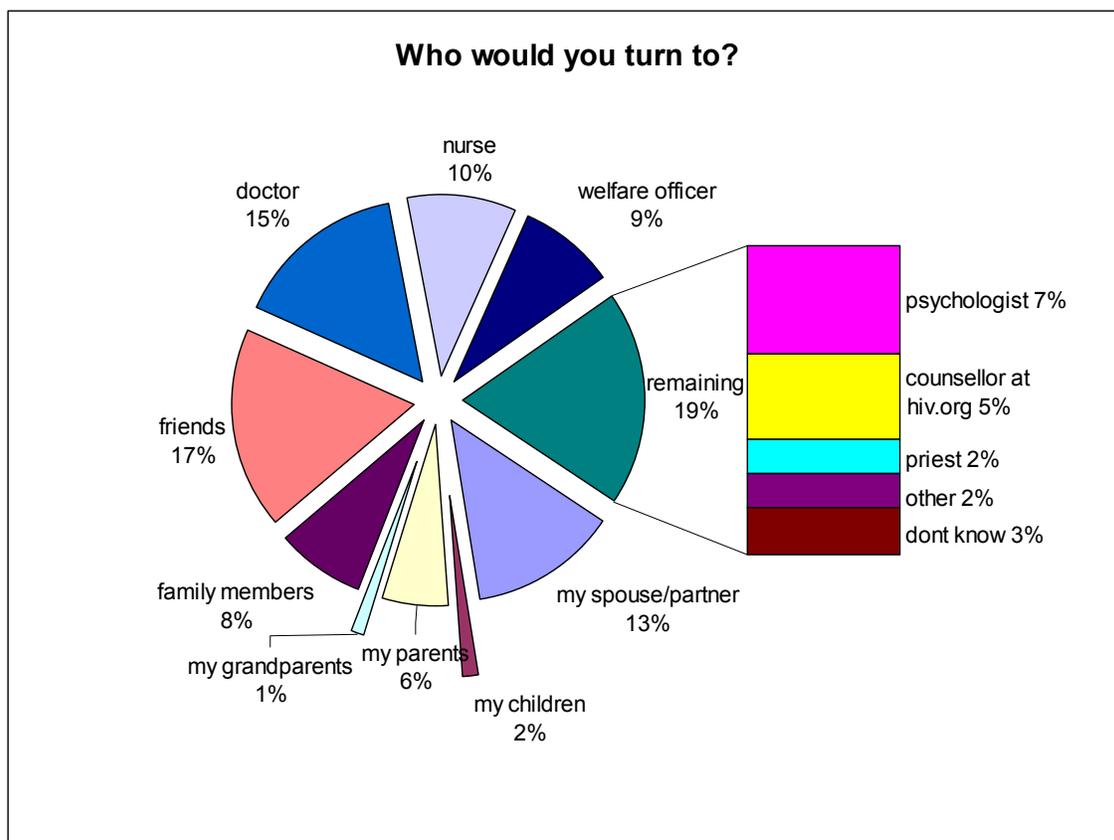
One can also see that the earlier a person is diagnosed, the more the disease has affected his or her ability to work or study. Nearly half says that they would start working if they receive extra support.

Social life

The solitude is a problem at all life stages. The survey shows that 59 percent of respondents feel themselves alone often or once in a while, even though they prefer to be together with others.

The respondents who have personal problems often turns to friends, spouse/partner or the doctor at the HIV-out-patient clinic. The younger respondents are often more disposed to turn to friends, spouse or partner than the older respondents.

The majority of the respondents have no children but 58 percent of the heterosexuals have children.

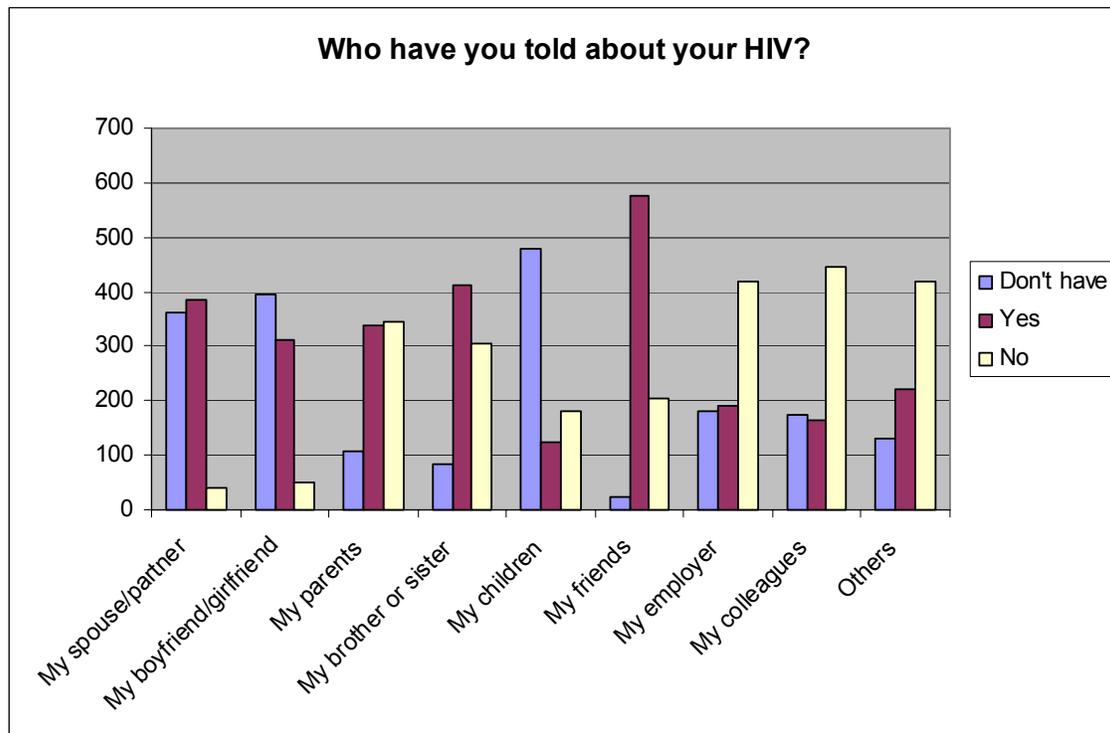


Sometimes the respondents feel isolated and sense that other people keep a physical distance to them and are afraid of them. Fortunately a majority of respondents feels that they now have more contact with family and friends.

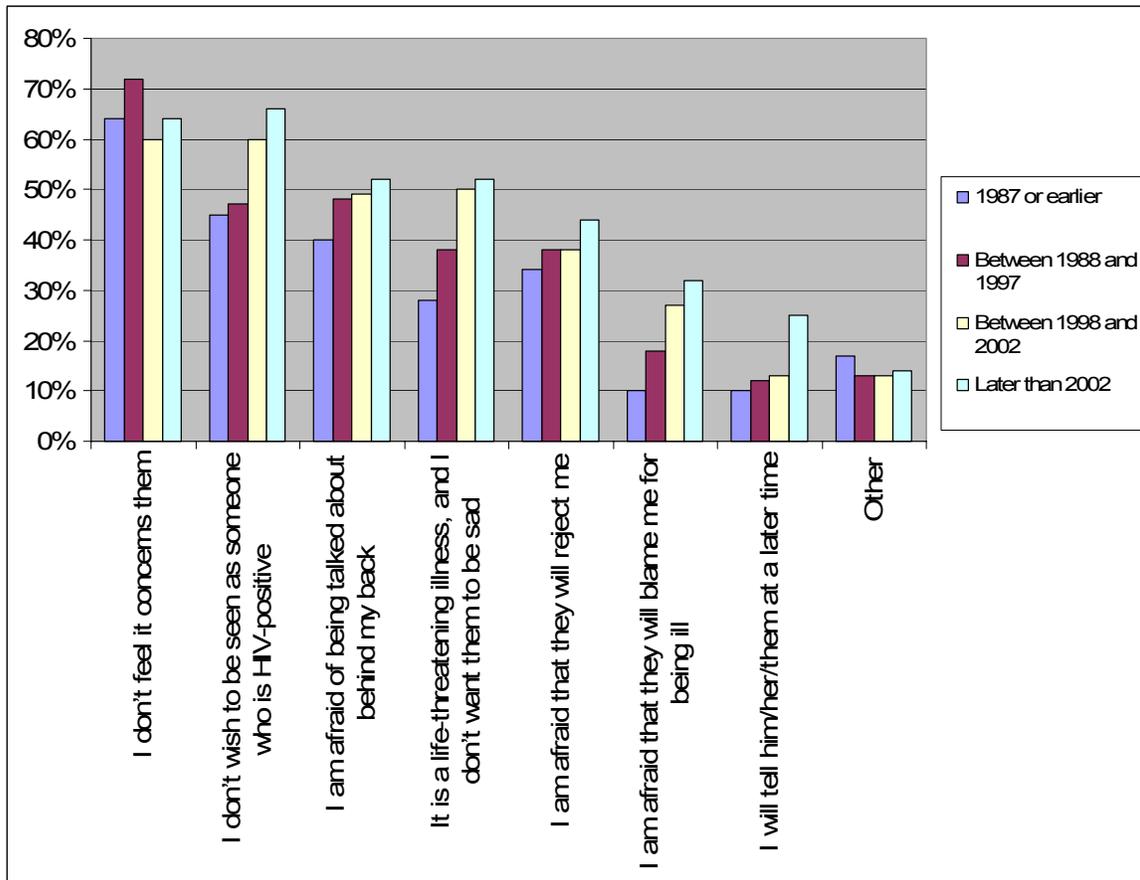
Telling people about your HIV-status

Many people find it difficult to tell their family, friends, employer and colleagues that they are HIV-positive. Most people think twice before they tell anyone. Some of the respondents have experienced that they can help others to make their choices.

Most of the respondents have told their spouse, partner, boyfriend or girlfriend that they are HIV-positive. The family knows to a greater extend than work colleagues.



The reason why people choose not to tell is mostly because they feel that it does not concern other people. They do not want to be seen as HIV-positive. This is a rather big problem because many are afraid of how people are going to act. Some feel that they do not want to upset their loved ones because it is a life-threatening disease.



The respondents own health and care taking

In all countries over half of the respondents consider their health is either good or very good. Over 60 percent of the respondents who are younger than 35 years of age assess their health either good or very good and in the group of 45-54 years of age the corresponding number was 47 percent.

There were no differences among female, male, heterosexual or homosexual regarding their health being bad or very bad.

In the survey there were questions about how people take care of themselves today and before they got their diagnosis. In total the respondents answered that they nowadays eat healthier food, more fruit and take vitamins. Nevertheless more of the respondents take sleeping pills after they got the diagnosis. People still smoke almost as much as they did before but they do not drink as much alcohol as they used to.

About the contact with health service and the nature of this contact

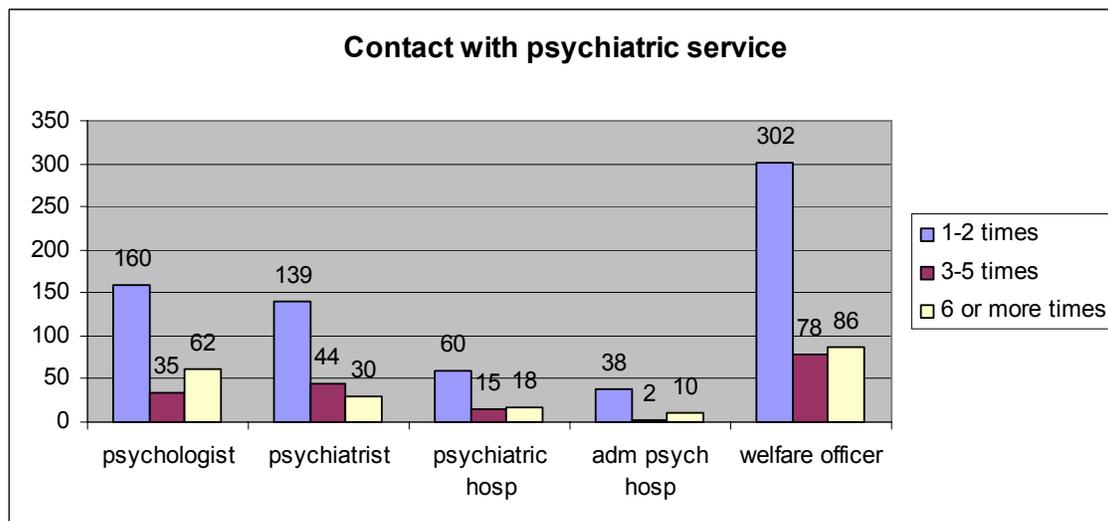
In this chapter we separated the contact with psychiatric service and the HIV-out-patient clinic. One important issue in this part is that the governmental health service is organized differently in the three compared countries. This fact can therefore result in high level of “not agree”, missing or “don’t relevant” to some questions. It can also lead to a high response due to that.

For example:

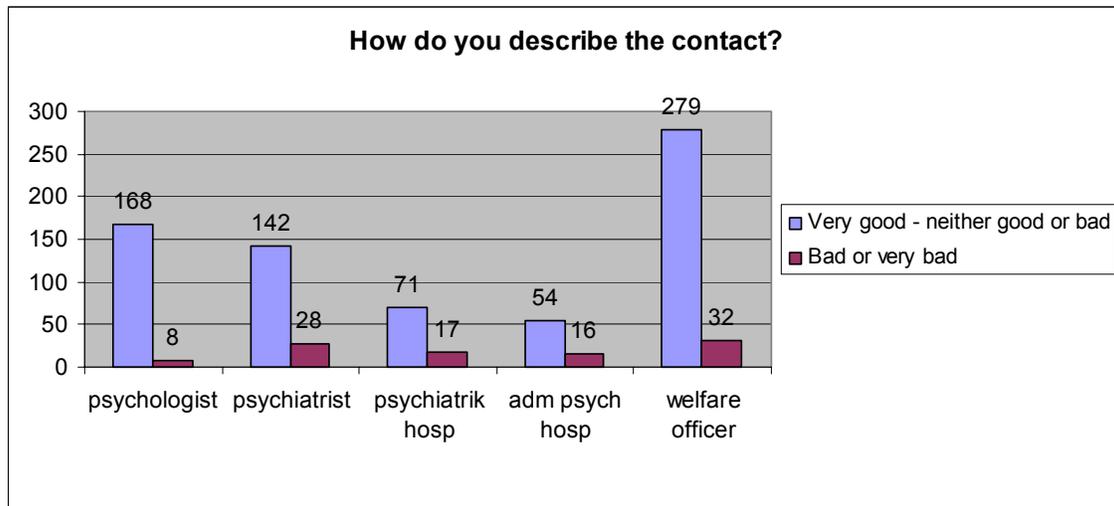
- In Iceland the nurse often is not a part/included in the medical treatment
- In Sweden all patients are supposed to visit a welfare officer when they get a positive test result. The welfare officers are often directly connected to the HIV-out-patient clinic and are therefore easy to make an appointment with
- In Finland there are no welfare officers at HIV-out-patient clinics. Usually people meet doctor and nurse when they go to HIV-out-patient clinic

Contact with the psychiatric service

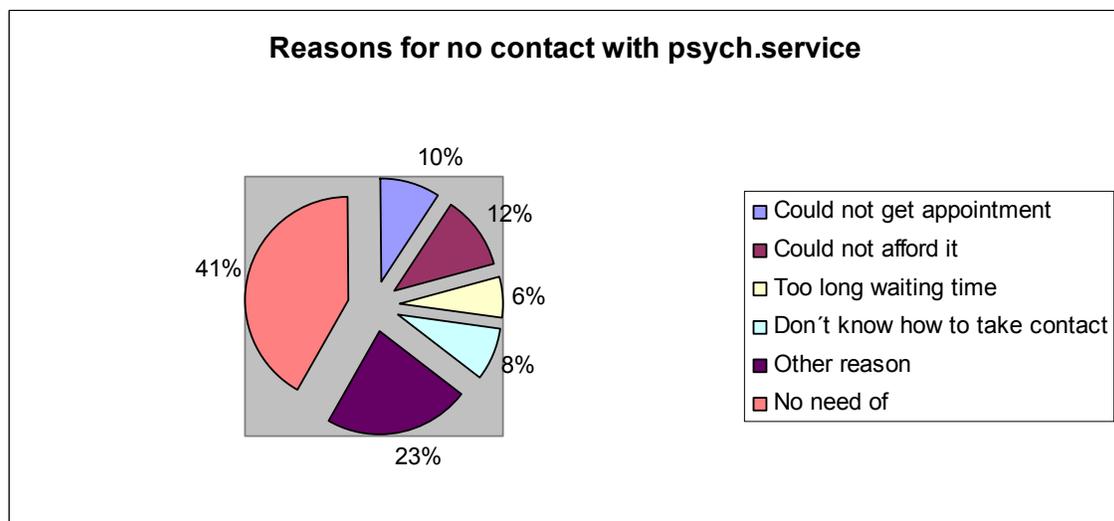
Mostly people have contacted welfare officer in the course of the last 12 months. Every fourth of respondents have met a psychologist/psychiatrist. If one looks at the socio-statistics one can see that those who have had the most contact with the psychiatric services are individuals younger than 35 years of age.



The respondents' answers regarding the help they received vary much in all groups, from very good to very bad. The help from welfare officer is described as mostly good or very good. Approximately half of the respondents are describing the help they received from psychologist to be good or very good. In the group of 55 years of age or older and in the group where the individuals were diagnosed 1987 or earlier 17 percent describe the help they received as very bad.



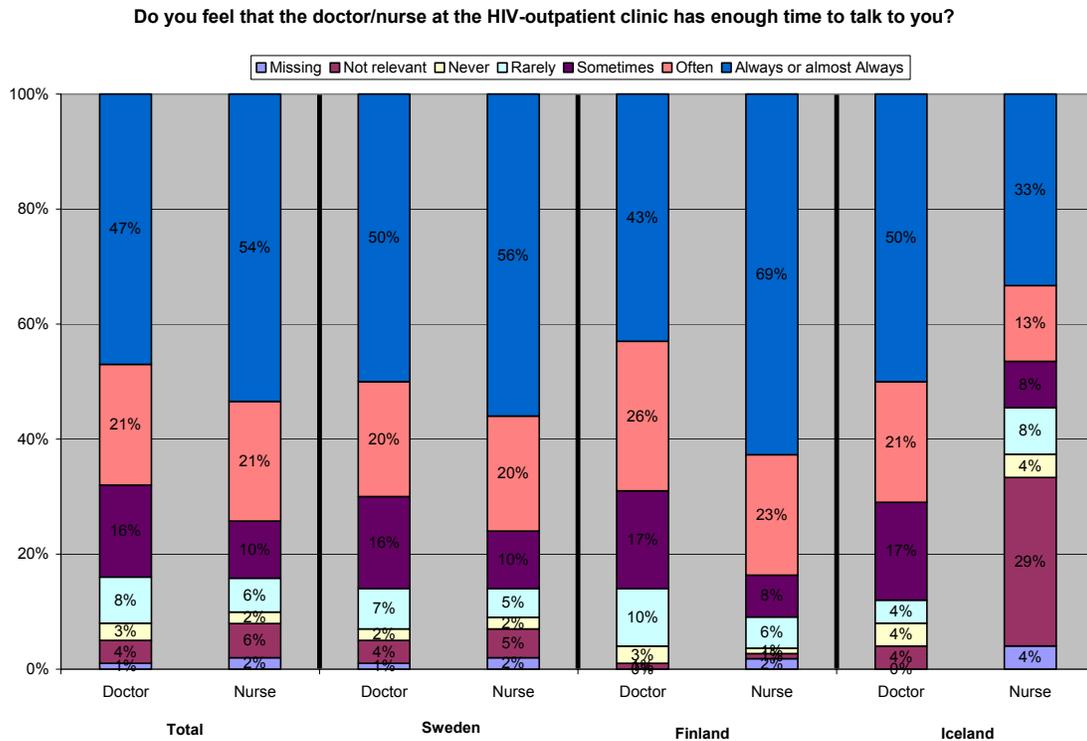
Every second respondent did not have need to talk to anyone in connection with their HIV-status.



For example 16 percent of the respondents under 35 years of age did not know how to contact one and 12 percent consider the period of waiting to be too long.

Contact with the HIV-out-patient clinic

In this survey the oldest group of respondents seems to be most satisfied while the youngest least satisfied. Especially younger individuals diagnosed later than 2002 seem to need more information about different subjects.



Respondents of 55 years or older seem to be most satisfied with the contact. They rate the contact with nurses/doctors more positive than other groups. They feel that nursing staff have time to talk to the patients and are concerned about their quality of life.

In one question we asked - *Do you feel that the doctor/nurse at the HIV-out-patient clinic has enough time to talk to you?* According to the answers it seems that nurses have more time to talk to the patients than doctors in Finland and Sweden, while in Iceland the nurses have less time.

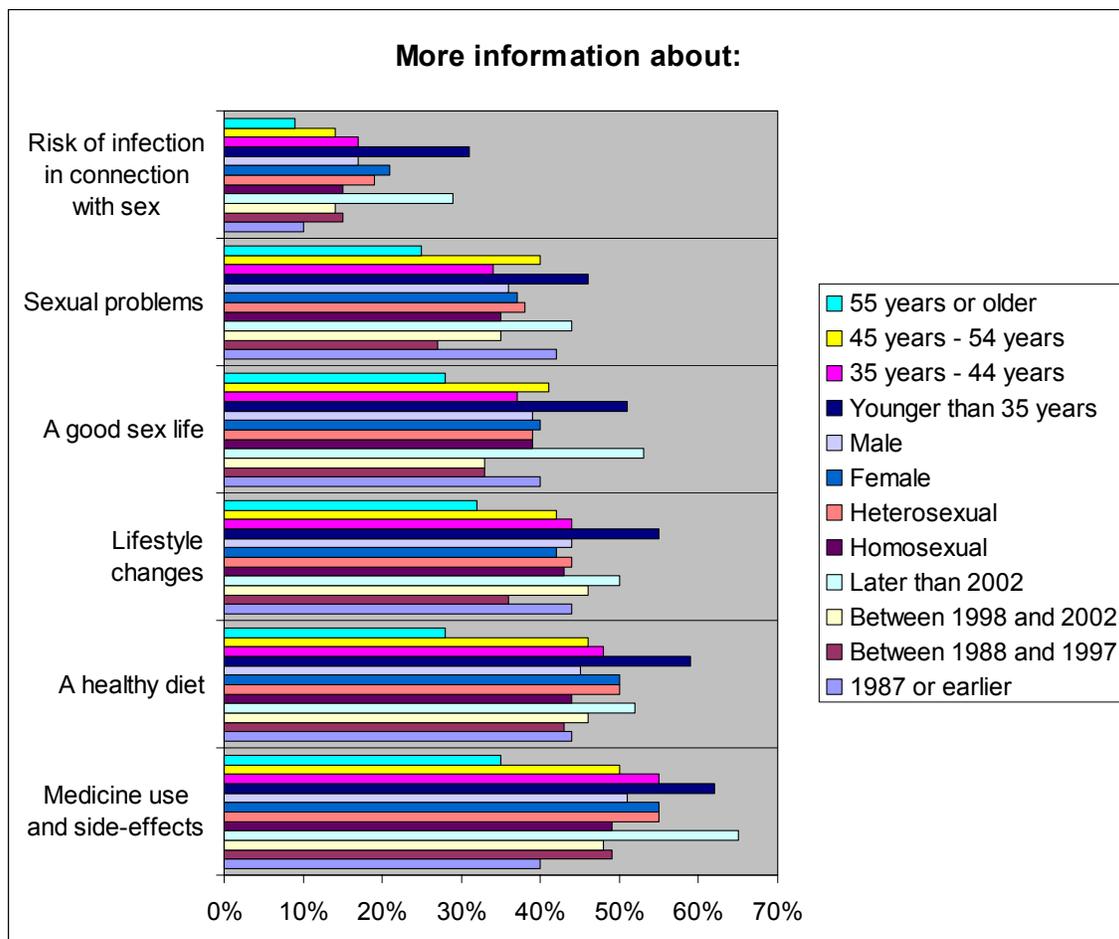
In Finland 82 percent feel that nurses has time often or always/almost always and 69 percent feel that doctors has time often or always/almost always.

In Sweden 76 percent feel that nurse has time often or always/almost always and 70 percent feel that doctors has time often or always/almost always.

In one question we asked - *How would you rate your contact with the doctor/nurse at the out-patient clinic?*

From the survey one can come to a conclusion that overall people seems to be satisfied with out-patient clinics. Patients are most satisfied with nurses in Sweden (86 percent good or very good) and lest satisfied with doctors in Finland (69 percent good or very good). Only few percent of the respondents rate the contact with nurses/doctors bad or very bad.

The type of information that respondents ask for in general considers healthy diet and side-effects.

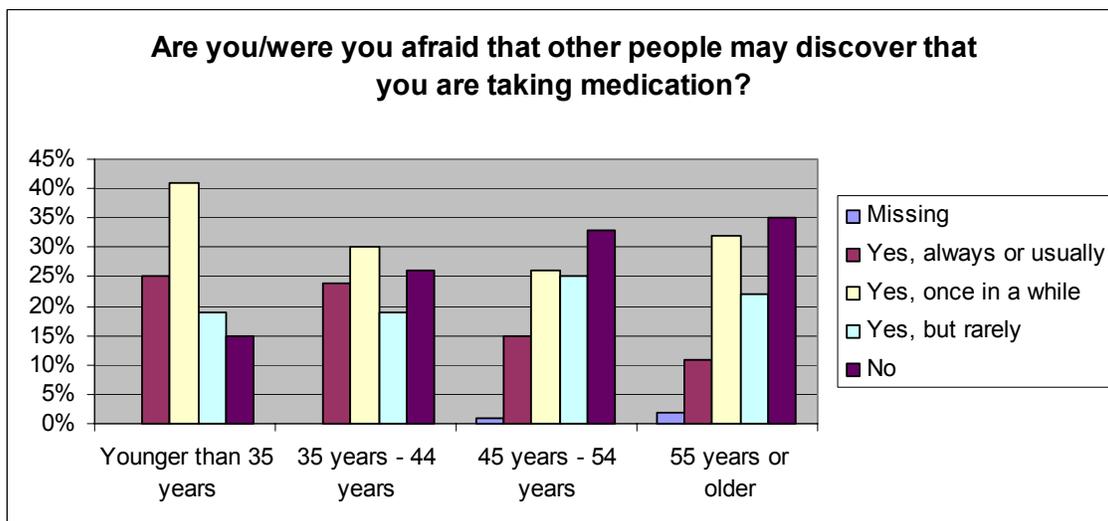
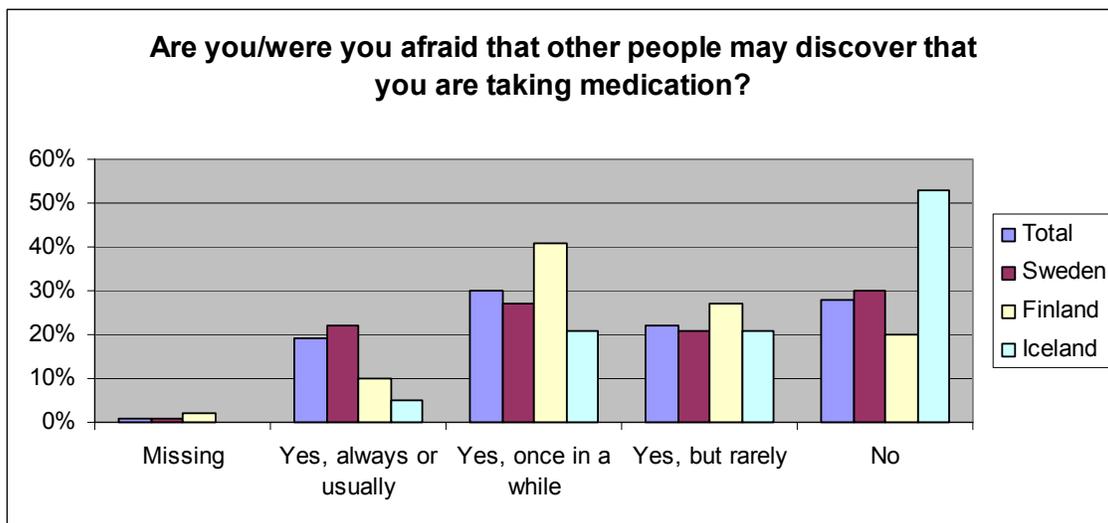


Treatment

For natural reasons there is a lower experience of treatment among the younger respondents. Most common is that respondents take HIV-medication twice a day.

Half of the respondents in Sweden and Finland are always, usually or once in a while afraid that other people may discover that they are taking medication. In Iceland 53 percent of respondents are not afraid.

The later diagnosed the more afraid people are that other people may discover that they are taking medication.

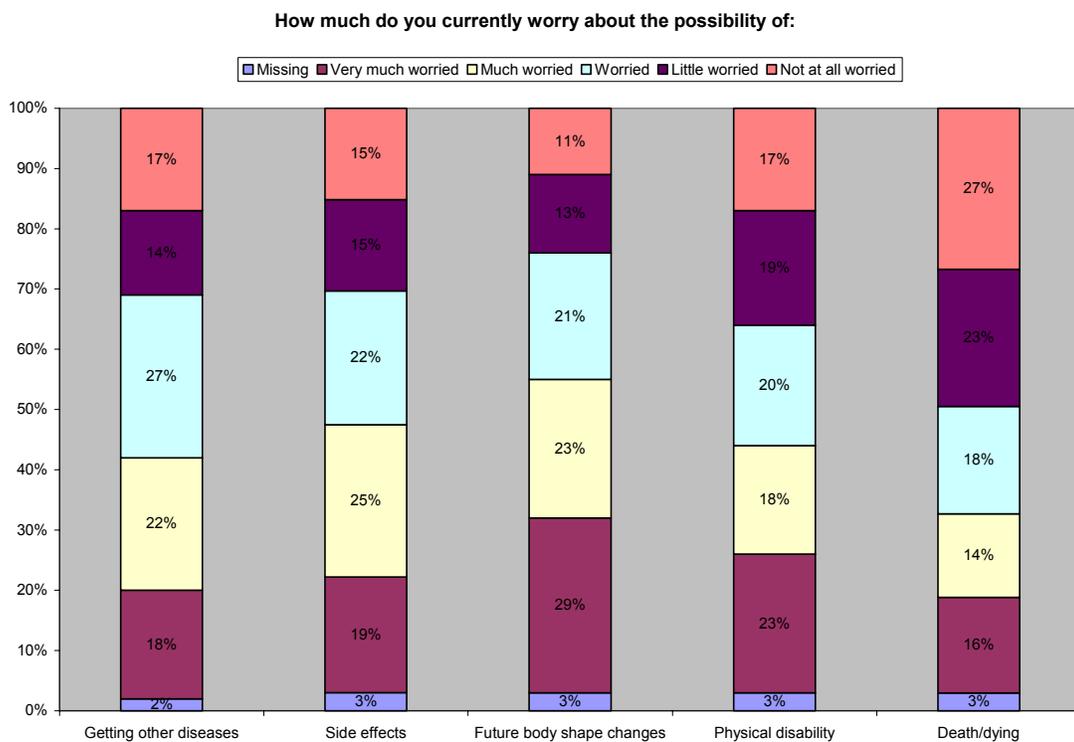


Side-effects and discomfort

People experience various side-effects or discomfort in connection with their HIV-medication. Mostly people feel tiredness, have sleeping problems, reduced fat on the face, arms, legs or buttocks, increased fat on the stomach or/and impotence or reduced sexual desire.

One can see that 86 percent manage to take the HIV-medication every day and that 70 percent never missed a medication moment. The main reason for not taking HIV-medication is that the patient forgets it.

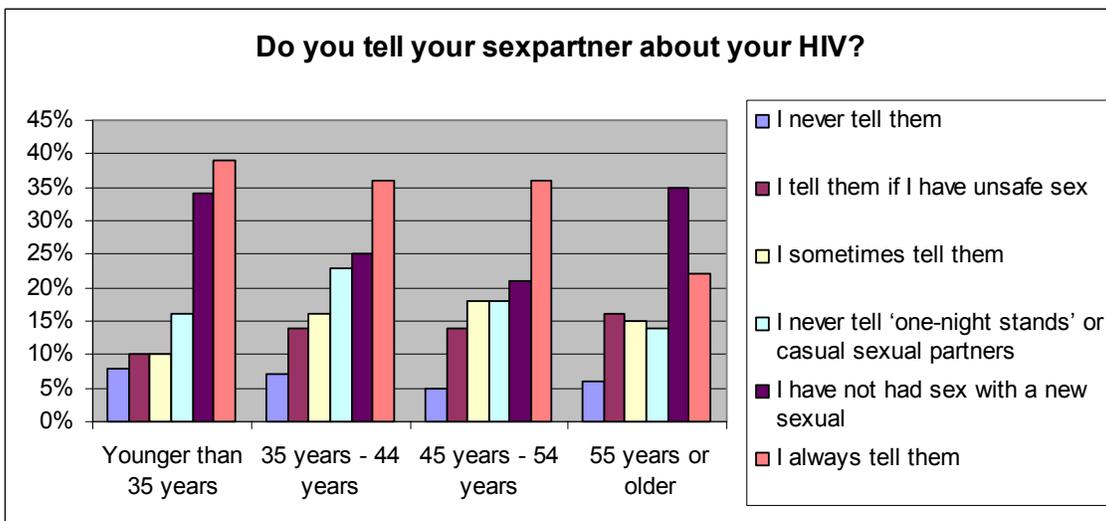
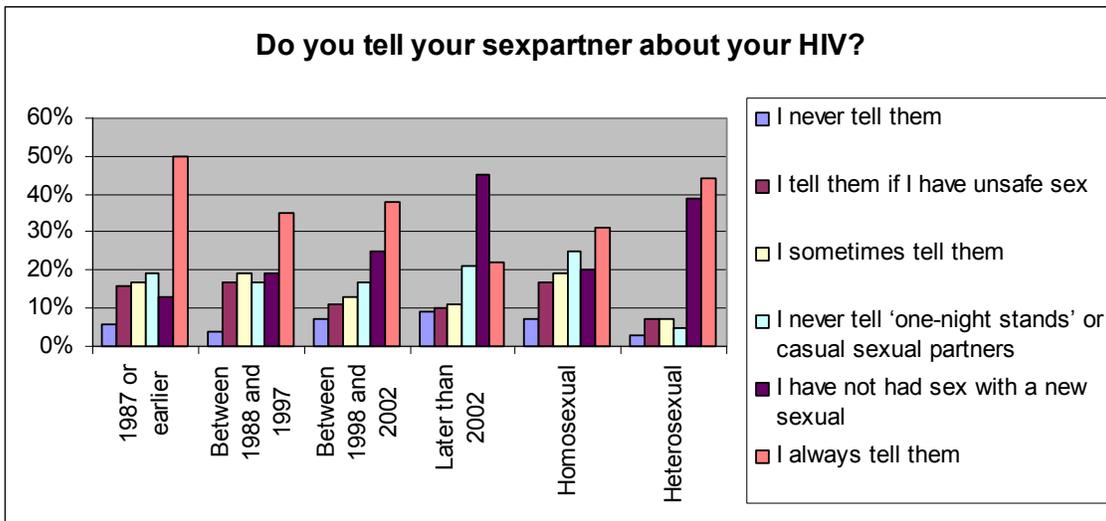
Most people are worried about the long-term effects of HIV-medication. The respondents are most worried about future body shape changes.



Sex-life and sexual issues

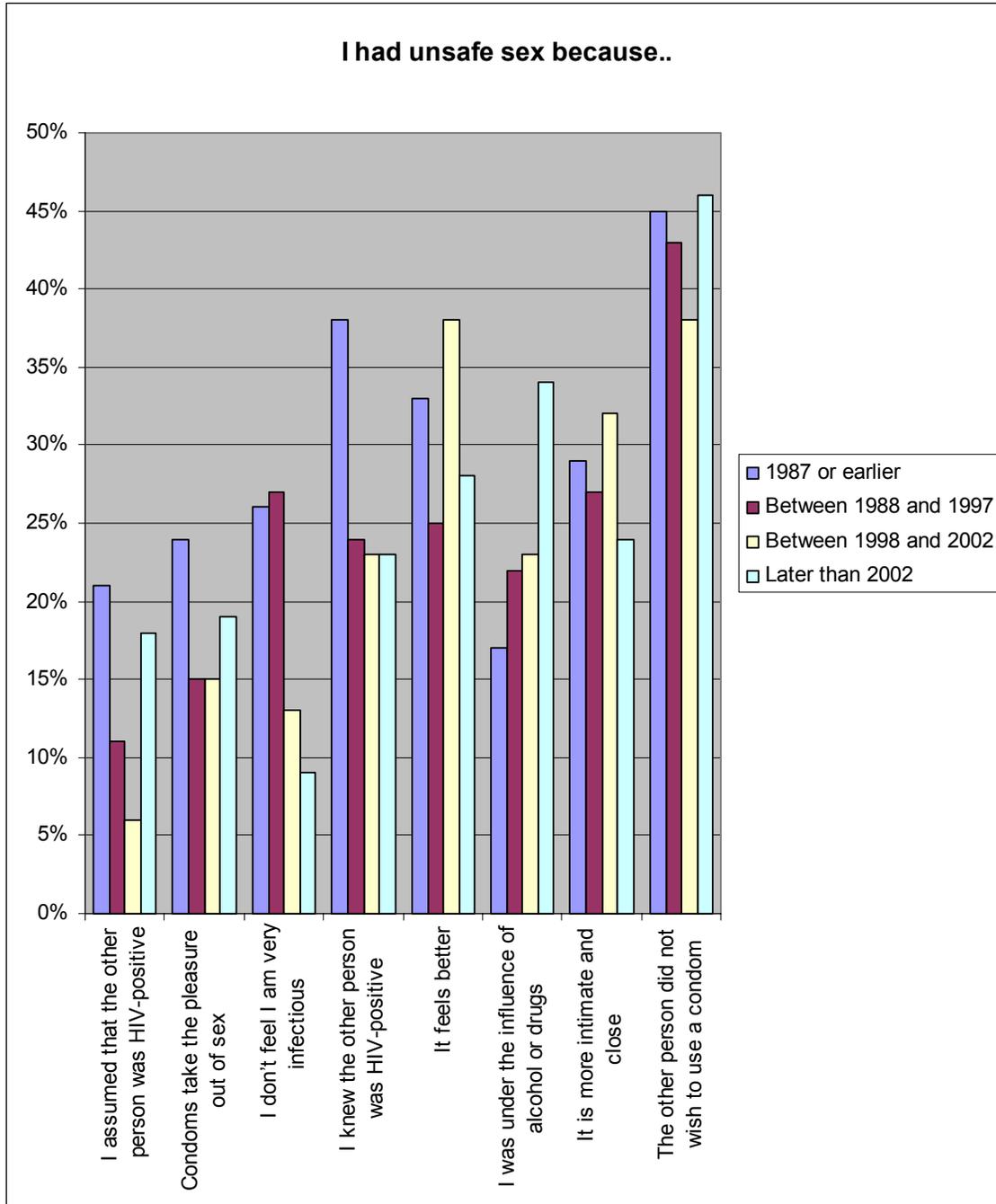
Half of the respondents always tell the new sex partner that they are HIV-positive. Approximately 20 percent does not tell their sex partner that they are HIV-positive if they are having sex with 'one-night stands' or casual sex partners.

About 50 percent in the group heterosexual and in the group diagnosed before 1987 or earlier tell about their HIV-status when they are having sex with a new partner.



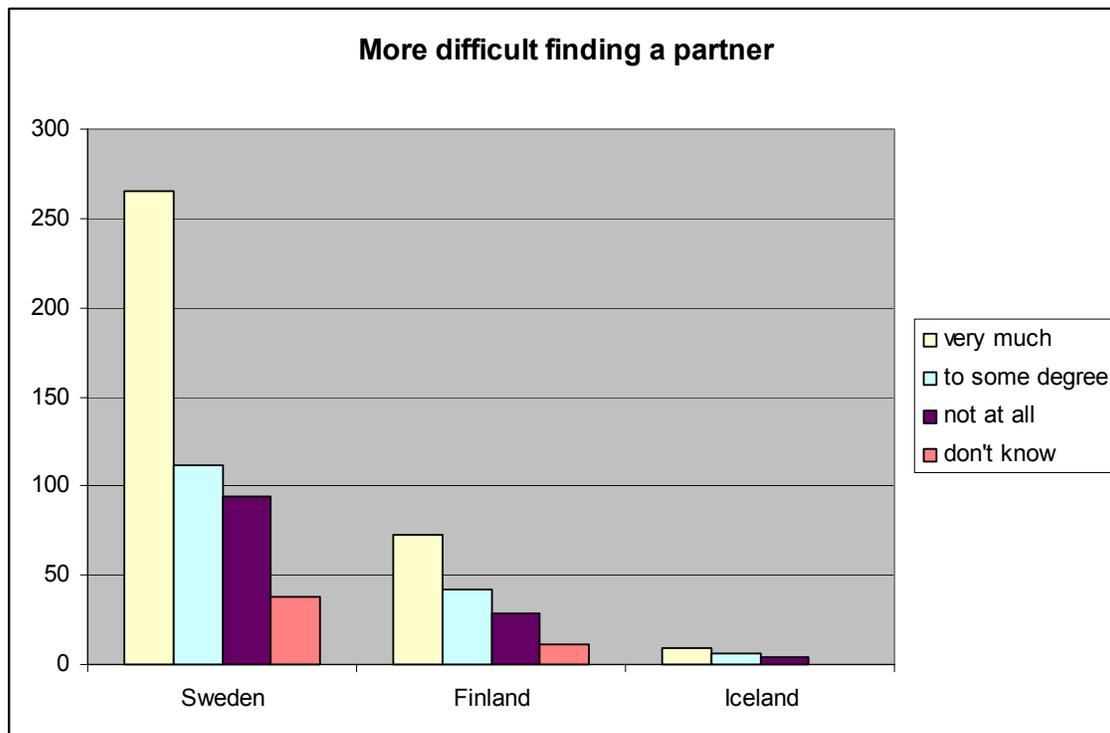
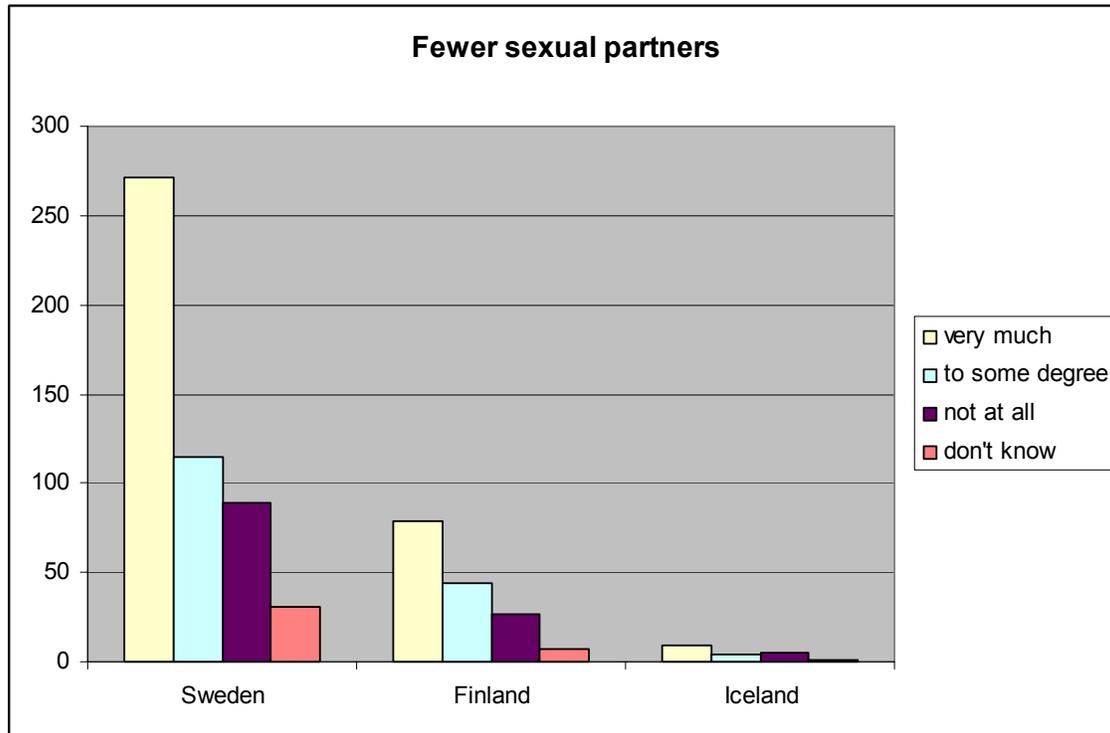
67 percent of the respondents have had unsafe sex during the last year. The group “younger than 35 years old”, later than 2002 diagnosed and homosexuals have had most unsafe sex.

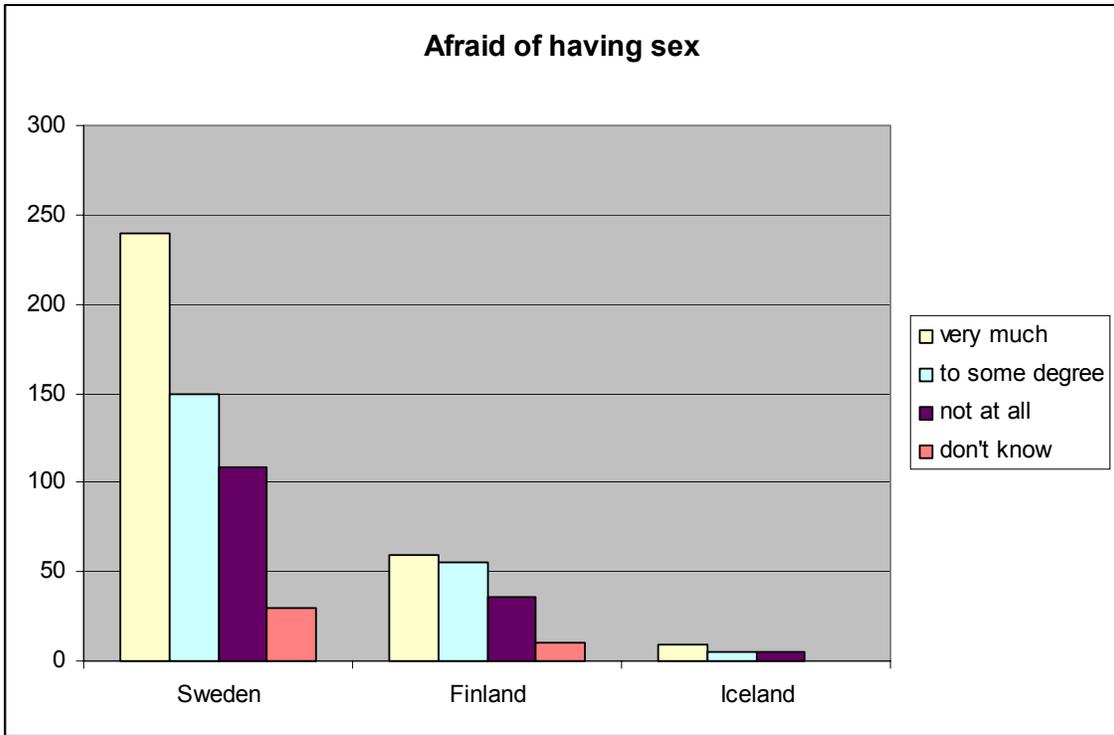
People are having unsafe sex for many reasons, mostly because their partner did not wish to use a condom.



This figures show the most frequent reasons

Every second of the respondents feels that they have had fewer sexual partners and difficulties finding a partner or boy/girlfriend since they were diagnosed HIV-positive. Many people feel that they have become afraid of having sex.





Summary of the free-text notes

At the end of the survey, question 49, made it possible for the respondents to feel free to write down thoughts about the questionnaire, own thoughts about the situation for a person living with HIV and whatever they wanted to tell us as an organisation.

The Swedes wrote a lot of comments (172 notes), the Finnish respondents 26 notes and the Icelandic persons had 2 comments in the alternative field of the questionnaire.

In this report we have only listed the main problems for each country. A more detailed analyze will be presented in the complete report in 2008.

Sweden

From an overall perspective the respondents had a lot of opinions and feelings about the difficulties with their own stigma in the society, isolation, non-comfort with the action of the gay-communities and the gay men's stigma against HIV-positive people within the community.

After reading all notes, below are the head subjects to keep in mind

- The Swedish law containing one-way information duty (Smittskyddslagen)
- Stigma and discrimination
- Difficulties and problems with sex life
- The low level of information about HIV to public and especially to younger persons and in school
- Aspects on the relation/contact with hospitals and employees regarding the health care in general, both dentists and doctors, but also on the HIV-out clinics
- Difficulties getting care for diseases and problems with side effects and body shape changes
- Problems with living in a smaller town

Finland

The respondents have written mostly about their feelings. They have also written about having sex, relationships and how difficult it is to find someone to live with.

- Feeling lonely, depression and fear about the future
- Treatment and dental care are good but psychiatric or psychological services/care is difficult to find and receive. Doctors and nurses received good feedback but also some bad

NordPol would like to thank everyone who has taken their time to answer the questionnaire. Your feedback is very important to us in our work to improve the lives of those who have HIV.

If you want to see the full survey, please visit www.hivhealthsurvey.com.

Thank you for your participation!

NordPol Management Board



Alnæmissamtökin
á Íslandi