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## Living with HIV in Norway – 2009





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## **Living with HIV in Norway – 2009**

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## Preface

In 2002 the Norwegian research foundation Fafo published the report *Levekår og livskvalitet blant hivpositive* ('*Living Conditions and Quality of Life among People with HIV*', Fangen et al. 2002, translated as *Living Conditions and Quality of Life among People Living with HIV in Norway*, Grønningsæter 2004). The results of this study have subsequently come into active use. That was almost seven years ago now and much has changed in Norwegian society, in the development of the HIV epidemic and in medical progress. Fafo and HivNorway in collaboration therefore took the initiative to have a new study carried out. The Norwegian Directorate of Health responded positively and granted the funds needed for the project.

In 2008 we released the results of an attitude and awareness study conducted among the population along with a state-of-knowledge study on living conditions among people with HIV (Mandal et al. 2008). It is important to read the present report in the light of the report from 2008. The project and the report we are now publishing may be described as one collective piece of work on the part of the project group. The project team at Fafo has been made up of five people. Arne Backer Grønningsæter has been project leader and he and Roland Mandal and Bjørn Richard Nuland have made up the core group for the project. Hilde Haug has helped by interviewing the female informants and, along the way, been part of the project team, taken part in assignment discussions, come forward with input on the analysis and contributed comments on the manuscript of the report. Heidi Gautun has played the part of quality controller, been a discussion partner and helped with the work on the report.

HivNorway has been an active collaborator and helped in particular with the recruitment of informants and respondents, as well as with discussions and input. It has also had three representatives in the reference group. This has been made up of the following people: Per Miljeteig (HivNorway), Willy Shanti (HivNorway), Dorte Stokka (LAR – Medication-Assisted Rehabilitation), Randi Nordby (LAR), Vidar Ormaasen (Ullevål University Hospital), Roger Cassidy (Aksept – a psychosocial support centre in Oslo), Arild Johan Myrberg (Norwegian Directorate of Health) and Rolf Angeltvedt (Gay & Lesbian Health Norway). One of the representatives of HivNorway wishes to remain anonymous. We should like to thank the reference group for its commitment and fine contributions.

We wish to thank HivNorway for its cooperation. In addition to the members of the reference group, we must mention Evy-Aina Røe as an important collaborator. Special

thanks go to the Norwegian Directorate of Health for making the project possible and for continuous and inspiring contact.

The market research company Synovate took charge of the practical execution of the questionnaire study. It would not have been possible to carry out the project without the help of the employees of a number of hospitals, polyclinics, organisations and institutions. We would also like to thank Claire Scammell and Bertrand Abadie at The Language Factory for providing the English translation of the report originally in Norwegian. Bente Bakken and Agneta Kolstad at the Fafo communications department have made the report fine and legible. We thank them all for their good, committed, professional work.

The biggest thanks go to the informants and respondents who have given their time and shared their life experiences. We hope we manage to give something back in the form of such knowledge as may play a part in laying the basis for improving prevention, treatment and care for people living with HIV in Norway.

Oslo, October 2009

Arne Backer Grønningsæter, Roland Mandal, Bjørn Richard Nuland and  
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# Summary

## The background to the study

This study is the main report on Fafo's project on living conditions among people with HIV in Norway, conducted in 2008–9. In 2008 Fafo published a report in two parts. The first part was an attitude study carried out among the population, the second a knowledge update (Mandal et al. 2008). The findings of the attitude study provide an important framework for the interpretation of many of the findings presented in this report. The knowledge update was a first step in the work of studying the living conditions of people with HIV.

Fafo's previous report on living conditions among people with HIV came out in 2002 (Fangen et al. 2002). The conditions for people with HIV have changed a lot since then. The anti-viral medicines that appeared in 1997 have steadily improved. There was therefore a need for an update of the knowledge on the living conditions of people with HIV.

In spite of the successes as far as medical progress is concerned, there does not seem to have been any corresponding progress when it comes to openness, knowledge and attitudes in society. One of the goals of the study is therefore to find out how the tension between individual prospects on the one hand and knowledge, attitudes and stigmatisation on the other hand affects the living conditions of people with HIV.

## Data and method

As of 31 December 2008, there were 4,086 people diagnosed with HIV in Norway. In 2009, 299 more people were diagnosed with HIV. This is the largest number that has been recorded in Norway in the history of the epidemic. One estimate suggests there are around 3,000 people living with HIV in Norway today. The two biggest groups are people who have contracted the infection heterosexually before coming to Norway and homosexual men.<sup>1</sup> The two other most important groups are intravenous drug

<sup>1</sup>The term 'men who have sex with men' is not used in the report. In the questionnaire, there are questions about self-identified sexual orientation and mode of infection. The terms 'homosexually infected' and 'gay' are therefore used when the reference is to men who have sex with men.

users and people who contract the infection heterosexually while living in Norway. Around one-third of people with HIV in Norway are women.

The study is based on two types of data. Firstly a questionnaire study was carried out among those who live in Norway and know they have HIV. There is no register from which to extract a representative sample. We therefore tried to reach as many in the population as possible. To achieve this, several channels were used. Firstly the questionnaire was distributed via departments of infectious medicine. Everyone with HIV is supposed to visit these for check-ups and we hoped that by circulating the questionnaire for half a year we would reach most of them. The questionnaire was also sent to HivNorway's listed members and to Aksept's listed contacts. Other channels we supposed were important with a view to reaching the target group were also used. A significant amount of work was done on informing people and encouraging them to take part. However, the number of those who answered proved lower than we had hoped. There were 271 people who submitted completed forms.

The other source of data was the in-depth interviews with twenty-five people with HIV (fifteen men and ten women). The informants were recruited with the goal in mind of reaching out to a group of people from various backgrounds with respect both to the most important infection groups and to age, sex and geography.<sup>2</sup>

By combining data from the two sources, we have managed to obtain a body of data that is not representative but is nonetheless extensive, comprising a lot of information.

### **Income, accommodation and finances**

The mean gross annual income among the respondents is 300,000 Norwegian kroner. The data suggests that the income of people with HIV is roughly on a par with that of the population in general but that there are big differences between the groups and that, in particular, HIV-positive women from countries in the South are at high risk of poverty. Low income can be problematic, especially when HIV starts to affect people's health and they start on medication. Then, for example, dietary requirements can be relatively expensive.

The standard of accommodation is generally good and most also say their accommodation is tailored to the practical needs their health situation dictates. Around one in five, however, says this is not the case. A number of the informants are concerned about their accommodation situation in case they should fall ill.

Some of the informants complain that their financial situation has deteriorated as a result of their having HIV. Among the respondents, there are a significant group

<sup>2</sup> In this report, the term 'respondents' refers to those who have given responses in the questionnaire study, the term 'informants' to those who have been interviewed.

who report financial problems. We do not find big variations between different groups of HIV-positive people in this respect. We found a similar situation in 2001–2. The explanation for this is presumably that the financial problems can be due to several factors and often a combination of them. One may be a fall in income – another may be increased expenses. A third factor may be inadequate oversight owing to the fact that people are occupied with matters quite apart from money when they are given such a diagnosis. One-third of the respondents say a fall in income may be a cause of the difficulties. One-quarter connect the fall in income with the fact that they have received disability benefit.

### **Work activity and arrangements in working life**

More than half the respondents work and roughly as many rate their working capacity at over 90 per cent. Approximately one in four receives disability benefit. The group who receive disability benefit are dominated by men from the North. Some of those who receive disability benefit want to work part-time but find it difficult to get into such a position.

A little more than one-third of the respondents who work say their connection to the labour market has changed. Just over two-thirds of these in turn say this is due to their HIV diagnosis. These figures suggest having HIV has an effect on work activity, not least with respect to the workload and work burden. Even if many work and many feel their working capacity is almost full, there are a significant group who have felt the need for change and there are many in this group who have not been able to get this need fulfilled.

### **Openness in work in the workplace**

Only one-third of the respondents who are in work have opened up to colleagues or workmates. Even if the majority of the respondents have no negative experiences, there are a relatively large group of those who work and have been open in the workplace who report that colleagues become distant or that there are other negative consequences. In other words, the respondents are open in the workplace only to a small degree and a relatively large number of those who actually are open have negative experiences.

Discussing an HIV diagnosis openly in the workplace is difficult and a decision and conclusion many take a long time to reach. Overall the results of the attitude study, the in-depth interviews and the questionnaire study suggest one thing: that working life is an area where there is still a lot to do as regards both room for openness and protection of rights. Working life would seem to be a challenge for HIV policy.

### **Physical and mental health and the use of medicine**

Two-thirds of the respondents say they are in good or very good physical health. As a result of medical advances, we may regard the HIV infection as a chronic condition. Two out of three undergo anti-viral treatment. There seems to have been a positive trend with regard to the perception of the medicines in comparison to 2002. However, half find the medicines cause them side effects and many are also anxious about the side effects. Several of the informants report that they are sick and tired of holding themselves to lives of medication and advice on how to live. For many, the experience of being diagnosed and living with HIV is an emotional rollercoaster, where ups and downs closely follow each other.

There are grounds to assert that the mental health of the respondents is good. Though fewer of the respondents seem to have experienced depression and anxiety in 2008 than in 2002, there are still a significant group who talk of such conditions and express the need for psychological help.

### **Contact with health services**

Regular check-ups and blood sampling are provided for anyone with HIV in Norway. Some people with HIV have symptoms and pain in connection with the illness, which in addition makes it necessary to stay in close contact with various health services. As far as living conditions are concerned, individuals' perceptions and experience of encounters with such services will therefore be important with a view to our being able to assess the situation among the group as regards living conditions. It seems younger people with HIV use health services more than elder ones.

In general more people are pleased than displeased with the follow-up from hospitals, polyclinics and regular doctors. However, a somewhat lower proportion are pleased with their regular doctors than with hospitals and polyclinics. The group made up of people who are very displeased with their regular doctors is also significantly larger than that made up of people who are displeased with the other institutions. Though it may not be a big group, this critical view of the regular doctors also emerges from the informants' interviews. The regular doctors are criticised for a lack of knowledge and for inadequate sensitivity to the situation of people with HIV.

The picture emerges that to a large extent it is on the psychological and mental plane that people with HIV have their most prevalent needs. While a large majority rate their health as good and many report positive experiences of the use of medicine – for example, 82 per cent say anti-virals help to improve their general condition – there is, at the same time, great need for services and provisions that take into account their psychological needs.

The informants' interviews revealed several examples of people with HIV who find it difficult to make dental appointments if their dentists have learned of their

HIV diagnosis. Some have also found themselves subjected to extremely excessive regimes of infection control when their dentists have learned of their HIV diagnosis. In the qualitative interviews, few informants talk about their dental health. On the other hand, several talk about problems with dentists, negative reaction and problems of access. There are also stories from the last few years involving specific examples of dentists' turning patients away or introducing unreasonable anti-infection measures. The stories bear witness to the profound mistrust people with HIV have of dentists as a result of the many horror stories.

### **Contact with NAV (the Norwegian Labour and Welfare Administration)/ social services and other public institutions**

Around half the respondents had been in contact with NAV/the National Insurance Service in the previous year. Of these, roughly equal numbers were pleased and displeased with the quality of the help they had received. A certain amount of criticism about NAV also emerged among the informants. This relates in particular to difficulty in achieving a dialogue with state employees about what it means to have HIV. Some are also critical of the information that is given out and of the shortage of information.

Only one in six of the respondents has received any social security benefit. A somewhat larger proportion of those who have been in contact with social services than of those who have been in contact with the national insurance administration say they are displeased with the help.

Because of the problems of being open about HIV status, the question was asked whether the individual had faith in the confidentiality of NAV and social services. Well over half of those who have been open with these institutions are afraid this confidentiality may be breached. More people today than in 2002 say they have not disclosed their HIV status to these institutions.

No clear conclusion can be drawn from the very limited data we have when it comes to encounters between people with HIV and asylum authorities but some important questions do nonetheless emerge. Is testing felt to be voluntary? Is there a need for more awareness as to how HIV-Aids is dealt with at asylum reception centres? The data does not provide any clear answer but does confirm that these are questions that require closer examination.

### **Openness and isolation**

Over 90 per cent have told someone they have HIV, but it seems many open up to only a limited group of people. There are 61 per cent who say they have told no one or under ten people. Many informants speak of loneliness and living complicated lives keeping tabs on when they can be open and when they cannot. Limited openness is a

stress factor in the lives of many, and many struggle to maintain an overview of who in their surroundings knows and who does not.

There is more openness among people from the North than among people from the South. Though several of the informants say it is difficult to be open in gay circles, there is more openness among homosexuals than among heterosexuals. The longer ago a person learned of the diagnosis, the greater the number of people with whom he or she is open. The secrecy seems to be due to anxiety over how others will react, though few report that the reaction to their openness has predominantly been negative. In particular, HIV-positive people with backgrounds in immigrant communities report that it is difficult to be open in these communities. Some report that they only dare to open up to Norwegian friends and colleagues.

### **Friends and networks**

Many people with HIV seem to have good networks of friends but there also appear to be a significant group who are lonely. Only a minority think it is easy to obtain support from family and friends, and there are a significant group for whom the most important people in terms of support are professional helpers. In addition, contact with friends who have HIV is important for many.

Gay circles are described as both inclusive and exclusive. They are described as circles that demand a lot as regards success and those with HIV feel that they break with this convention. On the other hand, gay circles are also described as circles where HIV is a point of business for better or for worse. Many gay informants actively use the Internet. The Internet offers opportunities for contact with others in the same situation but it is also a place where anonymity gives people the room to play out prejudices and negative attitudes to which some find it hard to relate.

HIV-positive people from immigrant backgrounds portray their ethnic communities as communities where it is difficult to be open. At the same time, several of the informants say there is little understanding for their situation among other people who have HIV. HIV-positive gays from immigrant backgrounds are a barely visible group. They are a group upon whom more attention should probably be focused.

### **Organisations and other support services**

Organisations, networks and psychosocial therapy and support provision represent a wealth of meeting points and provision. They run the range from HivNorway and Aksept on the one hand to closed online networks on the other.

A large group, a little under half, have no contact with any such organisation, network or support service. On the other hand, there are a slightly larger group who have contact with several networks or organisations, on average almost two organisations

or networks. Most of the respondents who have such contact are pleased with the provision.

The polarised situation that emerges here may be symptomatic of the polarisation we seem to see among people with HIV who have taken part in the study. For some, being HIV positive is an identity, something on which to spend time and energy. Others want HIV to take up as little of their lives as possible.

### **Family and relationships**

Around half of those whose parents or siblings are alive have told them they have HIV. At the same time, a significantly larger proportion report they have good or very good relations with their parents and/or siblings. The informants have both positive and negative experiences when it comes to their families and relatives and, among other things there are calls for better provision for them.

One-quarter of the respondents are parents, and of these, half have children under 18. Those who have had children after being diagnosed have predominantly met with positive reaction. They report little negative reaction. Around half of those who have children of their own are open with them. The proportion of people who have told their children they have HIV seems to be somewhat lower among those with children under 18 than among those with children over 18.

### **Sexuality**

Somewhat over half the respondents, whether they have contracted the infection homosexually or heterosexually, are rather or very worried about infecting others. Almost nine out of ten say their sex lives have changed. Three out of four say they have fewer partners and just fewer than two out of three say it has become difficult to find regular partners. Just over one-third say they choose partners who have HIV, and one-third say their HIV status means they no longer dare to have sex. Many report that their sex lives have become more difficult. To find out a little more about the changes in sexual life, we have looked at whether there are differences between the relevant infection groups. It turns out there are no big differences. There are, however, differences along two dimensions, namely age and sex. The proportion of people who say they have fewer partners increases with age and men describe their sex lives as more important than women do.

## **The Penal Code**

The qualitative interviews revealed grave concern in relation to §155 of the Norwegian Penal Code. This section makes it a criminal offence to infect other people or expose them to the threat of infection.

Around half of the respondents say the Penal Code worries them. When they are asked how the Penal Code affects their sex lives, their responses point to their having less and safer sex. At the same time, the informants describe how the Penal Code compounds both their problems in relation to partners and the deterioration in their quality of life.

## **Perspectives on life**

Having HIV since anti-virals became available is described in ambiguous terms. Many find they regain their perspective on life and their spirits, and there is a lot of support and encouragement to be had along the way. At the same time, there are many hard battles and some have lost both their spark and their quality of life or struggle with a lack of the latter for occasional spells.

Many will grow old with HIV and they are beginning to think about what the future will bring. The rise in the number of elderly people with HIV will pose a challenge to health services with regard to the provision of both psychosocial and physiological support.

Upon analysis of the qualitative interviews, an ambiguous picture emerges. There are several people who say they are fine. At the same time, it emerges in an oblique way that there is something incongruous about this depiction. It is natural to ask whether, given the new medicines, people are allowed to say that, being HIV positive, they have problems. Is it the case that though, in spite of everything, they feel their lives are rather difficult, they spend a lot of time and effort convincing themselves and those around them they are fine?

The chapters on openness, relationships and social life point to a polarisation among people with HIV. Many are fine and have good lives. For some, the diagnosis of HIV has brought increased social capital. At the same time, there are many who have serious problems in relation to their HIV status, and for a significant group, this HIV status has meant a significant reduction of social capital. This polarisation seems to apply within all the 'infection groups' and perhaps constitutes the biggest challenge for the authorities.



## **Recommendations**

The following points summarise some of the themes that it is important to do further work on in order to be able better to provide for HIV-positive people to take part in working life and society on an equal footing with others:

- Attitudes, arrangements and information at work
- Awareness of HIV in generalist services (regular doctors and NAV)
- The potential for openness in general, and especially in immigrant communities
- All the groups report limited openness. Even in gay circles it seems to be a challenge to create an environment where people with HIV can be open without experiencing negative feedback.
- §155 of the Penal Code
- The need for psychosocial follow-up – not least for guidance as far as financial affairs and financial problems are concerned. This is also a question of access to those providing professional help, such as psychologists.
- We achieved a very low response rate in the questionnaire study. This may also be seen as a finding and may be an expression of the diminished accessibility of the group made up of people with HIV. For some, this may be a result of better provision of treatment – for others, it may unfortunately mean they live an isolated existence.



## PART I BACKGROUND AND METHOD

A description of the living conditions of people with HIV in Norway is a story of which there are at least two versions. One version of this story is about people diagnosed with HIV who for various reasons want this to be as small a part of their lives as possible. The other version of the story is about people who give a completely different place in their lives over to having HIV. For many of them, being HIV positive becomes an identity and is linked to activities and procedures that take up quite a lot of their lives and their time.

It is not immediately apparent which strategy is best. Both involve problems and challenges and stories can seem rather varied within these groups.

What these stories have in common is that they are about people who have been given a serious diagnosis. They are also about the ambiguity of living with HIV in Norway in 2009. On the one hand, anti-virals have led to a dramatic increase in the number of years HIV-positive people can live with HIV. In addition, the Norwegian welfare state has a regime that gives everyone access to medicines, and, if and when health fails, everyone has recourse to income assurance schemes. On the other hand, we saw in the attitude study in 2008 that people still have substantial misconceptions, especially about how HIV spreads. This can lead to stigmatisation and discrimination. Furthermore, many people with HIV represent groups that in one way or another are marginalised from the outset.

These stories differ fundamentally as far as life strategy is concerned. It is not our task to judge what is a good strategy for dealing with the diagnosis of HIV. For some the 'closed' strategy probably works well, especially at the stage when HIV has not started causing obvious symptoms. The downside of the closed strategy may be profound loneliness, having few people if anyone to talk to when one fears for one's health, and poor communication with partners and other close relatives. When one has been carrying HIV inside one's body so long that it starts to become noticeable and one perhaps needs to take medicine, this strategy becomes much more complicated. For the ones who choose an open strategy, it can be a positive thing to get essential feedback from those around, and it is obvious that they have more, easier access to both public and private helpers and figures of support. The downside of the open strategy is that one may experience significantly more confrontation in the form of prejudice and discrimination.

As will become clear from the analysis in the report, there is a clear polarisation in the data collected. Above we have presented a picture of diverging strategies – open and closed. From the data collected we can also see the contours of different social reactions – both discrimination and inclusion. Aside from this we have a picture of a support system that in general works well but in individual cases works very badly. We have made both encouraging and disheartening findings.

The biggest social challenge perhaps falls to those who endure the sum of life strategies that do not work, experience of discrimination and unduly poor support – be it from the community and family or from the state. Even if we see what we have called a polarisation in our material, there are of course some who have found life strategies that work notwithstanding the fact that they encounter hindrance and/or strain in other areas. Norwegian society faces a significant challenge when it comes to prevention, support and treatment.

Having HIV in itself puts a strain on the living conditions of people with HIV and often on their communities and families too. We hope that, with this study, we can contribute to better understanding of what it means to have HIV in Norway in 2009, and thus also help to give society a better basis for putting measures in place to reduce the strain on the individual.

# 1 From attitudes to living conditions – the background to the study

This study represents the main report and, at the same time, the conclusion of Fafø's project on living conditions among people with HIV in Norway. The first part of the project consisted of a knowledge and attitude study that came out last year (Mandal et al. 2008). The study showed there were significant gaps in awareness among the population in relation to how HIV spreads and does not spread and what HIV actually is. The findings that gave a measure of people's attitudes toward people with HIV in working life were also quite remarkable; of those questioned, 60 per cent thought that people with HIV should be obliged to notify employers of their HIV status, while 50 per cent thought that people with HIV must accept employers' suspension of their employment in consideration of the safety of other employees. The study met with great interest and gave rise to several notices in the media. Along with the attitude study, a state-of-knowledge study on the living conditions of people with HIV was also presented. This has formed an important opening to the work of charting these living conditions.

The findings of the attitude study have provided an important framework for interpreting many of the findings presented in this report. At the same time, charting the knowledge and attitudes among the population is a natural precursor to the study of living conditions that has now been conducted, because the level of knowledge and the attitudes in the population have great bearing on the living conditions of the individual. The title of the report – *From Attitudes to Living Conditions* – is intended to capture a sense of this 'thread' of the project.

Fafø's previous report on living conditions among people with HIV in Norway (Fangen et al. 2002) came out in 2002. This generated a lot of discussion and debate but has, by and by, become somewhat outdated in regard of the findings it presents. This is due not only to the fact that almost eight years have passed since the data was collected but also to the fact that, as a result of medical progress, having HIV can be different today. There has thus been a need to conduct a new study of living conditions in order to see how people with HIV are doing now. Has there been any change in the living conditions of people with HIV – or do we find many of the same experiences and perceptions now that we did in 2002?

As far as medical progress is concerned, this has come a long way in recent years, with anti-virals and treatment regimes that have radically improved the prospects among people with HIV of being able to live good long lives without symptoms and pain. This medical progress thus influences the living conditions of people with HIV. People's living conditions, however, are not influenced solely by their physical health – at least as important are the awareness, attitudes and openness that people with HIV meet with in society. Living conditions are defined in an interplay of individual factors and requirements and the opportunities people have to fulfil the latter in various arenas such as the labour market, the education and training system and encounters with public services.

In spite of the medical progress in recent years, which has given people with HIV radically different conditions for living good lives, there has not been any corresponding progress with regard to openness, knowledge and attitudes in society (see Mandal et al. 2008). Inadequate knowledge and prejudice are, unfortunately, still conspicuous and obviously somewhat restrict how people with HIV can live their lives.

This contrast – between, on the one hand, improved prospects of being able to live longer on the individual level *and*, on the other hand, the knowledge, attitudes and reactions among other people – is an important point of departure for this study of living conditions. It is a positive thing that medical progress has improved the prospects among people with HIV of living long lives, but unless it is the case that the reactions and attitudes people with HIV meet with in society have moved in a more positive direction, there is still a long way to go. It has been an important aim of this study to find out how the tension between *individual prospects* (especially in relation to medical treatment) on the one hand and *knowledge, attitudes and stigmatisation* in society on the other hand influences the living conditions of people with HIV.

## Problems and research issues

The aim of the study is to produce a broad knowledge base in order for us to be able to evaluate various issues and problems in relation to the living conditions of people with HIV in Norway. The project is intended to chart how people with HIV perceive their health situations, their participation in the labour market, their residential situations, their financial situations and relationships with family and friends, as well as what experiences they have of encounters with public services and offices. Through the charting of living conditions, there is the aim of producing research-based knowledge about what it is like to live with HIV in Norway, and, in this way, of establishing a knowledge base that has something to say about what changes are necessary so the

variety of provisions and services for people with HIV may be even better adapted to their needs.

## **The structure of the report**

The structure of the report to a large extent follows the set-up of Fafo's 2002 report on living conditions (Fangen et al. 2002), for instance in the questionnaire we issued this time to people with HIV. Generally following the thematic structure of the 2002 report has made it easier to compare findings. The chapter division also to a large extent follows a division into various 'life arenas'. The last chapter summarises the main findings and presents some suggestions as to what can be done in the future to improve the everyday lives of people with HIV in Norway. In the report, we have consistently tried to use the term 'respondents' for those who have given responses in the questionnaire study and 'informants' for those who have given in-depth interviews.





## 2 HIV in Norway – facts and figures

Aids (acquired immunodeficiency syndrome) was first recorded in Norway in January 1983 and the illness became compulsorily notifiable in the same year (Jakobsen 1998). Since 1986, HIV (human immunodeficiency virus) has also been compulsorily notifiable – that is, doctors report the detection of HIV antibodies to the Norwegian Institute of Public Health. Aids was originally defined as a surveillance issue until HIV was discovered (Aavitsland and Nilsen 2006). Today it is clear that Aids is rather an incidental element in the gradual deterioration of the functioning of the immune system among people with HIV. Modern treatment has made it possible to delay the onset of Aids and perhaps completely prevent it. The term has therefore lost a lot of its relevance in everyday clinical practice and doctors do not use it to any great extent (*ibid.*). In this report, therefore, we shall mainly use the term ‘HIV’.

The records at the Norwegian Institute of Public Health show that at the end of 2008 there were a little more than 4,000 people registered HIV-positive in Norway, a completely different and far lower figure than those quoted in the pessimistic forecasts of the 1980s. Back then it was estimated that by 1990 there would be 3,000 Aids cases and 30,000 people with HIV in Norway (Degrè 1987, Jakobsen 1998).

Table 2.1 Cases of HIV infection in Norway by mode of infection and year of diagnosis. (source: Norwegian Institute of Public Health)

Mode of infection	before 1999	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Total	Percentage
Heterosexual	641	92	131	105	151	153	163	134	164	141	185	2060	50.4
infected while living in Norway	289	27	38	27	28	34	43	33	42	41	46	648	15.9
infected before coming to Norway	352	65	93	78	123	119	120	101	122	100	139	1412	34.6
Homosexual	699	36	32	39	30	57	70	56	90	77	92	1278	31.3
Intravenous drug abuse	430	12	7	8	16	13	15	20	7	13	12	553	13.5
Via blood/blood product	46											46	1.1
From mother to child	18	4	3	2	2	5	1	5	6	9	4	59	1.4
Other/not known	37	3	2	3	6	10	2	4	9	8	6	90	2.2
<b>Total</b>	<b>1871</b>	<b>147</b>	<b>175</b>	<b>157</b>	<b>205</b>	<b>238</b>	<b>251</b>	<b>219</b>	<b>276</b>	<b>248</b>	<b>299</b>	<b>4086</b>	<b>100</b>

When an account was given of the HIV situation in Norway as of 31 December 2008, there were 4,086 people diagnosed with HIV – 2,748 men and 1,338 women (Nilsen et al. 2009). In 2008, 299 new cases of HIV infection were diagnosed in Norway. This is the highest number diagnosed in any year in Norway. The increase on 2007 is due in particular to a significant increase among the groups made up of immigrants infected before coming to Norway and men who have contracted the infection homosexually. The average age among the cases of 2008 (*ibid.*) was 36 (20–72).

Gay men have from the outset been the group most associated with HIV and Aids. Today, men who contract the infection homosexually are the group at most risk as regards infection in Norway (Mandal et al. 2008). Homosexual men have witnessed a disturbing trend in the last few years as far as infection is concerned, the annual figures of HIV cases detected among homosexual men having more than doubled since the 1990s (Nilsen et al. 2009). The proportion of homosexual men who come from immigrant backgrounds has remained stable at about 15–20 per cent in the last few years (*ibid.*). Relatively few of the immigrants who have contracted the infection before coming to Norway report that they have contracted the infection homosexually, so most homosexual men from immigrant backgrounds contract the infection in Norway.

In 2008, 185 new cases of heterosexual infection were recorded and most of the people concerned are of foreign origin. The Norwegian Institute of Public Health distinguishes between people who contract the infection before arriving in Norway and people who do so afterward. In 2008, forty-six people (twenty-eight men and eighteen women) were diagnosed after contracting the infection heterosexually while living in Norway. Of these, twenty-five men and seven women had been born in Norway, whereas the other fourteen were persons of foreign origin. The latter have mainly contracted the infection domestically within their immigrant communities in Norway, on visits to their former homelands or while travelling in Europe. As before, most heterosexual men contract the infection abroad, and Thailand remains by far the most common point of infection for Norwegian men, with sixteen new cases detected in 2008 (*ibid.*). The average age at the time of diagnosis was 46 (27–76) for the men and 32 (18–49) for the women.

There were 139 people (92 women and 47 men) diagnosed with HIV in 2008 after coming to Norway as asylum seekers, refugees or by way of reunion with family in Norway. About half contracted the infection in their former homelands in East Africa. Thai women who have married Norwegian men make up a relatively large group of infected immigrants, with fourteen women in 2008. In 2008 the average age for those diagnosed in this group was 36 (20–53) for the men and 30 (17–58) for the women (*ibid.*).

Few drug users were diagnosed with HIV in Norway in 2008. Among the twelve cases reported in 2008, there were seven men and five women, of whom four are im-

migrants who contracted the infection in their original homelands before coming to Norway (ibid.). The average age among these cases was 34 (25–53).

There are few cases where children have contracted the infection from their mothers (perinatal infection). There were four cases in 2008 and all those concerned were born in Africa (ibid.). The last detected case of perinatal infection in a child born in Norway happened in 2000.

The Norwegian Institute of Public Health estimates that today there are around 3,500 people living with HIV in Norway (Blystad 2009). Of these, an estimated 50 per cent have contracted the infection by heterosexual means, the majority being immigrants who have contracted it before coming to Norway. Homosexual men represent about 40 per cent. If one estimates that this group makes up 3–5 per cent of the human population, the figures show an extremely uneven distribution among those living with HIV in Norway. Those who have contracted the infection through other causes, mainly intravenous drug abuse, make up 10 per cent. The Norwegian Institute of Public Health estimates that around 300–500 people are living with HIV without knowing they are infected (about 15 per cent) and that around 3,000 of those who have been diagnosed since the Norwegian Institute of Public Health began keeping records are alive today.

The figures from the Norwegian Institute of Public Health also show that three out of four Norwegians who contract HIV are men who contract the infection from other men or from Thai women. This suggests Norwegian men continue to practise unprotected sex in known high-risk environments although one would think the level of awareness of HIV and of the risk of infection must be high (Nilsen et al. 2009). Fafo's attitude study showed that there is exaggerated fear of infection among the population, inasmuch as, for example, almost one person in four thinks it is possible to contract it by kissing someone with HIV and almost one in six thinks it is possible to contract it by drinking from the same glass (Mandal et al. 2008). It is paradoxical that exaggerated fear of infection does not lead people to protect themselves more.

In parallel with the work on our study of the living conditions of people with HIV, the government is working to develop a new action plan. The present strategy plan – 'Ansvar og omtanke. Strategiplan for forebygging av hiv og seksuelt overførbare sykdommer' ('Responsibility and Thought. The Strategy Plan for Prevention of HIV and Sexually Transmitted Diseases') – was adopted in 2001 and is still in effect (Norwegian Ministry of Health 2001). It is based on two main aims: reducing the number of new cases and ensuring follow-up of those who have contracted the infection. As far as new cases of HIV are concerned, one can scarcely say the authorities have succeeded, since the number of those newly diagnosed has risen in the last few years. On the other hand, Norway still has a low infection rate compared with most countries in the world. The ministries indicate that the new plan will concentrate on the HIV-Aids problem and not deal with other sexually transmitted infections. This may be seen as a sign that the

problems surrounding HIV-Aids are seen as different from those surrounding other sexually transmitted infections. This study of living conditions probably supports this. Contracting HIV means living with a state of illness that causes stigmatisation and a number of psychosocial challenges for the individual.

## Fafo's HIV research

Fafo has for many years been actively making a name for itself in research dealing with HIV-Aids, both nationally and internationally. Other research projects on the social aspects of the epidemic have been conducted (in Norway, South Africa and Russia) and Fafo has produced several reports that throw light both nationally and internationally on Norway's HIV problem. They are:

- *Levekår og livskvalitet blant hivpositive* ('*Living Conditions and Quality of Life among People with HIV*', Fangen et al. 2002)
- *Living Conditions and Quality of Life among People Living with HIV in Norway* (Grønningsæter 2004)
- *Fortsatt farlig å kysse? Kunnskap om og holdninger til hiv* ('*Still Dangerous to Kiss? Knowledge about and Attitudes toward HIV*', Mandal et al. 2008)
- *Diskriminering av lesbiske, homofile og bifile, og av hivpositive. En litteraturgjennomgang* ('*Discrimination against Lesbians, Gays and Bisexuals, and against People with HIV: a Cross-Section of the Literature*', Grønningsæter and Nuland 2008)
- *HIV in Norway: Knowledge and Attitudes* (Mandal et al. 2008)

## 3 Data and method

### On research into living conditions

Living conditions tell us something about how we as people are doing in a community (Fløtten et al. 2008). Though definitions of living conditions may vary over time and across nations and cultures, there is agreement in the Norwegian research on living conditions that these are played out in a number of different *arenas*. Good living conditions – the resources and potential, that is, to participate and fulfil oneself within these arenas – in turn give people the chance to live good lives (see for example Fløtten et al. 2008, Fyhn and Dahl 2000 and Ringen 1995).

Some ten years since the research on living conditions began, agreement has emerged, little by little, as to what elements within society play a part in defining the living conditions of the individual. These include (Norwegian Official Reports 1993:17):

- health and access to medical treatment
- employment and working conditions
- financial resources and consumer conditions
- skills and training opportunities
- family and social relationships
- residential circumstances and access to services in the immediate environment
- recreation and culture
- security of life and property
- political resources and democratic rights

Because the list of elements of living conditions presented above may be seen as a 'standard list', we have made certain adjustments within our study in view of the target group we are studying and the available knowledge as to what needs and challenges it has. Nonetheless, the list has served a normative function and provided important inspiration as regards what to concentrate on in order to be able to say something about the living conditions of various groups. The aim of this study is to gain insight into how having HIV affects the individual's living conditions, with special attention to working life, family, friends, health and welfare services.

Two different sources of data have formed the basis for this study: twenty-five qualitative in-depth interviews and a questionnaire study among people with HIV in Norway. As a whole, the two sources of data have resulted in a substantial body of data, in which the combination of qualitative and quantitative methods has facilitated a far broader analysis and interpretation of the data than would have been possible had we taken only one source of data as our basis. We shall now describe in more detail how the two rounds of data collection were conducted. We will also spend some time describing what challenges pursuing research into the living conditions among people with HIV involves in practical/methodological terms.

## **The questionnaire study**

### **Issues the questionnaire study was intended to clarify**

The aim of the questionnaire study was to gather together the broadest possible knowledge base on the living conditions of people with HIV in Norway today. This was done by drawing up a comprehensive questionnaire containing questions connected with the elements of living conditions described above. The questionnaire was split up into various topics and under each topic specific questions were asked, which were intended to gauge the respondents' scores on the various measures of living conditions (see Appendix 1 for complete questionnaire). One important aim of the questionnaire was to ask the most detailed questions possible in order thereby to make it possible in a tangible way to chart the experiences people with HIV have had in various contexts. The questionnaire was developed in collaboration with Synovate, who also took charge of the collection and organisation of the data. Finally the data was sent to Fafo as an SPSS file.

### **On the execution of the questionnaire study**

The questionnaire study was conducted during the August 2008–February 2009 period. During this period, the questionnaire was in circulation at infectious-medicine polyclinics, within various organisations all around Norway and at the Medication-Assisted Rehabilitation centre for Eastern Norway (LAR Øst) – that is, at places a large proportion of people with HIV frequent (see detailed description below). Before the questionnaires were sent out, those taking part in the project went out and briefed some of the collaborators about it (polyclinics and organisations). At the meetings, we explained how important it was that they got as many of their patients and members to return the questionnaire as possible. Each respondent was given or sent an envelope containing the questionnaire, a covering letter and an addressed return envelope. The

questionnaires and the covering letter were done in both English and Norwegian. In addition, there was a shorter covering letter written in English, Spanish, French and Somali. The distribution channels that saw fit to help us to distribute the questionnaires were the following:

- *Infectious-medicine departments/polyclinics* – all the departments of infectious medicine in the country were sent bundles of questionnaires to distribute to all their patients. Because most people with HIV visit the polyclinics for check-ups at regular intervals, the polyclinics were initially the most important recruitment channel for the questionnaire study.
- *The Olafia Clinic* – a centre for counselling, research and treatment of sexually transmitted infections and HIV. On 1 January 2008 the Olafia Clinic became part of Rikshospitalet University Hospital HF. People diagnosed with HIV can go for check-ups at the Olafia Clinic until they have to start taking medication. The Olafia Clinic issued questionnaires to those of its patients who had HIV.
- *The Social Medical Centre in Tromsø* – comprises three units: Health Services, Intoxicant Services (Social Services) and the Intoxicant Polyclinic. The centre does work in relation to sexuality, sexually transmitted infections, contraception, HIV, hepatitis and substance problems. The primary target groups are young people and people with varying degrees of problems linked to substance abuse. The centre handed out the questionnaire to the people with HIV who frequent it.
- *Aksept* – a psychosocial support centre for everyone affected by HIV, whether through having HIV themselves or through being close to someone with HIV. Aksept runs a community service, a polyclinic and an in-patient treatment service and is a centre where it is possible to meet people of all ages and in various life situations. Aksept is run by the Oslo Church City Mission. Aksept sent the questionnaire to those frequenting it.
- *HivNorway* – a special-interest organisation for people with HIV that works to safeguard the rights and interests of people with HIV in the community. HivNorway sent out the questionnaire to all its members and also made the questionnaire available in its offices.
- *LAR Øst* – the Medication-Assisted Rehabilitation centre for Eastern Norway, part of the Department of Specialist Polyclinics at the Clinic of Abuse and Dependence in Oslo University Hospital, Aker. LAR Øst is a national resource centre and the regional centre for the Eastern Norway health region (Akershus, Oppland, Hedmark, Østfold and Oslo counties) as well as being part of the specialist health services for Oslo patients. LAR Øst issued the forms among those of its users who had HIV.

- *Gay & Lesbian Health Norway* – aims, in the light of contemporary health issues, to carry out health-promoting and preventive work with respect to the group made up of men who have sex with men. Gay & Lesbian Health Norway aims to further the rights of people with HIV and contribute to the increased empowerment of the individual. Gay & Lesbian Health Norway issued the questionnaire to several of the people taking advantage of its efforts.
- *The Brynseng Doctors* – a medical centre that by order of the Norwegian Directorate of Health also runs an evening polyclinic for the testing for and treatment of sexually transmitted infections for men who have sex with men. Since starting up in 2004, this low-threshold service has diagnosed around 10 per cent of all the newly diagnosed homosexual men on a national basis each year. The centre issued the questionnaire to its HIV-positive patients.

The decision to circulate the questionnaire for around half a year was motivated by the desire to achieve as high a response rate as possible. In circulating the forms for such a long time, we also hoped to reach those who visit the infectious-medicine polyclinics once every three or four months or perhaps only every six months. By using various channels to distribute the forms, we also hoped to ensure variety and diversity among the respondents, for the reason that people with HIV, like most people in society, are different and have varying preferences and needs with respect to the services of which they take advantage. Making use of several recruitment channels increases our chances of reaching farther out into the HIV-positive population, for instance when it comes to crucial background variables such as age, sex, mode of infection and geographical place of residence. This is also important because we assume variations relating to factors of this kind can themselves be important with a view to accounting for the disparity in living conditions among people with HIV. Table 3.1 shows the numbers of questionnaires returned and how many people were recruited via the various channels.

Table 3.1 Number of respondents recruited via the various channels.

Channel	Number
Infectious-medicine departments/polyclinics	122
HivNorway	73
Aksept	48
Other	28
Total	271

As Table 3.1 shows, 271 questionnaires were completed and submitted during the course of the half-year period when the forms were in circulation. In all, 4,000 forms



were sent out. The Norwegian Institute of Public Health has estimated that there are around 3,000 people in Norway today who have been diagnosed with HIV (Blystad 2009). Therefore some of the potential respondents probably received the questionnaire a number of times, because they have contact with several of the channels that were used. On the basis of the assumption that there are 3,000 people with HIV in Norway who know they have the infection, we ended up with a response rate of 9 per cent. In the light of the fact that Fafo achieved a response rate of 20 per cent in a similar study of living conditions in 2002 (Fangen et al. 2002), we find the response rate surprisingly low. There may be several reasons the response rate was so low.

How many people in Norway have HIV at any particular time is difficult to determine categorically, because there are dark figures, including people who have HIV without knowing it. These are first and foremost people who have contracted the infection recently and have not been registered HIV positive. However, it need not only be a question of new cases – there may also be people who have unwittingly lived with HIV for longer periods. The population in this study is made up of people who live in Norway and know they have HIV. The estimate that there are 3,000 people with HIV in Norway who know they are HIV positive was presented at the start of 2009 (Blystad 2009). We may therefore reckon on a somewhat lower number of people in the population at the time when the questionnaire was sent out. Perhaps, then, we are talking about a response rate closer to 10 per cent. All the same, we are still talking about a low response rate.

### The composition of the sample

Table 3.2 shows the sample divided up according to mode of infection, in comparison to the estimates of the Norwegian Institute of Public Health for the population.

Table 3.2 Sample divided according to sex and mode of infection. Fafo's sample compared to Norwegian Institute of Public Health (NIPH) figures for the population. Percentages.

Mode of infection	Men	Women	Total	NIPH
Via heterosexual contact	13.0	71.2	25.8	50.1
Via homosexual contact	74.4		57.7	31.3
Via intravenous drug abuse	3.4	1.7	3.0	13.7
Via purchase or sale of sexual services	1.0		0.7	
Via blood transfusion/blood product	2.4		1.9	1.1
Other	1.9	6.8	3.0	2.2
Not sure	3.9	20.3	7.9	
Total	100 (N = 207)	100 (N = 59)	100 (N = 267)	

Table 3.2 shows that the sample is unevenly distributed when we look at the modes of infection. The same problem characterised Fafo's study of living conditions in 2002 (Fangen et al. 2002). In comparison to the figures of the Norwegian Institute of Public Health for the whole population, the distribution in the sample is especially uneven with regard to heterosexual modes of infection (underrepresented) and homosexual ones (overrepresented). Another striking feature is that the proportion of intravenous drug users who returned the questionnaire is very low. Though one explanation for this may be that the group are not readily accessible, there is nonetheless the possibility that the body of data includes more drug users than the table shows. The reason for this is that some drug users may be uncertain how they actually contracted the infection (intravenously or sexually). Some perhaps tick the box to say they contracted the infection sexually (though they may not have done). Because individual respondents may have been exposed to several potential sources of infection, it may be that some people who have contracted the infection via intravenous drug abuse are in the 'don't know' category.

One finding from Table 3.2 that *may* be construed as encouraging, both for the analytical aims of this study and perhaps also in other ways, is that the proportions responding 'other'/'don't know' are considerably lower now than they were in the 2002 study (10.5 per cent and 19.4 per cent respectively). Even if we cannot rule out the possibility that this may in part be due to a number of incidental variations in the two samples of people with HIV, the *marked* reduction in the 'other' category (of around 10 per cent) may suggest that the 'system' of diagnosis has improved and that the respondents in our sample generally have a better understanding of how they contracted the infection than the respondents in 2002 did. It may also be because a larger proportion in this study have found it comparatively easy to admit (first and foremost to themselves but perhaps also to others) how they actually contracted HIV.

We can also see that a much larger proportion of women than men are uncertain how they contracted the infection. This may be connected to the fact that some of the women in question here may have been involved in prostitution and/or drug abuse and that some women may therefore have been exposed to several sources of infection. That heterosexual modes of infection are clearly the more common among women and that heterosexual intercourse is associated with the danger of HIV infection to a far lesser extent than homosexual intercourse, for instance, may also explain the greater uncertainty among women with regard to how they contracted the infection.

We have so far looked at the distribution of the sample on the basis of modes of infection. To get an impression of how representative the sample is of the population, it is necessary to look more closely at other variables as well. Table 3.3 shows the age distribution in the sample in comparison to the population.

The sample also seems to be unevenly distributed when we look at age. People with HIV under 40 are underrepresented. As we do not have any directly comparable figures

Table 3.3 Sample divided according to age. Percentages. (N=269)

18–29 years	7.8
30–39 years	20.4
40–49 years	38.7
50–64 years	27.9
65 years or over	5.2
Total	100

for the population, it is difficult to assess what implications this has for the analysis in the report. As far as gender is concerned, 210 of those who returned the questionnaire are men (78.1 per cent) and 59 are women (21.9 per cent). In other words, the sample is also unevenly distributed as far as gender is concerned. Men are overrepresented. The overrepresentation of men may be viewed in the context of modes of infection. The homosexual mode of infection is the most common among our sample (cf. Table 3.2). At the same time, the uneven distribution with regard to gender is less pronounced than that for the mode of infection variable. For some reason or other, two people in the body of data did not specify their gender. A closer inspection of the data matrix shows these two did not give any other background information either. However, they did answer some of the questions on living conditions in the study. Fear of inadequate anonymity may be the reason these two declined to provide personal information of this kind.

The last variable we shall look at is the *time of diagnosis*. The reason this is a factor of interest is that the perceptions and experiences a person has as someone with HIV may to a certain extent be influenced by *when* that person was diagnosed. There is, for example, reason to think that having HIV in the 1980s, when HIV was regarded as a deadly disease and there were many predictions to the effect that this was an epidemic the scale of which would explode (Degrè 1987, Jakobsen 1998), is in some ways different from being given the diagnosis in the twenty-first century. In particular, there is reason to think the introduction of anti-virals in 1997 has had great bearing on the living conditions of people with HIV. Since then, HIV-positive people have been able to expect to live with HIV for a long time. Those who were diagnosed before that time thus had a more difficult point of departure than those who have been aware since

Table 3.4 Sample according to time of diagnosis by decade. Numbers and percentages.

Time of diagnosis	Number	Percentage
1983–1989	46	18
1990–1999	78	30
2000–2008	133	52
Total	257	100

day one of the option of taking anti-virals (see Carstensen and Dahl 2007). Table 3.4 shows the sample divided up according to time of diagnosis.

The table shows we have a broad representation of HIV-positive people from the last three decades. The same is true of the informants who were recruited for the in-depth interviews. We think this variation as to when the people in the sample contracted the infection is important with a view to ensuring breadth and diversity in the experiences and perceptions we have been concerned to chart with the questionnaire. A second distinction and one of interest in this context is whether people were diagnosed before or after the introduction of anti-virals in 1997. In the context of living conditions, it is probably fair to say that the introduction of the medicines in 1997 represented a milestone for people with HIV in radically altering the prospects for living long lives with HIV. In our sample, 32 per cent of respondents were diagnosed before 1997, whereas 68 per cent were diagnosed afterward.

### **Why such a low response rate?**

Firstly, it is not realistic to start out expecting to get as high a response rate in this group of informants as in studies of living conditions conducted among the rest of the population. In question are vulnerable groups and also people who want to hide away and be anonymous. The fact that we obtained a certain number of responses in itself provides society with valuable knowledge as to what the experience of having HIV is like for many people, though the low response rate may make it difficult to say what numbers experience different conditions – but in view of the fact that the response rate in the 2002 study was about 20 per cent, and that this time we spent more time publicising the project in hospitals, institutions and organisations, a response rate of 10 per cent may be regarded as disappointing. However, it is important to look behind the figure and try to find explanations for the fact that the response rate was so low. One possible explanation is that, because of mental problems, unemployment and social isolation, many people with HIV are difficult to reach. There are probably also some people with HIV who do not take advantage of the organisations and network provision we closely cooperated with in the recruitment for this study. This has made it harder to reach out to some among the target group. Most likely there are two groups it is hard to get to talk – those with the worst living conditions and those who are least open. There are also differences among people with HIV when it comes to how often they visit infectious-medicine polyclinics for sampling and virus counts. We regarded the infectious-medicine polyclinics as the most reliable ‘meeting place’ to reach out to the greatest possible number of people. The qualitative interviews, however, revealed that not everyone with HIV visits the clinics as regularly as one might think. In addition, there are some who wait for long intervals between visits to the polyclinics. In other

words, although the questionnaire was in circulation for around half a year, it is not likely that we reached 'everyone' with HIV.

Another potential explanation for the low response rate is that, in terms of both the number of pages and the content, the form is hard to complete. Firstly, it requires basic proficiency in reading and writing. In addition, completing the questionnaire may have presented many people with a linguistic obstacle because it was available only in Norwegian and English (cf. Carstensen and Dahl 2007). Secondly, in terms of subject matter, many may find it emotionally difficult and harrowing to answer the questions asked, for instance because some questions require people to 'rake up' the reactions and feelings they have had in connection with what for many has been the hardest and most uncomfortable experience of their lives (cf. Grierson et al. 2008). There is therefore the possibility that some people may have started filling in the questionnaire but found it too difficult and uncomfortable to go through with it. It is also conceivable that some of those who have had HIV for many years and have perhaps come to terms with difficult feelings and 'got on' in life do not want to answer questions that would rake up a difficult past.

If the low response rate reflects a reduction in the accessibility of people with HIV in recent years, that is something more serious. Fafo's attitude study in 2008 (Mandal et al. 2008) showed there were big challenges connected with both awareness of and attitudes toward people with HIV in Norwegian society. The ignorance and negative attitudes the study revealed may therefore have played a part in counteracting a trend toward more openness about HIV and more participation in working life and society on the part of people with HIV. In this case, then, there is the danger that a low response rate indicates both a reduction in the accessibility of the group and that many lead an isolated existence. Viewed in this way, the low response rate is perhaps one of the study's most important findings.

When we specify a response rate of about 10 per cent, this is calculated on the basis of the number of questionnaires that were actually sent out (which coincided with the number from the Norwegian Institute of Public Health for all the people with HIV in Norway today). Though in many ways what the population is (corresponding to all those with HIV now living in Norway) goes without saying, it may nonetheless be a disputable point how big the real population in this context actually is. By this we mean it is important to point out that today there are some people with HIV who notice few or almost no signs of illness or side effects and who live 'normal' lives with jobs, families and friends. Many people with HIV who feel well and are fully active in working life and society probably have big problems defining themselves as part of the HIV positive as a group, for instance because having HIV is usually presented as something associated first and foremost with various stigmatised groups (prostitutes, immigrants, drug users). Such a 'trend' not to see oneself as part of the group of people with HIV was identified in the Danish study of living conditions (see Carstensen and

Dahl 2007). ‘High-functioning’ people with HIV who do not see themselves as ill or infected may object to completing a questionnaire that focuses on the perceptions and experiences of the individual as someone with HIV. During the course of the project, we have received responses from contacts in the infection departments that point in this direction inasmuch as they have spoken of people with HIV who have not wanted to talk to them or complete the questionnaire, precisely because they do not *identify* themselves as HIV positive and therefore do not see themselves as part of the study’s target group. This may particularly apply to heterosexual men, and younger people who have contracted HIV recently. This too is something that may have had an impact on the response rate.

That there are differences when it comes to how people view having HIV also emerged from the interviews. One of the informants put it as follows:

I also feel there’s a difference between people who’re diagnosed with HIV now [...] and those who were diagnosed in the past. Previously it was a much more serious illness, and it’s a serious illness now, but it’s not serious in the same way [...] I feel tremendous pressure to maybe feel unhappy and bloody awful about myself – pressure to look out for the whole community so it doesn’t end up in the same damn situation. But you get that just as much with people who were diagnosed with HIV 10–15 years ago [...]. But it seems to be different than with many who’re diagnosed now.

## The qualitative interviews

### Issues the qualitative interviews were intended to clarify

The purpose of the qualitative interviews was to provide more insight into how various aspects of the situation of people with HIV are perceived. We wanted to obtain more knowledge on specific experiences of how life has changed since the informants were diagnosed and how they have perceived and tackled the changes in various areas of life. The questionnaire gives only a stylised picture of such information. We aimed to obtain interviews from informants from various groups of HIV-positive people.

An interview guide was used that contained the most important main topics from the questionnaire but also emphasised the individual’s perceptions and experiences. The interview guide has been structured in such a way that the questionnaire and the qualitative interviews complement each other and in such a way that between them they assist with the interpretation of the data. The interview guide is in Appendix 2 of the report. Each interview started with a question about when the individual had been diagnosed and how life had changed since then. The informants spoke freely, some

in more detail than others. The interview guide was used as an aide-memoire for the topics the interviews were supposed to cover, with specific stand-by questions about how life had changed in particular areas such as family, work, finances and accommodation. Questions were also asked about physical and mental health, contact with other people with HIV, amorous relationships and sexual life as well as experiences of health services, the public health system and organisations for people with HIV. The individual informant's experiences influenced the relative emphasis on the various parts of the interview guide, but all the same, all the informants spoke of their experiences in all the areas about which we wanted to obtain knowledge.

### **The recruitment of informants**

The qualitative interviews took place in the autumn of 2008. In all, twenty-five people with HIV were interviewed. Various organisations helped to recruit informants. The help with recruitment was quite essential to gain access to enough informants and to ensure a sample in which there was a certain variation when it came to infection groups, age, sex, immigrant/non-immigrant backgrounds and places of residence. However, we soon realised it was virtually impossible to obtain an 'optimal' variation, because, with respect to groups such as people with HIV, in which many are hard to reach, it is not practically possible to 'pick out' informants according to predefined criteria. To ensure a certain variation, we therefore depended on collaboration with organisations and communities of HIV-positive people. Table 3.5 (see next page) shows how the informants in the qualitative interviews are divided up in terms of some of the attributes mentioned.

Table 3.5 shows that there is good variation among the informants with respect to criteria such as sex, age, mode of infection, time of diagnosis and geographical affiliation. As a result of the breadth among the informants, we have succeeded in capturing *different* experiences and life stories connected to having HIV. The interview study is not representative but we think the breadth and variation in the stories told are greater than a 'narrower' recruitment of informants would have produced. At the same time, it is important to point out that it is not one of the purposes of such a sample of informants to constitute a representative 'cross section' of a population, because qualitative interviews are not intended to produce representative knowledge of different issues or phenomena. The purpose of the interviews was rather to go farther into *examples* and *personal histories* illustrating what it is like to live with HIV today – and thereby present a picture of the options and challenges having HIV in Norway involves (cf. Fangen et al. 2002). Just like the rest of the population, everyone with HIV has a unique life story; through the interviews, we have tried to capture these unique stories and experiences.



Table 3.5 Informants from qualitative interviews grouped according to various key variables. Numbers.

Sex	Female	10
	Male	15
Age	18–29 years	1
	30–39 years	5
	40–49 years	11
	50–64 years	7
	65 years and over	1
Mode of infection	Homosexually infected	10
	Heterosexually infected	9
	Infected via use of hypodermic syringes	3
	Other/don't know	3
Geography	Northern Norway (Finnmark, Troms, Nordland)	3
	Central Norway (Nord-Trøndelag, Sør-Trøndelag, Møre and Romsdal)	4
	Western Norway (Sogn and Fjordane, Hordaland, Rogaland)	6
	Southern Norway (Vest-Agder, Aust-Agder, Telemark, Buskerud, Vestfold)	1
	Eastern Norway (Oslo and Akershus)	10
	Inland, east (Hedmark, Oppland and Østfold)	1
Time of diagnosis	1983–1989	8
	1990–1999	7
	2000–2008	10

## An extensive but unrepresentative body of data

In terms of methodology, one important aim of questionnaire studies is to provide knowledge that is representative of a larger population. For the findings obtained in a sample-based study to be representative, one must have selected respondents at random from a larger population and everyone in the population must have a known and equal probability of being selected. In many areas of research, the fact is that, for practical and/or ethical reasons, one cannot follow such a random sampling procedure. One common reason for this is that one does not have a complete overview of which and how many people make up the population – consequently one ends up with a sample consisting of people who are not randomly selected, with the result that the findings made are not representative of the whole population (Ringdal 2001).



In conducting this study, we have not had the option of following the criteria for random sampling. The reason for this is that there is no register where everyone with HIV in Norway is registered. Because we therefore cannot 'define' the HIV-positive population in Norway, we cannot select a random sample to complete the questionnaire either – and since, further, we have not had the option of keeping check on the sampling procedure, we end up with a sample that is not randomly selected. Consequently this questionnaire study does not yield representative findings; the findings that this report represents *say something about the living conditions and life situations of those who returned the questionnaire and not the population of people with HIV in general.*

There are also other factors of a practical kind that probably had an effect on recruitment to our sample. It is clear that people with HIV make up a very heterogeneous and composite group who differ when it comes to degrees of openness, accessibility and participation in society. There are also differences as regards what help they need, something that in turn has an effect on the individual's need to call on various support provisions and institutions. In other words, these are all factors that, from a research standpoint, have an effect on the accessibility of people with HIV. Likewise, they will have a direct impact on our study, inasmuch as factors of the type indicated here to a large extent influence the recruitment of respondents and the individual's likelihood of being 'exposed' to the questionnaire. Consequently we see that who returned the questionnaire is far from being 100 per cent random – it is influenced by how often people call on various services and institutions, the degree of openness, whether or not they are employed and, in general, what need they have for health and welfare services.

When the people selected for the sample are in one or a number of ways better off than the rest of the population, in the methodological literature this is called *positive selection* (see for instance Ragin 1994). For example, we have positive selection if people in a sample have a higher overall level of education than the population in general. There may be several mechanisms in our study that entail a risk of obtaining a sample that in various ways has more positive attributes than the rest of the population. For example, the motivation for taking part in such a study will vary according to what 'position' a person is in – physically, mentally and socially. The Danish study (Carstensen and Dahl 2007) makes an issue of the fact that the motivation and strength to take part in such a study are least common among those worst off in social terms. It is possible that such a tendency has also been in evidence in our study. For example, the sample is characterised by the fact that those usually considered the worst off among people with HIV (as regards finances, accommodation and health), namely intravenous drug users, are poorly represented. Further, there are individual differences when it comes to how well/ill people are, how open they are about the illness and whether they are well enough and have the strength to 'take part' in various arenas in society. Attributes and behaviour on the part of the individual – that is to say, the motivation, resources

and strength the individual has (so-called unobservable attributes) – will, in other words, influence whether the individual actually has the energy to fill in a questionnaire. The fact that various HIV organisations have been so central to the recruitment of respondents for the questionnaire study may have compounded the tendency for positive selection. The reason for this is that those ‘recruited’ by various organisations usually set out from different starting points and have a different awareness of and different strategies in relation to their diagnosis of HIV than those who do not call on these organisations.

On the other hand, the opposite is also conceivable – that is, that the sample is characterised by *negative selection*. As previously mentioned, it is likely that the healthiest and ‘highest-functioning’ people with HIV – that is to say, those who are in work, have normal relationships with family and friends and to little or no extent notice the illness – are underrepresented among those who make use of the various organisations and network services. If anything, the organisations provide for those who find they face challenges connected to having HIV. In other words, there is reason to believe that the organisations to a large extent capture a kind of ‘middle stratum’ of HIV-positive people, consisting of people who in daily life experience relatively big challenges connected to having HIV. This also implies that the highest functioning *and* the worst off probably make less use of the organisations as meeting places. Given these considerations, and that we do not have such statistical background information on the population as might make it possible to compare it to the sample, it is difficult to judge whether there has been positive or negative selection in our sample. What we are reasonably confident about, however, is that those people with HIV who function best in daily life *and* those people with HIV who are worst off (physically, mentally and socially) are underrepresented in the sample.

Engaging the hospitals in the recruitment of informants via the polyclinics was initially supposed to be of advantage with a view to achieving more random recruitment of HIV-positive people for the study. The most important reason for this is that virtually everyone with HIV, to some extent or another, has contact with the hospitals. In other words, we meant to circumvent some of the selection mechanisms that are probably in evidence in connection with the HIV organisations (whether people ‘define’ themselves as HIV positive, whether they agree with the aims of the organisations and so on). In contrast to the organisations, the polyclinics represent a purely *medical provision* that practically everyone with HIV takes advantage of to some extent or other. The proviso here relates, however, to people with HIV who are so well and have such low virus counts that they do not visit the polyclinics – cf. the description above. In spite of this, the infectious-medicine polyclinics are, after all, the point of contact of which most people with HIV make use. With regard to our study, however, there are several factors, often purely practical, which mean the polyclinics do not work as a channel for random recruitment of respondents. Firstly, the polyclinics

probably do not keep track of everyone with HIV to the same extent. The reason for this is that individual requirements for support and follow-up vary. The hospitals must also continuously prioritise procedures and the application of resources at the level of both the individual and the system, something that in this context will have an impact on the probability that the questionnaire was presented in like fashion to ‘everyone’ with HIV who visited the polyclinics. Perhaps the nurses made handing out the forms a priority in some cases, whereas on other occasions they quite understandably did not have time to do so. We did not have any chance to check up on what the polyclinics actually did to distribute the questionnaire, either. If this was done within individual polyclinics or between different polyclinics in a way that created systematic (and not random) variations with regard to who was asked to fill out the questionnaire, this will have had an effect on who filled out the questionnaire.

That we did not have the option of recruiting a random sample means we cannot use various statistical methods (t-test and chi-square test) to find significant connections between different living condition indicators and various background variables (such as sex, age, mode of infection, wage income and level of education). The reason is that statistical test methods of this kind require random samples (Ringdal 2001). The data will therefore be presented in the form of frequency distributions and cross tabulations showing the sample’s distribution with regard to various questions that give a measure of living conditions. All the same, percentage distributions of this kind are often used in such studies of living conditions.

As was mentioned earlier, Fafø’s previous study of living conditions (Fangen et al. 2002) was characterised by the same challenges when it came to imbalances in the sample. We also find this problem, once again, in studies of the living conditions of people with HIV that have been conducted in other countries. The Danish study we refer to in this report (Carstensen and Dahl 2007) achieved a response rate of around 34 per cent. The sample in the Danish study was unevenly distributed too, with similar imbalances to those in our study. In a survey study in New Zealand, responses were obtained from 261 people with HIV, which is estimated to correspond to about 21 per cent of the population of people diagnosed with HIV in the country (Grierson et al. 2008). Compared with the population, the sample was much more unevenly distributed than is the case with our data. In an Australian survey study too (Grierson et al. 2006), a relatively small proportion of the estimated HIV-positive population was reached (6.4 per cent). In that one, there was an even greater predominance of homosexually infected men (80.6 per cent) than in the study in New Zealand. All these examples illustrate how difficult it is to achieve a high response rate in studies of living conditions aimed at those with HIV.

In spite of the methodological challenges we have described up until now, it is important to state that together the qualitative interviews and the questionnaire study have resulted in a rich body of data that presents the possibility of exciting analysis. By

means of the qualitative interviews, we have studied many interesting problems in depth and made findings that are both serious and remarkable – nor do we fail to appreciate that there were in fact 271 individuals who took the time to fill out an extensive questionnaire relating to various aspects of their lives and experiences as people with HIV in Norwegian society. We believe the facts, experiences and insights contained within this overall body of data are substantial.

The findings from the qualitative interviews and those from the questionnaire study will be conveyed in a two-way dialogue with each other. The main reason for this is that the two studies deal with many of the same questions and problems. Many findings and insights are intricately interwoven, *irrespective* of how the information was collected. In our view, it would therefore be strange to split the analytical component in two. At the same time, we believe such a triangulation of findings and results contributes to a richer and more dynamic presentation, where depth of knowledge helps to complement and add nuance to breadth of knowledge and vice versa.

### **Ethical problems**

To research a group such as people with HIV involves ethical challenges. Later in the report, we deal with one of the most important reasons this is a particular challenge: the fact that many people with HIV are not open about their status. This means anonymity is especially important. In the questionnaire study, there were at least two challenges. Firstly, we had to get the questionnaire out to a group who must remain anonymous to us. Sending out and distributing the questionnaire therefore had to happen entirely through the institutions that had contact with the relevant people. Secondly we had to design the questionnaire so there would not be any indirectly identifiable information on the forms. Some of the response categories were designed with precisely this in mind. What to do so the questionnaire would be anonymous was discussed with the Privacy Ombudsman for Research (Norwegian Social Science Data Services). Since we were going to use health care institutions to collect data, the project was sent to the regional ethical committee for medical research. It came back with the response that the questionnaire study did not need approval, because the questionnaire was anonymous.

In the in-depth interviews, it was not possible to maintain anonymity between interviewer and informant. We have, however, taken great care not to store information that might identify the informants. Most of the interviews were recorded but the recordings were deleted once the interviews had been transcribed. The transcripts are stored in Fafo's system in such a way that only the four researchers involved have had access to them. Recruitment took place via contacts among people with HIV.

Anonymity – particularly with respect to the informants – is also a challenge in the writing-up of the report. We have therefore chosen not to provide background

information in connection with the quotations – nor will it be possible to put together quotations from individuals so as thereby to be able to identify them.

Even the interview process has in itself been challenging, because we have been interviewing people on issues and topics that are both personal and, for some, rather difficult. It has been our aim in this process to show the necessary respect for the people we have interviewed, to be clear with them as to what our role is, to inform them thoroughly of their rights and to bear in mind the care and respect the situation demands. It is our hope that we manage to convey the results with due respect for the informants and respondents who came forward with stories and experiences from their lives.



## **PART II MATERIAL LIVING CONDITIONS AND WORKING LIFE**

We know HIV affects particular groups who from the outset are at serious risk of living in poverty (see for instance Fløtten et al. 2001). For example, people from immigrant backgrounds and those who use or have used hypodermic syringes are both overrepresented among poor people. On the other hand, we know gay groups achieve relatively high scores and thus can play a part in raising the levels of living condition indicators (Hegna et al. 1999). It is also common knowledge that there is a connection between health and other living condition indicators – see for example Report no. 20 to the Storting, the Norwegian parliament (2006–7). Internationally, HIV is largely a poor people’s health problem (UNAIDS 2008).

In this section, on material living conditions, we will, in addition to income, look at housing as an indicator of living conditions. Another important question is whether people with HIV have other or more financial problems than the population in general.

In this part of the report, furthermore, we take up issues of labour market participation and openness in working life.





## 4 Income and housing

The respondents in the study of the living conditions of people with HIV in 2001–2 (Fangen et al. 2002) were confusingly similar to the population in general as far as income distribution was concerned. The explanation for this was that some of the groups in question – for example, gay men – raised the level, whereas other groups – such as immigrants – dragged it down. Table 4.1 shows how the respondents are distributed with regard to the question on main sources of income.

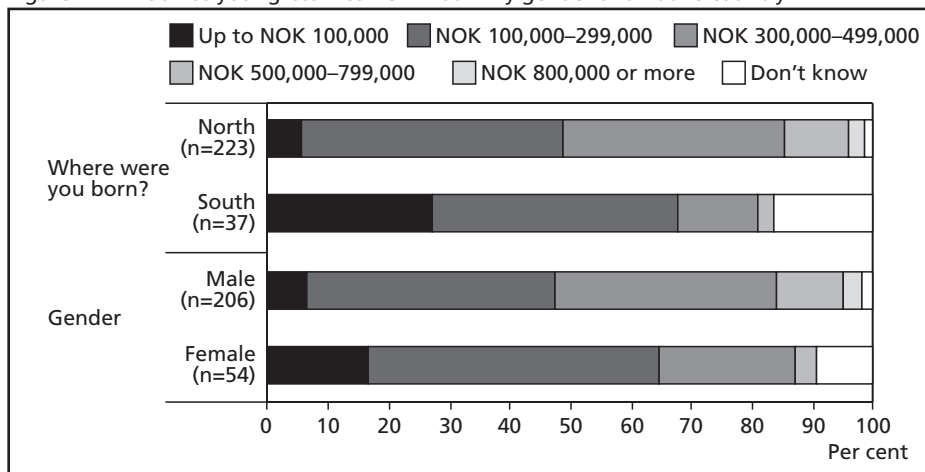
Table 4.1 Main source of income among respondents in sample. Percentages. (N=249)

Vocational rehabilitation	7
Receiving social benefit	3
Student/pupil	4
Houseparent	1
Old-age pensioner	4
Receiving disability benefit	23
Long-term sick leave	2
Other	4
Unemployed	4
Working	56

We see from Table 4.1 that work is the main source of income for a little over one-half, whereas disability benefit is the main source of income for almost one-quarter. The average income among the respondents – a respondent's gross income – is 300,000 kroner. Across the population as a whole, the average income per household was 339,000 kroner in 2006.<sup>3</sup> However, this is a measure of households' net incomes and not individuals' gross incomes. In Norway, average net income among lone occupants in the 30–44 age group was 237,000 kroner in 2006. It is difficult to compare these figures directly but the figures may nonetheless indicate that there is no big difference between the respondents and the general population. The respondents' income level lies just a little below the income level among the rest of the population. However, there are big variations between groups of respondents. Women's incomes are lower

<sup>3</sup> <http://www.ssb.no/inntekt/>

Figure 4.1 What was your gross income in 2007? By gender and native country.



than men's and people born in the North (Europe and North America) have better incomes than people born in the South (Asia, Africa and Latin America).<sup>4</sup>

Figure 4.1 reveals that 49 per cent of those who were born in the North had gross incomes of less than 300,000 kroner, whereas 67 per cent of those born in the South had gross incomes of less than 300,000 kroner. Gross income means income before tax and deductions. Pensions, disability benefit and social security payments are counted as income. Of those born in the North, 5 per cent had gross incomes of less than 100,000 kroner, whereas 27 per cent of those born in the South had gross incomes of less than 100,000 kroner. In other words, income is decidedly lower among those originally from the South than among those originally from the North.

Of the men, 48 per cent had gross incomes of less than 300,000 kroner, whereas 65 per cent of the women had gross incomes of less than 300,000 kroner. Of the men, 6 per cent had gross incomes of less than 100,000 kroner, whereas 17 per cent of the women had gross incomes of less than 100,000 kroner.

Among the HIV-positive people we have made contact with in this study, as in the rest of society, there is clear disparity in income between women and men. However, this disparity would seem to be greater than in the rest of society. This is probably due to the fact that, among the women, there are a significant group who come from groups at high risk of low income – not least in the immigrant groups. From Figure

<sup>4</sup> To simplify the analysis and obtain adequate numbers of respondents in each group, we have constructed larger categories by combining respondents from different countries. We have combined those who were born in Norway, the rest of Europe, North America and Australia/New Zealand in a group we have called 'North'. We have also combined those who were born in Latin America, Asia and Africa in a group called 'South'. The North group thus consists of industrialised, wealthy countries, whereas the South group consists of so-called Third World countries.

4.1 we can also see that incomes are significantly lower among those born in the South than among those born in the North. That over one-quarter have gross annual incomes of less than 100,000 kroner means that, in this group, there are a significant number of people at risk of poverty. Of the Norwegian population, 11 per cent have incomes below the EU poverty threshold (60 per cent of average income).<sup>5</sup> Even if we do not have comparable figures, then, it is obvious that a significant proportion of the group of HIV-positive people born in the South fall below the poverty threshold.

As far as the informants in the qualitative interviews are concerned, the incomes of those who remain in work are the same or better than they were before they contracted HIV, but the incomes of most are reduced as a result of multiple sick periods or vocational rehabilitation periods. The majority of the informants who were interviewed receive disability benefit and several have received disability pensions at early ages as a result of their HIV diagnosis. They thus receive low monthly payments. For some, it is fixed-term disability support that has resulted in a reduction of income. Though several of those whose main source of income is disability pension talk of low income, it would seem they have nonetheless adjusted to their lower levels of income:

It [the informant's income] was considerably worse when I received benefit. It was considerably worse than I had when I was working, because actually my income fell by almost half. My earnings were very good in the last three years I was working, really good. So it was a bit like – 'oof'. There was this U-turn, but now it's OK, because now I've got used to it.

Some of the informants who receive disability benefit want to get back to work. All the same, disability benefit has been important to them at a time when they have felt down-at-heel or sick and have not been able to hold down jobs:

When I visited the psychologist, he told me I ought to apply for disability support. I wasn't really ready for that but I said yes because he said so. And I'm very glad I did. The disability support gave me room to breathe. I started getting tired, you know. I didn't have as much to give any more. My immune defence mechanism is, so to speak, moderately compromised. So that means it's ruined in a way, then. So it'll never be as good as a normal person's, but all the same, I feel that, where I've got to now, I want out of the disability thing again. I need that activity – I want to work again. But it gave me room to breathe, where I didn't have to worry about [...]. Now I don't get so much disability benefit, because I haven't been working so consistently all the way along, but I did get enough to get by.

Some of the informants are on fixed-term disability support. This rather often gives lower payments than a permanent disability pension and requires NAV to follow up and clarify whether a person should return to working life or, in the long term, move

<sup>5</sup> [http://www.ssb.no/vis/magasinet/norge\\_verden/art-2007-04-18-01.html](http://www.ssb.no/vis/magasinet/norge_verden/art-2007-04-18-01.html)

over to a permanent disability pension. It is not an arrangement that is supposed to go on applying to anyone. All the same, some of our informants feel that they have not been followed up by NAV, which has consequences for both income and activity in daily life:

I think it said it was supposed to be reviewed but it's never been done. It said it on the papers for four years but I've never been asked any questions. I should've been called in to NAV but it's not happened. I should've had a meeting to discuss whether I ought to start working again, three days a week, but it's not happened.

In summary, we can thus say that the data suggests that the income of people with HIV is roughly on a par with that of the population in general but that there are big differences between the groups and that, in particular, HIV-positive women from countries in the South are at high risk of poverty. Low income can be problematic, especially when HIV starts to affect people's health and they start on medication, not least because then, for example, diets are required that can be relatively expensive.

## Housing

The main finding of the questionnaire study is that people live well in the sense that they have access to the usual facilities we find in Norwegian housing. There are 98 per cent who say their residences have toilets, baths/showers and hot water. Almost nine out of ten have more than one room in addition to the kitchen. In other words, there are so few people who report worse accommodation standards that it is not possible statistically to identify which group they represent.

The qualitative interviews indicate that there is also diversity among people with HIV when it comes to housing. How people live and have established themselves seems to be connected with factors such as their financial situations, where they were in life when they contracted HIV, their training and positions in working life and their family situations. Many of the informants rent accommodation and few are themselves homeowners. Several live in council accommodation. Those who are themselves homeowners seem to be happier with their accommodation. We get the impression that those who have contracted the infection early in life have not had the opportunity to buy their own housing, on account of uncertain finances. Some of the informants are concerned that their accommodation is of a standard that makes it a challenge for them to take care of their health. In some rented accommodation and especially council flats, the informants are concerned for their health on account of features and poor standards that they feel make them ill.

Their positions in the housing market are also important to their prospects and to how they view life with a chronic diagnosis. Several point to the fear of falling ill and to being in an uncertain financial situation as concerns:

The situation I'm in now is that I have rent and I have living expenses but I don't get enough to cover it. That's the thing that's a struggle now, because if I get very poorly now then I'll not be able to manage. I'll have to move out of my flat and it's a frightening and uncomfortable situation. I could get poorly after all, couldn't I?

In the questionnaire study, the question was also asked whether housing was adapted to the individual's health requirements. Table 4.2 shows the response distributions. Table 4.2 reveals that four out of five respondents say their accommodation is adapted to their practical needs. A small group – one-fifth – say their accommodation is not adapted to their health needs.

Table 4.2 Is your accommodation adapted to your practical needs, such as your health situation is today? Numbers and percentages.

	Number	Percentage
Yes	207	80.5
No	50	19.5
Total	257	100.0



## 5 Financial problems

The informants we have been in contact with are variously well-off as regards their financial situations. In connection with the fact that many of the informants receive disability benefit, with rather low monthly payments, there are several who say their finances are straitened. Several have also struggled with accumulated debt. Others mention that they are dependent on family to make ends meet. Some of the informants directly link the difficult financial situations they now experience to contracting HIV, because it has ruined their health so much that they cannot work. At the same time, several of them have major expenses on account of the diagnosis, in connection, among other things, with medicines and diet, which means that their expenses are greater now than they were before they contracted the infection. Apart from this, their incomes have fallen. One of the informants expressed it as follows:

The financial situation has been awful – I don't know how I manage to make ends meet.

For several of the informants, this difficult financial situation linked to having HIV is one of the most challenging things about it, not least for informants who are also looking after their families:

To be perfectly honest, I feel that finances are very much the reason I struggle, when I struggle – they are a constant worry, as big as or bigger than other worries. If it'd just been me, I'd have lived differently, but I feel I have to have a certain standard of living, a sort of conventional life. If it'd just been me, maybe I'd have gone to another country and done voluntary work or something. Finances make everything so much harder. Money isn't everything – I don't want to have a lot of money – but there's something about always knowing you have a small amount to hand if something or other falls to pieces.

There is not necessarily a strong connection between level of income and financial freedom of action within a household. We have therefore looked at other aspects of the finances of people with HIV and asked about financial problems and about change in financial circumstances as a result of the HIV diagnosis. Table 5.1 shows what answers the respondents gave to the question whether having HIV has had any effect on their financial situations.

Table 5.1 Proportion of people who say having HIV has had an effect on financial situation. Percentages. (N=262)

It has resulted in lower income	32
It has meant that I have poorer management of finances	11
It has meant that I have better management of finances	6
Have received disability benefit	23
Other	8

We can see that 32 per cent of the respondents say the HIV diagnosis has led to a reduction in their income. There are 23 per cent who say they have received benefit because of the HIV diagnosis. This last figure is virtually identical to the number of those who state that disability benefit is their main source of income, and indicates that virtually all those in the sample who receive disability benefit do so because of the HIV diagnosis.

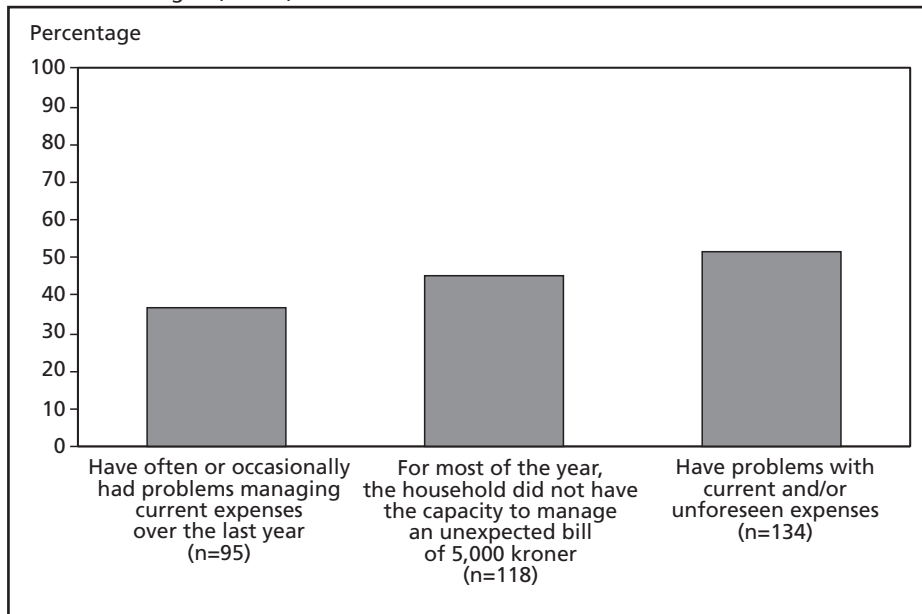
During the previous year, more than one-third experienced difficulties managing current expenses for food, transport, accommodation and the like. Even more, namely half, say their finances were such that, for most of the year, their households did not have the capacity to deal with unexpected bills of 5,000 kroner. If we view these questions together and insert 'and/or' then there are 55 per cent who have experienced difficulties managing current expenses for food, transport, accommodation and the like in the previous year and/or whose financial circumstances were such that, for most of the year, their households did not have the capacity to deal with unexpected bills of 5,000 kroner. This means more than half have experienced financial problems. In the general population, 23 per cent say they do not have the capacity to manage unforeseen expenses (Statistics Norway 2009).<sup>6</sup> Fløtten et al. (2008) put the same questions to a sample of cancer patients. The cancer patients achieve roughly the same scores on these questions as the population in general. We see that people with HIV who have returned the questionnaire achieve significantly higher scores than the cancer patients.

In other words, there are a significant group who report financial problems. On this point, we do not find big differences between the various groups of people who have HIV. The fact that the level of income is somewhat low in comparison with the level among the population in general cannot explain why there are so many with financial problems. The explanation must therefore be found elsewhere. We found a similar situation in 2001–2. We think the financial problems may be due to several factors. One may be a fall in income – another may be increased expenses. A third factor may be inadequate oversight owing to the fact that people are occupied with matters quite apart from personal finances when they are given such a diagnosis. As has been mentioned above, we also asked the respondents whether they thought that the HIV diagnosis

<sup>6</sup> <http://www.ssb.no/magasinet/analyse/tab-2009-02-26-03.html>



Figure 5.1 The proportion of people who report that they often or occasionally have problems managing current expenses and/or that they cannot manage unforeseen expenses of 5,000 kroner. Percentages. (N=259)



had had financial consequences. Table 5.1 reveals that one-third of the respondents say they have suffered a fall in income as a result of the HIV diagnosis. Fewer say their HIV diagnosis has had financial consequences than report financial problems. If, however, we view these questions together, we get an indication that the most common explanation people with HIV themselves have for their financial problems in connection with the HIV diagnosis is reduction of income. Only one-tenth say poorer management of their finances as a result of the HIV diagnosis has been significant.



## 6 Participation in working life

In Norwegian social policy and labour market policy, the ‘work-line’ is a central concept (see for example Dølvik et al. 2007). The ‘work-line’ means, among other things, that the aim of the income insurance system is that all those who are capable of work must provide for themselves through their own work and that both those administering the schemes and the schemes themselves must be conducive to this end. Given the change that anti-virals have brought about in the state of health of people with HIV, one can easily imagine that some of those who obtained disability status before 1997 (the year the medicines were introduced) might actually have been in a position to take part in working life in the years since then.

We also asked about primary occupations at two different junctures – when people were diagnosed with HIV and today. Table 6.1 shows that more than half the respondents (55 per cent) are in work. Almost one in four receives disability benefit.

Table 6.1 Main occupation at time of diagnosis and now. Percentages.

	When you were given the diagnosis, were you...?	Are you now...?
Working	67.2	55.4
Unemployed/looking for work	5.7	4.5
In rehabilitation/vocational rehabilitation	6.1	6.4
Taking part in the introductory programme for new immigrants	1.1	0.4
Receiving social benefit	3.4	3.0
A student/pupil	5.0	4.1
Working at home/a houseparent	0.8	0.7
An old-age pensioner	0.4	4.5
On disability benefit	2.7	23.2
On long-term sick leave	2.3	2.2
Other	5.3	4.1
Total	100.0	108.5*
N	262	267

\* In reporting their current situations, some people have ticked several options and the sum is therefore more than 100 per cent.

The big change Table 6.1 reveals is the fall in the number of people in work and the rise in the number of those who receive disability benefit. Therefore we also tried to find out something more about who makes up the group of people who receive disability benefit.

Table 6.2 Proportion of people receiving disability benefit by gender and native country. Numbers and percentages. (N=265)

		Number	Percentage
Gender	Male	56	27
	Female	6	10
Native country	North	59	26
	South	3	8

Table 6.2 shows that men from the North make up almost the entire group of people who receive disability benefit. There are very few women or people from the South among those who receive disability benefit. This may be connected to the fact that gay men from the North and from Europe dominate the group who have had the infection longest.

There is also an overrepresentation of people who receive disability benefit in the qualitative interviews. Of twenty-five informants, fourteen receive disability benefit. Of these, two people are 50 per cent disabled and work part-time on the side. In addition, there are two informants who have applied for disability benefit but who, at the time of their interviews, were receiving rehabilitation allowance or were unemployed. Several of the informants who receive disability benefit claim that they now feel fitter and that they want to work. However, they find it difficult to open a dialogue about this with NAV. All the same, several of the informants on disability benefit say that, at the time the benefit was granted, it was important. They have been through the experience of staying in jobs for which, because of their HIV diagnosis, they have no longer had the physical strength. For some, it has been the side effects of medicines that have meant they have no longer had the strength to work. In spite of this, there are several informants who want to get back to work:

Many times I've thought that I'd like to go back to work [...] It's not 'fitting' for a man not to work and just to stay at home – there's no pride in that. But it's not possible with my state of health. [...] I've never been contacted by NAV regarding my disability or any changes in my state of health that mean options other than disability pension can be considered.

One of the informants was unemployed and looking for work, one was in vocational rehabilitation (which soon came to an end). Five informants were in work but two of them were off sick at the time the interviews took place. One of the informants was a pensioner and one was a student.

One general finding from the interviews was that contracting HIV had had an impact on participation in working life – on whether or not people were in work today. As one of our informants says:

Very few people with HIV carry on as before – you can probably count them on one hand.

## Working hours and conditions

Table 6.1 revealed that 55 per cent of the respondents were working. With a view to gaining a better understanding of their experiences in the labour market, they were also asked about their working capacity. Table 6.3 reveals the responses to that question.

Table 6.3 Let us suppose that your working capacity at its best would have been 100 per cent. How many percentage points, then, would you give your current working capacity? Numbers and percentages. (N=220\*)

Percentage working capacity	Number	Percentage
0–29	22	10
30–59	45	20
60–89	30	14
90–110	123	56

\* The question was put to those who were in work, but others in fact answered the question on working capacity.

We see from Table 6.3 that more than half of the respondents rate their working capacity at over 90 per cent. There are a significant group – as many as 44 per cent – who feel that their working capacity is reduced.

The Norwegian labour market is tight and, with such strong socio-political emphasis on the ‘welfare to work’ policy, one might imagine that people with a strain on their health, such as HIV, would want to work fewer hours – that the goal for individuals would be to maintain contact with the labour market at a level their health situations allowed.

Only to a very small extent were working hours a theme of the informants’ interviews – although several of the informants who are disabled reported that they wanted to

Table 6.4 Working hours per week at time of diagnosis and now. Numbers and percentages.

	Time of diagnosis		Now	
	Number	Percentage	Number	Percentage
2–10 hours	3	1.7	4	2.6
11–20 hours	1	0.6	12	7.7
21–30 hours	5	2.8	12	7.7
31–40 hours	115	65.3	80	51.6
41–50 hours	39	22.2	30	19.4
Over 50 hours	13	7.4	17	11.0
N	176	100.0	155	100.0

work part-time but that it is difficult to find opportunities to do so. Some work part-time aside from disability benefit. Most, however, do not find NAV very cooperative when it comes to finding solutions whereby they can combine work with disability benefit. By way of a substitute for working part-time, some choose instead to engage in voluntary work. There they can be active and sociable. One challenge for the public support system will be to find opportunities, to a greater extent, for part-time work and provision of activities for people on disability benefit who feel well enough to return to work in tailored positions.

Table 6.4 shows how the respondents describe changes in working hours from the time they were diagnosed until today. As far as working hours are concerned, the change seems first and foremost to be that fewer work, but the pattern is by and large quite similar. However, there is a reduction in the number of those who work normal hours, while there is an increase in the number of those who work more hours than normal and those who work part-time.

## Arrangements in the workplace

The responsibility of employers to create good conditions for HIV-positive people in the workplace is an important topic internationally (see for example Hodges 2004, ILO 2001). For people with HIV, it can often be necessary both to have the option of working part-time and to have flexitime arrangements. Several of the informants, as has previously been mentioned, have expressed the desire to find out more about opportunities to work part-time and receive disability benefit simultaneously. People with HIV regularly have to attend departments of infectious medicine for medical appointments. Some of the informants find it difficult to explain to employers and colleagues why they visit their doctors so often:

Daily life would of course be easier if I didn't have HIV, because when I go to the infection department from work, for example, I'm away for almost half a day. It takes a long time. Then people at work start wondering why I'm away so often and so long – medical appointments don't last half a day, after all. Questions like that come up and then – you know – it's a bit like: 'What do I say now?' I have to lie, you know.

The strain having to explain absences of this kind can represent shows that people with HIV find it difficult to be open in the workplace. Some have also found that openness about their HIV diagnosis has meant that they have not been able to finish their training or that they have not remained in work, because employers or NAV have said they are not suitable for the work they want or do, as they have HIV. Though these stories relate to situations several years ago, they tell us a lack of acceptance toward HIV-positive people at work is also a problem today. These are situations that have had long-term consequences for the professional careers of those involved. Another of our informants reports the following:

I was refused training that time. [...] They didn't want to take on auxiliary nurses with HIV. I might represent a danger to third parties. [...] There was even an occupational psychologist who said that, via NAV. So the only thing they could suggest to me was just to take it really easy and I should avoid stress and things like that. So the best thing for me was to go home. So NAV, you see, dispensed with a problem. They thought it'd be a problem for them, you know. It wasn't very easy for them. You see, I didn't want to be open in that way as far as an employer was concerned, because I'd rather choose to do that myself, you know. So they thought it'd be a massive problem. To go and say you have a chronic illness is one thing but you kind of ought to say a little about what's at stake. You may fall ill from time to time, you know. Then you have the rights on your side but of course an employer ought to be allowed to know what's wrong with you, you know. But people don't really need to know, beyond the fact that I was chronically ill. In a way, I was just shunted onto disability benefit.

In the questionnaire study, we asked about the need for special arrangements in working life. Table 6.5 shows the distribution of the answers that were given. The table reveals that there are a small group of respondents who state that they have needed adjustments in the workplace. Three-quarters of those who are in work say they have not needed any adjustment. The adjustment that the greatest number of respondents mention is a change in the number of working hours. The question was also asked whether the needs had been fulfilled. Of the forty respondents who answered this, 67 per cent say the needs have not been fulfilled. In other words, in the relatively small group who have needed special arrangements, as many as two-thirds say no special arrangements have been made in the workplace.

Table 6.5 Special arrangements needed in the workplace. Multiple responses possible. Numbers and percentages. (N=143)

	Number	Percentage
Have needed...		
to change number of working hours	22	15
fewer assignments in order to reduce physical strain	12	8
fewer assignments in order to reduce mental strain	14	10
advice and direction in connection with work situation	8	6
Have not needed any	109	76

Table 6.6 shows how the respondents are divided on the question whether there has been any change in their connection to the labour market and to what extent this may be attributed to the HIV diagnosis. A little more than one-third of the respondents who work say their connection to working life has changed. Just over two-thirds of these in turn say this is due to the HIV diagnosis. These figures suggest having HIV has an effect on participation in working life, not least on how much work people have the energy to do. Even if many work and many feel their working capacity is almost full, there is a significant group who have felt the need for change and there are many in this group who have not been able to get this need fulfilled. This raises the question whether there are some people with HIV who receive disability benefit when really they might have managed, for example, to work part-time.

Table 6.6 If there has been any change in your connection to working life, to what extent is this due to the fact that you have HIV? Numbers and percentages.

	Number	Percentage
There has not been any change	84	63.2
The change has to a large extent been due to the HIV diagnosis	14	10.5
The change has to some extent been due to the HIV diagnosis	15	11.3
The change has not been due to the HIV diagnosis	20	15.0
Total	133	100.0

I had a good relationship with the employee adviser, I thought. I had a meeting with him and was informed that they couldn't have HIV-positive people working for them. Then I got in contact with the woman who's a lawyer at HivNorway – she tried to explain things a little to the man who was the manager where I was working. But I'd received a letter, after all – I know they've a copy of it at HivNorway [...] It said there that they couldn't have HIV-positive people working for them – it was a danger to others.



## 7 Openness in working life

Those who are diagnosed with HIV today can expect to live with the virus for many years. This may mean people with HIV have a new basis on which to evaluate openness about their HIV status with respect, for example, to family, friends and employers. Stigmatisation and shame are often pinpointed as obstacles to being open and not being open can itself lead to isolation and loneliness. Openness and degrees of openness were a central theme of all the interviews – and many point to the workplace in particular as the most difficult arena to be open in, especially when they feel ill or need special arrangements. There seems to be a difference between people who have contracted the infection recently and those who have had HIV for a long time. Those infected recently are less comfortable telling employers they have HIV. Two informants say the following:

No, I haven't had the inclination, and I've thought things over and realised no one has the right to know. And so I haven't thought of presenting myself as having it, either. So if an employer wants to google me and find things out then let him, but I haven't thought of presenting myself as having HIV.

I want to separate work and personal life. That makes it harder to be open. But it's also due to the shame I feel and the fact that I may meet with ignorance and fear because people are often irrational. An important reason I've not been open about my HIV is that the process of coming out of the closet as gay was long and difficult for me. When I became HIV positive, I felt I was placed in a new closet and I haven't been able to endure the thought of coming out of the closet once again and telling a story.

The informants who have had HIV for a long time, and perhaps especially those who were diagnosed with HIV before the advent of the medicines, look upon HIV as a disease more than a chronic condition. This means they feel differently about saying they have HIV than those who have not had the infection as long. For the group who were diagnosed long ago, it has to a larger extent become part of their own identity. Thus they are less sceptical about telling employers and colleagues about their HIV status.

Several of the informants have chosen to tell employers they have HIV. They have found themselves received in various ways. Some tell 'sunshine stories', others 'horror examples', of how they have been received. The following two narratives illustrate this.

With regard to my job, too, I went a very long time without telling anyone. I worked in a place where HIV-Aids cropped up as a topic now and then, [...] and there were also various attitudes toward it among the employees. So I suggested to my boss that we ought to hold a course on HIV-Aids for all the employees, on modes of infection but also with regard to attitudes. He thought it was a good idea. We got in touch with HivNorway to get them to give a seminar but at that time he didn't know I was infected and so I thought I could use the course as an opportunity to get the lay of the land as far as those around the table were concerned. Then one of the people taking the course asked the boss how he'd react if one of the employees came and said he/she was HIV positive. Then he answered in a quite politically correct way and said he'd ask what this person needed, whether there was any need for special arrangements in the work situation, whether there was anything an employer could help with in order to make the situation easier and so on. It sounded great, of course, and so I went and thought it over for a few weeks, and then I thought, 'He said it, after all, so in that case I can try and see whether it works in practice.' I said it and he did exactly as he said he'd do – it was absolutely fantastic. [...] He even came along to the hospital when I was about to start taking medication. He wanted to come along as my employer, he wanted to find out whether the fact that I was about to start using medication had any practical importance, and to find out whether there was anything he could make arrangements for. Or whether there would be any change. To gain some more knowledge about it, pure and simple. It was really unbelievably good.

This positive experience stands in contrast to the story of a man who reported his HIV status at the workplace early on, because he thought it was the right thing for him to do:

Then he called me and said that tomorrow we were going to have a crisis meeting with the works doctor. I just said, 'What do you mean by "crisis meeting"?' Then he said we were going to draw up a crisis plan. I didn't have a clue about that but I said, 'OK, fine – I can come.' [...] But it was a complete disaster. It turned into something really dramatic. So – he wanted to make further checks. So check. He got in touch with the works doctor and told her. Without asking me. So I got a bit angry. I said, 'What you've done now is illegal. You've violated your duty of confidentiality.' But he wasn't sure. He'd never had an employee with HIV, you know, so he wasn't sure. [...] My boss didn't really have the foggiest idea about it. And it turned out my boss wanted to go to the other employees and the parents about it, because I work in after-school care. So then I said, 'You can't do that – you have

a duty of confidentiality.’ Then he said he had a duty to inform the employees as well, so then I said, ‘I don’t understand.’ You see, I told him because I had a lot of faith in him. [...] Then in the beginning I didn’t notice any difference in the work situation. [...] And then there was another occasion – this time there was an adult who cut their finger. This time I was the one there and I was about to start helping, you see, and then he intervened. He took charge and so on. I did understand why it had happened and I took it up with him. I’m a grown-up person, after all, and I do really want to know what procedure to go by. [...] I really regret choosing to be open at work – really regret it.

It seems levels of knowledge among colleagues and employers are key to how people treat HIV-positive people in the workplace. The ‘sunshine story’ testifies to sound knowledge as to what was important for the employer’s part in order for the person with HIV to manage properly at work, whereas the negative story shows that poor knowledge of living with HIV, how HIV spreads (and does not spread), rights and the duty of confidentiality can lead to a very difficult situation for the person with HIV in the daily work situation too. Unfortunately we have heard more negative stories than positive ones. Several people have experienced negative reaction when they have talked about their HIV status, and several have even experienced direct discrimination and exclusion from the workplace. Working to make it easier to be open at work would seem to be a big challenge. One of the informants expressed profound despair in this regard:

It’s the people who discriminate against us who kill us. The doctors discriminate – those who work with us discriminate.

In last year’s attitude study (Mandal et al. 2008), 60 per cent responded that they thought people with HIV should be obliged to notify employers and colleagues of their HIV status. Furthermore, one-half responded that they thought that people with HIV must accept change to their workplace assignments in consideration of other employees. There were 18 per cent who would avoid close contact with infected work colleagues or fellow students. These may be seen as relatively high figures and may indicate that the workplace is an arena where people with HIV can encounter problems in connection with openness. Unfortunately the experiences of people with HIV seem to confirm this.

One important finding from Table 7.1 is that two out of three respondents have not been open about their HIV diagnosis in the workplace (the question was only put to those who are in work). Six out of ten of those who have opened up to colleagues report positive reaction but almost one in three (fifteen out of forty-nine) of those who have told their colleagues they have HIV has found that colleagues distance themselves, becoming more reserved or wary. There are also some who experience a reduction in professional or wage potential. This means that even if a majority of the

Table 7.1 Have you told any of the people you work with that you have HIV? Numbers and percentages.\*

	Number	Percentage
Yes	51	34.5
No	97	65.5
Total	148	100.0

\* The question was put only to those who are in work.

respondents have not experienced negative responses to openness at work, there are a relatively large group among those who work and have been open in the workplace who have had negative experiences. It is likely that experiences of this kind have an influence on the HIV-positive individual when he or she decides whether or not to be open in the workplace.

When we ask people’s reasons for not telling colleagues or workmates they have HIV, we get the following responses:

Table 7.2 Why have you not told your colleagues you have HIV? Multiple responses possible. Percentages. (N=96)

Afraid of losing the job	28
It is a private matter	78
Fear of social exclusion	44
Fear of diminished career prospects	41

The largest group in Table 7.2 is made up of those who say it is a private matter. However, one-quarter of those who have not said they have HIV at work say the reason for this is that they are afraid of losing their jobs. In other words, there is widespread fear among the respondents that they may be susceptible to such a strong form of discrimination. The attitude study (Mandal et al. 2008) revealed that many people were sceptical about working with HIV-positive people. The scepticism people with HIV have about being open in the workplace reflects this. Almost half are afraid of social exclusion and/or diminished career prospects. The fear goes so far that some are afraid of losing their jobs.

In Chapter 3 we showed that there is a wide variation in the sample as regards the time of infection, which ranges between 1983 and 2008, inclusive. Here we will look more closely at the connection between openness in the workplace and when the respondents were diagnosed with HIV. On the one hand, we might expect that it would be easier to come forward today than in the 1980s, for example, because back then there was less knowledge and more fear that HIV would affect a substantial number of people. On the other hand, we know that inadequate knowledge and restrictive,

Table 7.3 When people have contracted HIV and whether they have told any of the people they work with about the diagnosis. Percentages.

	Yes	No	N
1983–1989	56.5	43.5	23
1990–1999	48.6	51.4	35
2000–2008	25.0	75.0	84

negative attitudes toward people with HIV are still relatively widespread in Norwegian society – something which, for example, was confirmed by Fafo’s 2008 knowledge and attitude study (Mandal et al. 2008). It may, therefore, be just as difficult to be open about the diagnosis today.

Table 7.3 does not directly tell us whether it was easier to be open in the 1990s than in the 1980s. It provides no information about when those in question chose to talk about their diagnosis. Some, for example, may only have chosen to open up long after being diagnosed. A person who contracted the infection in the 1980s may have kept this secret for ten or twenty years before he or she talked about it. Also, the individual’s decision to be open about the diagnosis will often be the result of a long and demanding thought process, a process that need not necessarily be influenced by the views and conceptions of HIV that exist in society at any given time; being open about HIV is also to a large extent the result of a personal recognition process. Findings that Tables 7.2 and 7.3 present, however, may indicate whether there is any connection between when people contract HIV and the likelihood that those infected will have talked about this to any of the people with whom they work.

Table 7.3 points to a connection of a kind between the time of diagnosis and whether the subjects have told any of the people they work with that they have HIV. Having informed colleagues at work is most common among those who were diagnosed in the 1980s. Accordingly we see that only one in four of those who have been diagnosed in the 2000–2008 period has chosen to be open. Once again, however, the point must be made that the table must not be construed as showing that it was easier to be open in the 1980s; for all we know, many years may have passed for many of those diagnosed in this period before they talked about it in the context of work. We believe rather that the table says something about the fact that talking openly about an HIV diagnosis in the workplace is difficult and a decision and conclusion many take a long time to reach.

Overall the results from the attitude study, the in-depth interviews and the questionnaire study suggest one thing, namely that working life is an area where there is still a lot to do as regards both room for openness and protection of rights. Working life would seem to be a challenge for HIV policy.



## **PART III HEALTH AND EXPERIENCES OF PUBLIC SERVICES**

Research on living conditions among those afflicted with cancer in Norway has shown that many feel small and powerless in their encounters with a large and extensive support system, in which long application processes and inadequate support/aid from the state demand energy and resources (Grønningsæter et al. 2007). It is important to find out to what extent people with HIV share these experiences in their encounters with public services and provisions. This is the theme of this part of the report. First, however, we shall look more closely at how the people in the sample rate their physical health and the use of medicines.





## 8 Physical health and the use of medicine

### Physical health

Because of medical advances, HIV infection has become a chronic condition that it is common to regard as being on a par with other chronic illnesses, such as cancer (Fangen et al. 2002). Since it is a medical condition, HIV is to a large extent regarded as a medical phenomenon and a health problem. In this study of living conditions, we focus on what it is like to live with HIV, starting from a broad approach to the topic. Physical health is regarded as just one of many elements, constituting individuals' living conditions together with other elements of living conditions. At the same time, there is little doubt that individuals' states of health, physical as well as mental, are of major importance to their situations as regards living conditions. One reason physical health is perhaps especially important is that individuals' physical states of health also restrict the extent to which it is possible for them to realise their plans and ambitions in other arenas of living conditions. If physical health fails, it will quickly affect other areas of living conditions – inasmuch, for example, as people will be in less of a position to participate in working life and in social contexts and cannot to such a large extent avail themselves of a variety of cultural provisions.

As many as 68.2 per cent of those who gave responses in the questionnaire study rated their states of health as either good or very good. In view of the fact that HIV is a serious chronic infectious illness connected to various health problems, this figure is rather surprising. One explanation is probably that the medicines work well for many and help them to feel fit and free of illness. According to the 2005 study of health and

Table 8.1 Own assessment of health. Numbers and percentages.

	Number	Percentage
Very good	69	25.6
Good	115	42.6
Neither good nor bad	60	22.2
Bad	25	9.3
Very bad	1	0.4
Total	270	100.0

living conditions (Statistics Norway 2005) the proportion of the population in general who rated their health as good or very good in 2005 was 81 per cent.

Because of the low response rate and the danger of imbalances in the sample, however, we cannot generalise on the basis of this finding. It is difficult to determine to what extent this difference is due to contracting HIV and/or to the other attributes of the people in the sample. Among other things, we saw that some people in our sample contracted the infection through intravenous drug abuse, and these are probably people whose states of health are poor irrespective of the HIV diagnosis. In spite of this, we are fairly confident that the figures reflect a real difference in state of health between people with HIV and the population in general, because HIV is an infectious illness that very often has an effect on the state of health – by virtue of the fact, for instance, that it often results in increased risk of a number of other infections and illnesses too.

The response distribution is virtually identical to the Norwegian figures from 2002 and is also largely consistent with findings from Australia and New Zealand, where 68.1 per cent and 77.2 per cent, respectively, rated their health as either good or very good (Grierson et al. 2006, Grierson et al. 2008).

At the same time, there is a certain possibility that the people in the sample may have construed the concept of health differently; while some may have restricted it to physical health, others may have considered both physical and mental health. However, this is not a problem – with this question, we have, in any case, been concerned to map out HIV-positive people’s own views of their states of health, physical as well as mental.

Table 8.2 shows that a somewhat larger proportion of heterosexually infected people than homosexually infected people rate their general states of health as good or very good (72.5 per cent and 66.9 per cent respectively). This is virtually identical to the figures from 2002 (Fangen et al. 2002). At the same time, the proportion of those who rate their states of health as neither good nor bad is rather larger among those infected homosexually.

Table 8.2 How do you rate your own health? By mode of infection. Percentages.

	Via heterosexual contact	Via homosexual contact
Very good	31.9	26.0
Good	40.6	40.9
Neither good nor bad	17.4	24.7
Bad	10.1	7.8
Very bad	0.0	0.6
Total	100	100
N	69	154

People with HIV may, as a result of failure of their immune defences, be more susceptible to various HIV-related illnesses and conditions. However, it is not possible to deduce from the data we have collected whether the 8–9 per cent who report poor health have HIV-related illnesses. All the same, we can see that those who are in the category ‘other’ (drug users, prostitutes, et al.) rate their health as bad to a larger extent – though this may be connected not to HIV but, just as readily, to other illnesses and conditions, since these are groups who are often susceptible to illnesses and afflictions of other kinds (for example, hepatitis, as well as general ill health as a result of drug abuse). In the study from New Zealand, 24.9 per cent stated that they had, or had had, an HIV-related illness (Grierson et al. 2008). Our study also charts state of health in other ways. The respondents were asked how many of the previous fourteen days they had spent completely or partly bedridden at home as a result of the HIV diagnosis. The answers largely substantiate the picture Table 8.2 presents. Many in the sample rate their health as good. Admittedly, 10 per cent state that they have spent one day or more partly bedridden at home, but there are only eight people who declare that, over the previous fortnight, they have spent one day or more completely bedridden at home as a result of the HIV diagnosis. Given that HIV is a chronic infectious illness connected with various symptoms and pain, this figure does not seem high. The self-reported state of health in the sample, in other words, appears to be good. At the same time, 37.6 per cent answer yes to the question whether they have developed physical pain as a result of the fact that they have HIV. Further, 14 per cent respond that they are uncertain whether they have done so.

When it comes to the qualitative interviews, these to a large extent substantiate the findings of the questionnaire study. The informants generally report comparatively good physical health. However, there are some who report painful side effects from medication. All the same, our impression, in comparison to 2002, is that the stories of side effects are fewer and less dramatic. Several people testify to a connection between good physical health and the improvement in the medicines. One informant says:

I had some good news a fortnight ago – that I had a virus count of zero and that my immune defence mechanism was excellent. That was just completely brilliant, because I had a virus count that was through the roof last summer. And virtually zero immune defence. [...]

## The use of medicine

Before the anti-virals came onto the market, HIV in a medical sense was defined as a deadly infectious illness. With the introduction of these medicines, HIV became a chronic infectious illness. The medicines have led to a significant fall in the mortality

rate among people with HIV and helped to change both prognoses and life prospects radically (Carstensen and Dahl 2007). As a result of better medicines, people with HIV, like other people with chronic illnesses, can live for a long time. It is also obvious that this medical progress is very important to the living conditions of people with HIV and to their prospects of living good lives. All medicines, however, have potential side effects, and this is also true of anti-virals.

In the study, questions are asked about the use of medicine, because this is something that can undoubtedly have an impact on the individual's living conditions, in a positive sense if the medicines help to reduce aches and pains, but also potentially in a negative sense if the medicines have significant side effects. It will be of interest to compare the response distributions now with those in 2002 (Fangen et al. 2002). Has there been a positive trend since 2002? It is also useful to chart this since many people with HIV have now been taking the medicines over *longer periods* and thus have a broader base of experience and a better basis on which to assess effects and side effects.

With the first question about the use of medicine, we wanted to chart how many receive and do not receive anti-viral treatment. In 2002, 73 per cent of the subjects reported that they received treatment of this kind (Fangen et al. 2002). In our study, the proportion is lower – 67.9 per cent say they receive such treatment. However, this need not mean the use of medicines has fallen. It is conceivable that the differences are due to sample variations. What, then, about the effects of the medicines? Have the experiences and perception of these changed since 2002? To find out, we presented various statements about how the medicines work, with which the respondents were asked to say they agreed or disagreed. Table 8.3 shows the response distributions. The low numbers of respondents (N) are due to both the fact that only those who take medicines answered this question and the fact that some people who take medicines did not want to answer the question.

There are other results in Table 8.3 that are encouraging. Of those who answered the question (and who correspond to the part of the sample made up of people who take and have experience of anti-virals), 82 per cent say taking the medicines helps to improve their overall condition. Further, we see that two out of three say that it helps to reduce the frequency of infections. There are also more people who disagree than agree with the statement that the medication reduces their physical capacity. All in all, therefore, there are several findings here that suggest the *positive experiences* linked to taking medicine are more dominant than the negative ones. Most people by far say taking the medicines regularly is no problem (68.7 per cent against 23.3 per cent), and the proportion of people who say the medicines do not restrict their social participation is also significantly larger than the proportion who say they do.

If we compare the results in Table 8.3 with those in 2002, there seems to have been a positive trend with regard to the experiences the respondents have in connection with taking anti-virals. To be more precise, the response distributions in this study are

Table 8.3 Do you agree or disagree with the following statements on how medical treatment affects your daily life? Percentages.

	Completely or rather agree	Neither agree nor disagree	Completely or rather disagree	N
It improves my general condition	81.5	14.5	4.0	173
It eases the pain	11.3	53.1	35.6	160
It causes me troublesome side effects	50.3	9.6	40.1	167
It reduces the frequency of infections	67.3	23.6	9.1	165
It reduces my physical capacity	40.5	16.6	43.0	163
It makes it difficult to visit other people	24.6	9.6	65.9	167
It limits my social participation	29.0	8.6	62.3	162
It is difficult to take medicines regularly	23.3	8.0	68.7	163
I am concerned about possible side effects of the medicine	54.3	9.1	36.6	164

in every respect more positive with regard to the medicines than those in 2002 were. There is, then, little doubt that people with HIV find the medicines they take today work better than those in 2002 did. However, half still report that the medication gives them side effects. Most are also concerned about the potential side effects of the medication.

The qualitative interviews go some way toward confirming this bipartite picture. Several of the informants say they have experienced side effects from the medication, such as substantial wind, fatigue, night sweats, sleep problems and nightmares. At the same time, it would seem today's medicines do not cause major side effects to any great extent and that the stories of side effects are more from the period when the medicines were new. Today's medicines are described as much better, with fewer side effects – but there are exceptions. A theme that ran through the interviews was that it can be a mental challenge to start taking medicines that one will be on for the rest of one's life, and that several people talk of being 'pill weary'. All the same, the informants indicate the medicines are something they have to learn to accept:

Yes, I notice some [side effects], but I suppose the fact is I have to learn that that's the way it is, and I suppose I have to accept it if I'm going to handle having this crutch. Because in a way, you see, it is a crutch. So then, you have to face the consequences,

but – you know – living with it is, so to speak, something I have to deal with. I just hope it doesn't get too bad. I talk to my doctor about it all the time.

Some of the informants are opposed to medicine because they are afraid of the consequences. One informant says he stopped taking medicines because he is afraid of possible consequences arising from them and says he feels much better in health terms since he stopped taking the medicines. One put it rather strongly:

The doctors ask whether we have suicidal thoughts but it's the medicine and the stigmatisation that make us suicidal. I know of a woman in England who takes medicine off and on. She's fine.

Others say they will oppose taking medicine even if they come to a point where the doctors say it is necessary to start.

## Steps to improve health and fitness

While, little by little, taking anti-virals has come to be seen as a safe way to reduce symptoms and pain, there are also other ways to maintain or build up good health. Diet, exercise and the extent to which one uses various intoxicants are all important areas that are documented as being very important to the individual's health, whether or not the individual has HIV. At the same time, it is probably all the more important for people who have contracted HIV to be conscious about living healthily, because both a nutritious diet and regular exercise are important with a view to strengthening

Table 8.4 Steps to improve one's health and condition. The percentage of people who answered 'yes'.

	Percentage	N
Try to eat very healthily	66.5	179
Exercise	56.5	152
Try to smoke less	21.6	58
Have quit smoking	15.6	42
Try to reduce my alcohol consumption	21.9	59
Have stopped drinking alcohol	11.9	32
Try to reduce my substance use	11.5	31
Have stopped using substances	7.1	19
Take dietary and vitamin supplements	52.0	140
Don't do anything special	8.6	23

the immune defence mechanism. The individual's state of health will in many ways also form a basis for other living conditions, because one needs good, robust health to be able to live out whatever plans, ambitions and desires one may have in various areas of life. Table 8.4 shows how many people in the sample take various steps to improve their general health and fitness.

Diet, exercise and the use of dietary supplements are the commonest steps to improve one's health and fitness. These are also the steps that are probably most relevant to the majority of the people in the study. Reducing alcohol consumption, for example, is probably not relevant for as many on the basis that their substance use is moderate or low from the outset. As many as 66.5 per cent report that they try to eat very healthily. In comparison, this proportion was 53 per cent in 2002. Also, almost twice as many now say they do a lot of exercise (56.5 per cent as opposed to 30 per cent in 2002). This suggests there has been growing awareness of the importance of living a healthy life, with the focus on diet and exercise. Another important change in comparison to 2002 is that the proportion who says they do nothing special to improve their health is far smaller in our sample than it was in 2002. Granted that the differences may be due to sample imbalances, all in all there would seem to be a trend toward increased emphasis on health, fitness and diet when we compare the two samples.

If we differentiate by infection group, it seems those infected homosexually take various steps to a greater extent than those infected heterosexually. For example, the proportion of those infected homosexually who take dietary and vitamin supplements and the like is almost twice as large as the proportion of those infected heterosexually who do so. The proportion who states that they are trying to reduce their substance use is also larger in the former group. This involves a change in comparison to the figures for 2002, when the differences between the two groups were smaller. However, we must again make the proviso that the connections are not certain – the differences between the two groups may, in other words, be due to other attributes of the people in the sample than the infection groups to which they belong.

Diet and lifestyle were a theme of many interviews. Though taking medicine may play a part in ensuring a long life with HIV, many of the informants are concerned with making lifestyle choices to maintain good health. They exercise more than they used to, eat more healthily and have a desire to take more care of themselves, thus confirming the trends in the quantitative data:

So then, I've always taken great care never to compromise myself when it's come to my health, when it's come to work or whatever. And in particular it's stress I think HIV-positive people have to be wary of, because it really takes it out of the immune defence mechanism. It seems to me that other HIV-negative friends are ill all the time, but I'm well, and there's nothing that gets to me. So I don't think I'm going to die of anything HIV-related. I'm quite convinced of that. I look after my body,

I exercise a lot, I eat a lot of vitamins and I eat good food. As long as I do that, it's only age that can do for me.

But even if the diagnosis of HIV leads more of the informants to take various steps to improve their health and fitness, there are informants who get sick and tired of holding themselves to lives of medication and continual advice and directions on how to live:

But I'm pretty tired of medicine. I'm pretty tired of advice on how I should act and eat and live, even if those who offer the advice mean well by it.



## 9 Mental health

In the previous chapter, we saw how the respondents rated their physical health. We shall now look more closely at how they rate their mental health. Although HIV is defined first and foremost as a physical and medical condition, there is little doubt that having HIV also has major consequences for mental health and thus for quality of life (Smith 2000). Being diagnosed with HIV will, for most people, be a big psychological strain – something the following statement from one of the informants illustrates:

It was a shock to be given it [the HIV diagnosis] – life stopped dead and I wanted to die. I lived in a coma for several weeks and I just existed. I didn't know one thing from another. I didn't know who to talk to, who to tell, whether to tell friends or Mum or the family, how they'd react – it was really hard.

At the same time, it can often be spurious to distinguish between physical and mental states of health, because these are so closely interwoven – something the rise in the incidence of so-called psychosomatic illness illustrates. Besides, the benefit of being in good physical health will be limited if people with HIV live isolated, lonely lives as a result of psychological problems.

Several informants report that they have had mental health problems. Though the medicines may hold the virus in check, 'you don't get any medicine for the negative thoughts,' as one informant put it. There are also several informants who talk about the fear of 'looking ill' and in particular they are afraid of losing weight and becoming too thin. Several informants talk about apprehension and fear of death during periods when they experience illness. This also applies to illnesses that may not necessarily be directly related to HIV.

Then when I start getting well, then it starts to blow over, but it's not like it goes between one day and the next – it feels like a hangover, fear of death for a few days, even though I'm on the mend. I'm probably more afraid of death now than ever, even though I know it's not entirely rational.

Though several of the informants say that they are fine, or that they have been lucky, in some of the interviews it is apparent that they are very unhappy and have been through a great deal of hardship. It is conceivable that we live in a society that demands that people play a kind of 'be happy' game. There is a lot that one can make allowances

for but there is also a lot that is difficult and that it would seem to be difficult to accommodate:

In general, you know, my entire life has changed since I contracted HIV, but I think that I'm all right and that I'm lucky. But my doctor says something else – that I'm not all right. He says I'm dissimulating. That may of course be, but I don't know. That's why he's referred me to a psychologist, to bring more of it out. That's why I've said yes.

Several of the interviews bear witness to considerable loneliness, sadness and melancholy, when there is no one for the informants to share their concerns with – but for most people the difficult times seem to come for temporary periods and then to pass again:

It's a bit up-and-down. I say I don't think about HIV, but it's there. In the back of my mind. It's not something I talk about [...] I keep it very much to myself.

I don't sleep at night. That's why I'm off sick. I take pills to sleep but it doesn't work. At night I'm very restless, but I sleep a lot in the daytime. Because in the daytime there's nobody home. [...] Then I sleep. At night I'm afraid to close my eyes to sleep. I'm afraid about whether I'll wake up in the morning. This is something completely new. I have had sleep problems before, you know – but not like these. I really have a hard time sleeping.

Mental health seems in many cases to be directly linked to how individuals deal with their HIV diagnosis. For some, the diagnosis has meant a new life, in which they take life more seriously. These informants talk about the processes they have gone through as people with HIV, although the fact that they have been given a chronic diagnosis is not in itself something positive. For others, the diagnosis has been a difficult reversal and they take many years to take it in and accept it. One of the informants says the following:

The death sentence that contracting HIV is – it's like standing on a precipice. There's no way back. You have one option, and that's to jump, and then you have two options. You can choose to let yourself fall and smash against the rocks, or you can teach yourself to fly, and I know more people who've taught themselves to fly.

How the informants deal with the HIV diagnosis is also connected to the people they have around them. Several of the informants had children of their own, and they often mentioned the children as an important reason life must go on:

I am happy to have had her, you know. The only reason I'm alive is [...] her. If I hadn't had her, perhaps it would've been different. Perhaps I wouldn't have been here now, for example. I'd have committed suicide. I mean, why should I live – why

should I struggle with medicines? These are things I think, you know. I've thought those thoughts but I have to live because I have a daughter, you know.

Table 9.1 States experienced in the last fourteen days. Percentages.

	All or much of the time	Some of the time	At no time	N
Have felt fine and had plenty of energy	55.1	37.0	7.9	254
Have been happy and content	60.0	35.7	4.3	255
Have been troubled by nervousness and inner unease	21.2	44.7	34.1	255
Have been troubled by fear or anxiety	17.0	38.7	44.3	253
Have been worried and uneasy	22.0	43.5	34.5	255
Have had a feeling of helplessness with regard to the future	23.7	37.0	39.4	254
Have been feeling down and melancholy	16.7	42.0	41.2	257

Fafo's 2002 study of living conditions (Fangen et al. 2002) revealed that, in comparison to the rest of the population, a relatively large proportion of those questioned suffered from anxiety and depression. Table 9.1 shows to what extent the people in our study have experienced various mental conditions.

Of those who answered the question, 55.1 per cent say that, over the last few days, they have felt in good spirits and had plenty of energy as well as being happy and contented all or much of the time. Still more (60 per cent) say they feel happy and contented all or much of the time. In comparison to Fafo's previous study of living conditions (Fangen et al. 2002), this represents an increase (in 2002, 47 per cent and 51 per cent, respectively, reported that they experienced these two states much or all of the time).

The other statements in Table 9.1 are, according to Moum and co-authors (1991), indications of anxiety (statements 3, 4 and 5) and depression (statements 6 and 7). If we compare them to Fafo's previous study of living conditions (Fangen et al. 2002), we may regard the findings in Table 9.1 as encouraging. A markedly lower proportion say that they have much or all of the time experienced the states that are counted as indications of anxiety and depression. These results may indicate that the people in

our study deal with living with HIV better than was the case in 2002. At the same time, we find it somewhat remarkable that so many say they have not at any time felt any of the emotions the questionnaire specifies. We believe part of the explanation may be that the question is about how people have felt *over the previous fortnight*. Many more may therefore have felt the various emotions, albeit farther back in time. For example, it is conceivable that, among those who have had HIV for many years and now live 'normal' lives and have put things in perspective, longer periods may pass between the occasions when they experience the states Table 9.1 mentions. Another possibility is that Table 9.1 reflects what we describe later on in the report as the 'be happy' game. By this we mean that many people with HIV – not least against the backdrop of medical progress – perhaps feel a kind of pressure to be well and appear successful. Some of the findings from the qualitative interviews may point to this, by suggesting a slightly different reality than Table 9.1 does. Through the questions asked in the interviews, many of the informants paint a picture of their own thoughts and feelings that is decidedly more negative than the one of which Table 9.1 may give an impression. The following statement may illustrate this:

I find that I suffer from anxiety, sleep problems and melancholy now and then – not such massive anxiety, but it happens that I have days when I don't want to answer the telephone and don't want to meet anyone. It's been a bit up-and-down [...] A lot of the psychological part has happened little by little. I wish the follow-up of the psychological aspect was as good as that of the physical aspect.

Once again it is important to mention that the question is about the previous fortnight. If we had asked what emotions the respondents had felt since being diagnosed, the picture would perhaps have been different. Many will find being given the HIV diagnosis and living with HIV an emotional rollercoaster, where ups and downs closely follow each other. At the same time, for many the period of a fortnight will be too short to encompass the whole spectrum of emotions they have felt in connection with the HIV diagnosis. All in all, there are grounds to assert that the physical health of the respondents is good. As far as mental health is concerned, there are a significant group of the respondents who experienced depression and anxiety within the previous fortnight, although there seem to be fewer in 2008 than there were in 2002.

## 10 Contact with the health service

As a consequence of the infection and/or side effects from the use of medicine, people with HIV will have more need for various health services than the rest of the population (Carstensen and Dahl 2007). This chapter presents findings from questions that relate to the experiences people with HIV have of various health services, such as regular doctors, psychiatry, dental health services and the polyclinics/hospitals.

Regular check-ups and blood sampling are provided for anyone with HIV in Norway (Fangen et al. 2002). Some people with HIV have symptoms and pain in connection with the illness, which in addition mean it is necessary to stay in close contact with various health services. As far as living conditions are concerned, individuals' perceptions and experience of encounters with such services will therefore be important with a view to our being able to assess the situation among the group with regard to living conditions.

### Contact between people with HIV and doctors, psychologists and hospitals

Table 10.1 shows contact between people with HIV and regular doctors, general practitioners, private specialists, psychologists, hospitals or polyclinics, and hospitals/infirmaries in the form of in-patient care. The response distributions here provide information about the degree of contact between the people in the sample and various health services. However, it is important not to equate the frequency of contact with whether people with HIV live isolated lives. If a person has been in contact with several of these services several times during the course of the last twelve months, this is an insight that can be interpreted in at least two ways: on the one hand, as showing we are dealing with individuals who in various ways are ill and need support, and on the other hand, as showing we have a support system that at least to some extent encompasses and is in contact with people who have HIV.

We must first point out the following: the percentages in Table 10.1 have been calculated from the numbers of those who answered the question. In other words, the total does not correspond to the whole sample (271 people) but only to those who answered the various questions. As we can see, there are very big missing-answer

Table 10.1 How many times have you been in contact with the following health services over the last twelve months? Percentages.

	Zero times	1–2 times	3–5 times	6 times or more	N
With your regular doctor or with other general practitioners	19.0	30.6	24.6	25.8	252
With private specialists	70.8	16.7	8.3	4.2	192
With psychologists	72.6	6.1	5.6	15.7	197
With hospitals or polyclinics (without being admitted for in-patient care)	14.4	16.9	45.3	23.5	243
In-patient care in hospitals/infirmarys	76.3	17.9	4.8	1.0	207

categories in a few of the rows in the table. There may be several reasons for this – for example, that a few people perhaps did not understand the question and thus declined to answer. It is also conceivable that those who did not take advantage of a given service may have responded in two different ways: either by ticking the box for ‘zero times’ (which is what they ideally ought to have done) or by choosing not to answer (even though they could have ticked the box for ‘zero times’). It may also be that many of those who, for example, do not have psychologists or do not go to private specialists may have chosen not to tick any box whatsoever, in order to emphasise that they do not take advantage of these services at all.

A little more than 80 per cent have been in contact with their regular doctors over the previous 12 months (1–6 times). This corresponds to the figures from 2002, when 82 per cent reported they had regular doctors they consulted (Fangen et al. 2002). We find it reassuring that four out of five report that they have been in contact with regular doctors over the previous twelve months, even if, as we discussed above, people should beware of construing this as a ‘positive’ finding. As far as those who answer ‘zero times’ are concerned, these, as mentioned, may be people who have doctors *but* have not needed medical assistance over the previous twelve months, and/or people who do not take advantage of the permanent-doctor scheme – because although the permanent-doctor scheme entitles every inhabitant of Norway to have a general practitioner as regular doctor, it is a voluntary scheme (Sandvik 2006). The particular reasons for the pattern of contact we can observe in Table 10.1 may therefore vary.

It is customary for people with HIV to go to infectious-medicine polyclinics for check-ups at regular intervals. The checks people with HIV have at the polyclinics may reveal changes in the virus counts in their blood and possible failure in their immune defences and thus is important with a view to getting the right medical treatment

under way at the right time. The table shows that a little more than 85 per cent of those who gave responses in the study have visited polyclinics and/or hospitals one or more times over the previous twelve months. There are 68.8 per cent who have visited them three times or more, while 14.4 per cent of those who ticked the boxes report that they have not visited any hospital or infectious-medicine polyclinic over the previous twelve months. These are probably people with HIV who in daily life do not to any great extent notice symptoms or side effects due to the illness. When it comes to employing the services of psychologists, the figures are quite consistent with the figures from 2002 (Fangen et al. 2002, 188), which showed that about one in four had gone to see psychologists over the previous year.

If we divide the respondents up according to age, we see that younger people (aged 18–29 and 30–39) generally take advantage of the various health services to a greater extent than elder ones. This need not necessarily be because younger people have a greater need for medical or psychological follow-up. It may just as well be a result of a greater inclination on the part of younger generations to seek out a variety of provisions for their problems. In addition, several of the youngest people have been infected recently and, in the early stages after contracting the infection, they may well have a strong desire to talk to someone (be it a doctor, a psychologist or someone at a polyclinic) and to obtain information and knowledge. From a health standpoint, one would actually expect elder people with HIV to have greater need for various health services than younger ones. To a certain extent, the figures do bear this out; for example, it is among HIV-positive people aged 65 and over that we find the highest proportion who have visited their regular doctors or other general practitioners six times or more during the previous twelve months.

Further, we find that it is more common to have visited hospitals or polyclinics (without receiving in-patient care) three times or more during the previous twelve months among those aged 50 and over than among those under 50. One possible explanation for this is that elder people with HIV came to the infection departments at a time when the doctors there took care of every health need, whereas those infected more recently have had relations with their regular doctors before contracting the infection and have not had corresponding relations with the infection departments to such an extent. The interviews suggest this is the case. Several of those who have had HIV for a long time do not have relations with their regular doctors but instead refer to the doctors of infectious medicine as the ones they visit to meet their needs, even aside from HIV:

My doctor's like a friend – or a father to me. I can only go in if he's available. He talks to me about health but we also talk about other things, such as family and things like that.

The ones who work at the infection department almost act as regular doctors. Because my regular doctor doesn't have that much time.

Those who have not been infected as long do not talk in the same terms. They mention their regular doctors more and talk more about the infection departments' just being preoccupied with figures.

When it comes to the youngest age group (18–29), another interesting finding must be mentioned: whereas eleven respondents (64.7 per cent) had not visited a psychologist even once over the previous twelve months, the remaining six (35.3 per cent) had visited psychologists six times or more during the same period. In other words, no one had visited psychologists 1–5 times over the previous twelve months. One possible explanation for this is that many in the youngest age group may have contracted the infection so recently that they do not quite know how they are inclined or supposed to react – nor, perhaps, have they had time properly to grasp what their needs are. In addition, it may be that while some have a profound need to talk to someone, others opt for a different strategy whereby, at first, they repress what has happened and try to live as before. The figures appear to reflect an either-or pattern of reaction: those who have visited psychologists many times, on the one hand, versus those who have not done so at all.

Are there, then, any differences between heterosexually and homosexually infected people as far as the frequency of contact with the various health services is concerned? Table 10.2 points in this direction.

Table 10.2 The proportion of heterosexually and homosexually infected people who have/have not been in contact with various health services over the last twelve months. Percentages.

	Heterosexually infected		Homosexually infected	
	Contact	No contact	Contact	No contact
With your regular doctor or with another general practitioner	78.5	21.5	78.4	21.6
With private specialists	26.0	74.0	28.1	71.9
With psychologists	17.8	82.2	26.1	73.9
With hospitals or polyclinics (without being admitted for in-patient care)	83.9	16.1	86.4	13.6
In-patient care in hospitals or infirmaries	21.8	78.2	21.7	78.3

The most interesting finding in Table 10.2 is that the proportion of homosexually infected people in the sample who have been in contact with psychologists is larger than the proportion of heterosexually infected people who have done so. In the Danish study of living conditions among people with HIV, 15 per cent had been in contact with



psychologists and 6 per cent with psychiatrists (Carstensen and Dahl 2007). Among our respondents, the figures for contact with psychologists are even higher. When it comes to the use of the other health services, the differences are not significant. One possible shortcoming of the comparison the above table makes is the fact that, in particular, those infected heterosexually are a heterogeneous group. The representation in Table 10.2, which only divides the respondents up according to mode of infection, does not convey this. For example, 37.7 per cent of the heterosexually infected people in the sample were born outside Norway. The corresponding proportion for those infected homosexually is 11.7 per cent. Native land is an interesting variable in this context and may be considered significant in at least two ways. Firstly, having been born in a country other than Norway and in some part of the world other than Europe will in general terms be of importance to a person's cultural background, experiences and attitudes. Secondly, it is likely that a certain proportion of those born outside Norway have also contracted HIV outside Norway. They bring with them experiences connected with having HIV in countries that perhaps have completely different systems of follow-up for people with HIV and where having it may be either more or less stigmatised than in Norway. This experiential background will also have bearing on the lives people with HIV live in Norway and perhaps in particular with regard to openness and the extent to which they seek out and take advantage of various health services. However, it is difficult to find any pattern to corroborate this – something due, among other things, to the fact that too few people born outside Norway answered the questions on health services.<sup>7</sup>

## Satisfaction with treatment and follow-up

Table 10.3 shows the sample's response distributions on the question: 'How pleased or displeased are you overall with the treatment and follow-up you have received from hospitals, polyclinics and regular doctors?' We consider it very important and of great interest to know how pleased those questioned are with the treatment and follow-up they receive from the authorities mentioned. Since just over half the sample (50.4 per cent) have been in contact with regular doctors three times or more over the previous twelve months, and since as many as 68.8 per cent of those questioned say they have visited infectious-medicine polyclinics three times or more, it is obvious the experiences people with HIV have in their encounters with these services have an influence on their living conditions and quality of life. Such an interpretation is supported by the

<sup>7</sup> Although twenty-five people in the data set were born in Africa, for example, far fewer answered these questions.

Table 10.3 How pleased or displeased are you overall with the treatment and follow-up you have received from hospitals, polyclinics and regular doctors? Percentages.

	Very pleased	Rather pleased	Neither pleased nor displeased	Rather displeased	Very displeased	N
Treatment from hospitals	47.1	26.6	21.7	3.7	0.8	244
Treatment from polyclinics	51.8	27.1	16.2	3.2	1.6	247
Treatment from regular doctors	35.2	24.5	28.8	3.9	7.7	233

*frequency* of contact, but perhaps also by what, in view of the fact that HIV is a chronic infectious illness, one may describe as the *dependence* on the services mentioned.

For all the services mentioned, the majority of those who responded are more pleased than displeased with the treatment and follow-up they receive. That such big proportions as 47.1 per cent and 51.8 per cent are very pleased with the provision they receive from hospitals and polyclinics may be seen as encouraging. There are 73.7 per cent who are (very or rather) pleased with the treatment they receive in hospital, while 78.9 per cent are (very or rather) pleased with the treatment they receive from the polyclinics. The proportions of those who are rather or very displeased with the same treatment services may be seen as very low (4.5 per cent and 4.8 per cent respectively). However, one of the informants says the following:

It's actually health workers who're the worst. I still receive a surprising amount of poor treatment in hospitals where they've got infection regimes that are a throwback to the Eighties – where you're required to eat off plastic plates with plastic cutlery and preferably not near the other patients.

The results for the regular doctors are a little different; in comparison to other provisions, the proportion of people who are pleased with the treatment and follow-up they receive from their regular doctors is lower (57.9 per cent). We also note that 7.7 per cent of those who have responded say they are very displeased with their regular doctors. A few informants expressed themselves in the following manner:

The lack of awareness among regular doctors is shockingly profound.

The health service should have had training. There are these attitudes within it that are really sinister! People who come to have HIV tests – then the doctor refuses to do it, because you don't look like someone with HIV.

I've thought about replacing him. I've been seeing him since I was a little boy. He knows the whole story. You see, he's constantly asking whether I haven't quite got Aids yet. He's very curious about it. He says it each time I'm there. I see him once a year or something. 'Have you been diagnosed with Aids yet?' he says to me. 'No, I haven't.' 'Lord – how strange!' he says. 'Why's that, then?' I say. 'Well, after all, you've been walking around with it for more than twelve years,' he says to me. 'Well, yes, I have.'

It is a particularly difficult situation when the doctor has to notify the patient of the diagnosis of HIV. Many of the informants have found that their doctors handle this badly. The following is an example:

My regular doctor herself handled it very badly. She called me and said she'd forgotten to carry out a gonorrhoea test, so I'd have to come back. Maybe she wasn't allowed to say I'd tested positive over the telephone, but when I went there, her hands were really trembling. She sat in front of the computer and didn't really want to look at me. She asked me to lie on the examination table because she wanted to carry out a gonorrhoea test, and then she asked about the rash I had that she hadn't been concerned with in the months before. And then she said I had to have an HIV test, because I'd tested positive in the first one. I read the record afterward – it says: 'The patient takes it surprisingly calmly.' When I saw it, I thought, 'Well, that shows how much insight a doctor who works with people has,' because what happened was my mind was completely blown away. Actually I think I sat there glued to the chair – I don't think there was anything in my head.

However, it is important to state that the permanent-doctor scheme is probably more 'vulnerable' in a context like this, because the quality that the permanent-doctor scheme offers will be closely connected to the individual doctor's competence, knowledge and understanding. Whereas, for example, the infectious-medicine polyclinics may to a greater extent be considered to function as more integrated, targeted services, specially aimed at dealing with people who have HIV, the regular doctors' competence as regards HIV and what it is like to have it will often vary substantially – something a few of the qualitative interviews in fact underline.

As previously mentioned, the perceptions and experiences people have in their encounters with various health services will be very important to many people with HIV, because many rely on treatment and regular follow-up. Another important aspect of the private individual's contact with health services is *consideration of the need for information*. Conveying information lies at the heart of most services provided in society; this, therefore, is not a need specific to people with HIV but one that characterises all dealings between private individuals and, for example, the health service. However, we must expect people with HIV to have a particular need to receive information, in view

of the fact that they are living with a serious infectious illness. That HIV-positive people in such situations receive good, sound information is crucial to how they perceive the quality of the provision offered via hospitals and regular doctors. Table 10.4 shows to what extent the people who answered the question are pleased with the information they have received from the authorities mentioned.

Table 10.4 How pleased or displeased are you overall with the information you have received from hospitals, polyclinics and regular doctors? Percentages.

	Very pleased	Rather pleased	Neither pleased nor displeased	Rather displeased	Very displeased	N
Information from hospitals	40.6	26.3	23.9	6.0	3.2	251
Information from polyclinics	43.6	25.6	21.2	5.2	4.4	250
Information from regular doctors	26.8	20.9	37.2	6.7	8.4	239

Not surprisingly, we see that the pattern in Table 10.4 is quite like the one we saw in Table 10.3; the proportion of people who are (very or rather) pleased with the information from hospitals and polyclinics is rather similar to the proportion of people who are pleased with the treatment and follow-up from the same authorities. The findings give weight to the impression that how pleased people with HIV are with the information they receive has great bearing on how they rate the treatment and follow-up they receive. Here too the proportion of people who are rather or very displeased may be seen as low. At the same time, we can see that those questioned are least pleased with the information they have received from their regular doctors. This is also in line with the pattern in Table 10.3. Given that regular doctors are general practitioners and must therefore have a broad knowledge of medicine, this is not surprising. How much the individual regular doctor knows about HIV will as a rule depend on the extent to which he or she has had experience with HIV-positive patients. In order for the division of responsibility between specialist and local health services to work, however, a person will depend on the regular doctors' being able to deal with both HIV as such and the comorbidity that frequently occurs.

The respondents were also asked how great a need they had had for a variety of treatment and follow-up provisions in connection with the fact they have been diagnosed with HIV. The point of interest with this question is that it provides information on how people with HIV themselves rate their need for a variety of health and follow-up provisions. Table 10.5 represents the response distributions.

Table 10.5 How great a need have you had for the following provisions in connection with the fact that you have HIV? Percentages.

	Have needed	Have not needed
Physiotherapy	27.5	72.4
Recreational stays or similar	36.3	63.7
Psychological counselling/treatment	54.4	45.6
Ergotherapy	13.1	86.9
Group meetings for people with HIV	41.1	58.9
Consultations with social workers	34.3	65.7
Medication-assisted rehabilitation (methadone or Subutex)	6.9	93.1

The most interesting thing about Table 10.5 is that 54.4 per cent say they have needed psychological counselling/treatment in connection with the fact that they have HIV. By comparison, as we could see from Table 10.1, 27.4 per cent of the 197 people who answered reported that they had been to psychologists 1 or more times over the previous 12 months. The finding suggests, in other words, that there may be a discrepancy between the need for psychological counselling and treatment and how common such follow-up actually is among people with HIV.

Some of the informants also had problems getting access to psychologists:

I have tried to get hold of a psychologist but I find it terribly hard. The way the situation is for me now, I really need a psychologist again. It's terribly hard to grasp. It is, I think, a real pity, because I've come such a long way now, I think, and I'm ready to go further, but then I come up against a bit of a brick wall in matters like this.

The interviews showed that it was not difficult to find a psychologist but that several people in fact had had experiences with psychologists who had not had the necessary competence to deal with HIV-positive people.

My regular doctor printed out a list of psychologists and I called round and said who I was and why I wanted help. And one after another, they answered: 'No, we don't deal with HIV-positive people.' 'No, we don't have any experience of that.' 'No, we're full up here.' In the end, after getting quite far down the list, I just gave up.

When I say psychologists are difficult, it's not at all difficult to get a referral. My doctor does that and he's done that throughout the entire period. What is difficult is first and foremost to gain access to a psychologist. Not only that, though – I have met a few psychologists a few times, but it's difficult to make contact with a psychologist. For me, as someone with HIV, and a gay person, it can be quite a complicated business. I don't want to judge any psychologist, but going into these

things in depth with a woman of 45 can go a bit wrong, I've felt a little like: 'They don't understand what I'm talking about.' So it's kind of fallen between the two stools.

An informant with recent experience of psychiatric hospital in Norway said the following:

I actually got better help in '95 than I did last year, but it was really a bit hysterical there. Because they saw I had loads of sores and so on – shingles. They couldn't help me with bandages and so on. No, I had to sort that out for myself.

In addition to a great need for psychological counselling (cf. Table 10.5), it is interesting to note that a larger proportion of people say they have needed to consult social workers (34.3 per cent) and participate in group meetings for people with HIV (41.4 per cent) than say they have needed physiotherapy and ergotherapy, for example. At the same time, it can of course be a doubtful experience. As one informant put it:

I went to a social worker here – very nice woman, but she insisted I wasn't depressed: 'Depressed people don't write books – you're just reacting naturally to your difficult situation. Call me when you need to!' And then she asks me, 'What can I do for you?' Well, I don't know what she can do for me – that's why I'm there, you see! I don't know – since I didn't have any specific answer to that, she didn't see what she could do, so really I've just given up.

Overall, the figures in Table 10.5 seem to convey the impression that it is largely on the psychological level that people with HIV have the greatest needs. This is also a tendency that is confirmed elsewhere in the report: whereas a large majority rate their health as good (68.2 per cent) and many report positive experiences with the use of medicines (for example, 82 per cent say the anti-virals help to improve their general condition), there is, at the same time, a great need for services and provision directed toward psychological needs (see also Carstensen and Dahl 2007). This is also of interest in the light of the fact that HIV is first and foremost perceived and defined as a medical diagnosis and a physical condition.

## Dental health and dental health services

Recently, in January 2009, the Norwegian Dental Association published a document that queried dental health and dental health services for people with HIV (*Den norske tannlegeforenings Tidende* [*The Journal of the Norwegian Dental Association*] 2009, 119:52). Table 10.6 shows the response distributions for the questions asked about

dental health and dental health services. In the qualitative interviews, there are few informants who talk about their dental health. On the other hand, there are several who talk about problems with dentists, negative reactions and problems of access. The informants' interviews revealed several examples of people with HIV whose dentists, after becoming aware of their HIV diagnosis, have subjected them to 'inhumane' treatment. There are also stories from the last few years involving specific examples of dentists' turning patients away or introducing unreasonable anti-infection measures. The stories indeed bear witness to the profound mistrust people with HIV have of dentists as a result of the many horror stories.

So then, my mother had a dentist. So I called him and I was supposed to have an appointment. Then I didn't get it, because they can't deal with patients with HIV. That's not allowed, of course – they can't refuse, you know – but, you see, I have to inform people of that. I did get an appointment, only three months later. It was all I could get. Then my mother called to get an appointment, and of course, she got an appointment the following week. Then I started wondering, 'What is this?'

Dentists have been a problem over the years. If you get an appointment, you usually get the last appointment of the day, and then this astronaut comes into the room! I suppose it has started to get better but it's still difficult to establish a good, sound relationship with a dentist.

Table 10.6 HIV-positive people and dental health. Percentage response distributions.

	Yes	No	N
Has your dental health deteriorated since you contracted HIV?	39.0	61.0	264
Do you know your rights as regards dental health and the diagnosis of HIV?	55.5	44.5	265
Does your dentist know you have HIV?	67.2	32.8	271
Do you get help from your dentist with the reimbursement arrangements that are in place?	67.3	32.7	168

The findings from the questionnaire study show that dental health is a problem for many people with HIV. Though Table 10.6 may show that the majority come out of this well, there are a significant minority who do not. For example, 39 per cent respond that their dental health has deteriorated since they contracted HIV.

More than half know their rights when it comes to dental health. At the same time, it may be described as worrying that 44.5 per cent report that they do not know their rights. This is an indication that the information could be better.



Two out of three respondents in the sample (67.2 per cent) report that their dentists have been informed of their HIV diagnosis, which may be seen as encouraging in the light of the discussion on openness. At the same time, one should beware of presenting the case as if openness were for the best in every context. For example, it may be that several of those who answer no quite simply have no desire or need to inform their dentists of the diagnosis – for instance because they do not feel it is relevant, since it is something that in any case ought not to have any effect whatsoever on the service they receive. That people with HIV do not open up to their dentists need not, in other words, mean they cannot bring themselves to open up – it may just as well be a consequence of a carefully weighed-up decision.

We also asked the respondents whether they find their dentists treat them better or worse since becoming aware of the diagnosis. There were 39.9 per cent who did not answer this question (including those who have not opened up and those who do not feel they have any basis on which to answer). Of those who answered, 69.3 per cent say they find their dentists treat them as before. There are 9.2 per cent who say that they are treated worse, while 21.5 per cent say they are treated better than before. How are we to interpret this distribution? The most pleasing thing, in our view, is that nearly 70 per cent say they find themselves to be treated the same way as before – no better or worse. For many people with HIV, it doubtless feels better to be dealt with in the same way as before than to be dealt with in a better way. That 21.5 per cent say they are treated better need not be a wholly positive experience for those concerned, since one may experience the feeling of receiving special treatment on account of a medical diagnosis as a burden because one feels oneself by reason of this to be stigmatised and pitied.

A large percentage of those who answered (67.3 per cent) also say they receive assistance from their dentists in connection with the reimbursement arrangements in place. As many as 103 respondents did not answer this question. We are afraid this figure may reflect ignorance on the part of HIV-positive people with regard to their rights in connection with dental health, rather than indicating that there is no cause for concern. Table 10.6 also corroborates this, because as many as 44.5 per cent say they do not know their rights in this area.

Table 10.7 shows the distribution for the question whether people have opened up to their dentists, divided up according to age. We have brought up age here to see whether there is more of a tendency toward openness in some age groups than in others. The youngest people in the sample (18–29 years old) are the ones who have told their dentists about their HIV diagnosis the least. Those in the 40–64 age group in particular stand out as open in this context. Among the eldest too (65 and over) a higher proportion have told their dentists about the diagnosis than is the case in the two youngest age groups.



Table 10.7 Age and whether your dentist knows you have HIV. Percentages. (N=269)

	Does your dentist know you have HIV?		N
	Yes	No	
18–29 years	42.9	57.1	21
30–39 years	58.2	41.8	55
40–49 years	72.1	27.9	104
50–64 years	74.7	25.3	75
65 years or over	64.3	35.7	14
Total	67.3	32.7	269



## 11 Contact with NAV, social services and other public authorities

As far as welfare services are concerned, too, people with HIV will have many of the same needs with regard to information on rights, on follow-up and on various benefits as we find among the rest of the population. At the same time, there are a number of factors dictating that some people with HIV, for some of the same reasons described in the chapter on health services, will have great need of assistance from the welfare system, for example because they fall ill and/or the side effects mean they can no longer work and are forced to apply for some financial benefit. Table 6.1 showed that around 34 per cent of the respondents received one or another form of financial benefit (daily allowance, sickness benefit, vocational rehabilitation allowance or disability benefit). Among the population in general, a little under 700,000 people received financial benefits of this kind in 2005 (Fløtten 2007). One in five of the people in the sample is disabled either long-term or temporarily. The corresponding figure for the rest of the population is around one in ten (Viten 2007).

In Fafo's 2002 study (Fangen et al. 2002), the respondents were asked questions about their experiences with Norway's National Insurance Service, Aetat job centres and social services. We asked similar questions in this study. An important difference from 2002, however, is that a NAV reform is now in progress that means that the two former state services are to merge and that, together with social services, they will make up the local NAV offices. Given the goal of the NAV reform, which is to give people one place to turn to and to do away with the user's sensation of being thrown back and forth between different departments – see Report no. 9 to the Storting (2006–7) – it will be of particular interest with respect to a group such as people with HIV to find out whether the help and follow-up they receive from NAV are perceived to be better than the provision that was offered before. We can obtain some kind of impression of this by comparing the results from 2002 with the results within this sample. Since NAV offices have not been established all over Norway, the questions were asked about NAV/the National Insurance Service *and*, in addition, the social security offices.

Of those who took part in the questionnaire study, 48.7 per cent have been in contact with NAV/the National Insurance Service over the previous twelve months, which is quite similar to the figures from 2002 (Fangen et al. 2002). Among those who have been in contact with NAV, 'consultation with caseworker' (40.6 per cent) and

'information about rights' (30.5 per cent) are specified as the most important reasons for the contact with NAV. We have elected not to divide the sample up according to any further attributes here, both because the number of respondents is small and also because there is no particular reason to suppose that one infection group should have more need to go to NAV than any other. In the Danish questionnaire study (Carstensen and Dahl 2007), a division was carried out according to infection groups, but the differences it shows between the groups are small, with the exception of drug users (who have been in contact with the social services administration to a far larger extent), but, as we know, this may be due to many causes other than the HIV infection alone. The fact that almost half of those questioned have been in contact with NAV over the previous twelve months says something about the fact that NAV constitutes an important point of contact for many people with HIV. Viewed in this light, NAV and the welfare services it provides will play a part in influencing the living conditions of people with HIV. It is therefore necessary to map out the experiences and perceptions people with HIV have. We shall go into this in more detail below.

The next question asked was the following: 'How would you describe the assistance you received at NAV/the National Insurance Service?' Of those who have been in contact with NAV/national insurance offices over the previous twelve months, 37.3 per cent respond that they have found the contact good or very good. Almost as large a proportion describe the assistance they got as bad or very bad (35.7 per cent). These are very similar to the figures for 2002. Back then, 35 per cent and 37 per cent, respectively, responded in the same ways to the question about assistance from the national insurance offices (Fangen et al. 2002). The remaining 27 per cent say neither one thing nor another about the assistance they received. It is difficult to deduce anything specific from these findings – among other things, the individual's assessment of the quality of the assistance and follow-up received from NAV will be closely connected to the specific relationship and dialogue with the caseworker. As consumers, furthermore, we have different expectations in our encounters with the machinery of public service – how the individual interprets good assistance and follow-up may therefore vary substantially. In addition, it is difficult to assess to what extent the individual's experience of having HIV as opposed to being a completely 'normal' NAV consumer 'determines' the responses that are given here. We must make allowances for the fact that some are in contact with NAV regardless of the fact that they have HIV, and often, as a result, their experiences with NAV will not be closely connected to the HIV diagnosis.

Several have relationships with NAV as a result of receiving disability benefit. Many find their encounters with NAV (formerly the social security office) frustrating. The impression from the interviews is that the caseworkers at NAV have poor knowledge of rights and that it is difficult for people with HIV to open a dialogue with NAV about rights and needs. One of the informants who feel they have been 'overlooked by the system' says the following:

Now I've also quarrelled with the social security office a bit about the basic benefit – I was awarded it in 1996 and then I found out it was supposed to be taken up again after two years, in 1998. From '98 until now – until last year – I didn't hear anything, you see... Then suddenly last year they wanted to carry out a new reassessment. They said my disease pattern had changed so much that they had to carry out a reassessment. I thought, 'O Lord, I do have the same expenses, after all – there's no difference.' [...] I ended up going down a level, but I've appealed the matter. [...] They tell me, 'Actually you've been overlooked by the system. It should actually have been renewed every two or three years.' [...] 'Haven't I got it once and for all?' I say. 'Well, no. You've been a bit overlooked in the system,' they told me. 'I suppose I've been lucky for the twelve years I've had it,' I say. 'Have you had it that long?' they say to me. 'Yes,' I say.

Many people with HIV used to receive disability benefit as a result of their HIV status – but newer medicines have meant that others have had better health and feel they're in a position to return to the labour market. However, they find they fall between two stools: they're too ill to function normally in working life but too fit to go on receiving disability benefit. There are others who claim NAV only to a small extent proposes solutions in such situations. At the same time, the informants report that they meet with little understanding of the financial burden living with a chronic illness involves:

We're too fit to get any help there (NAV, the benefits system), at the same time that some of us are too ill to perform at work, but we can only just get this benefit for wear to clothing. I can't get what I've spent on health food and alternative treatment covered anywhere.

In the interviews, there are also several people with HIV who say that they feel they receive little information about rights and what they are entitled to in their encounters with NAV. Several told stories of difficulties getting in contact with NAV and to the effect that it is a struggle to get what they themselves feel to be legitimate help. One of the informants puts it as follows:

Very poor. My benefit entitlements – I had to find that out for myself. It's very poor. For instance, information about the fact that I have a right to a disabled-driver car. I had to find that out myself. [...] But that's the way it is here in the country. You have to find out for yourself what a person's entitled to. A person's entitled to so much, you see, but people just sit there open mouthed, you know. Luckily I've got a pal who's really clever. She understands and knows and it's really helped me a lot. Helped me an insane amount. Knows what my rights are.

In addition, a few say the national insurance offices work differently in different parts of the country:

This thing about what the National Insurance Service covers and does not cover is a bit unclear. In spite of the fact that we get that rights booklet with information on what we're entitled to get covered, it does vary massively from one part of the country to another, and from one national insurance office to another national insurance office. In reality it doesn't work as it should.

A few, however, have positive experiences with social security offices and NAV:

I got really good help from the social security office with financial advice and debt settlement. The city treasurer was also in on this – that is, the enforcement officer. They showed understanding about it and I'm really glad about that. I have also had contact with the National Insurance Service, which has now become NAV. Then I found out just half a year ago that there was something called housing benefit. I haven't been such a type that I've been all that aware what I'm entitled to, but I did find out about that.

## Social benefit

People regard social benefit as the very safety net of the Norwegian welfare system and it is aimed at people who have no national insurance entitlement and who for various reasons are not in work. Social benefit is disbursed on the basis of rough estimation and is needs-tested. In our sample, 45 people (16.6 per cent) say they have been in contact with the social security office over the previous twelve months. The proportion was higher in 2002 but this may be due to more or less random variations in the two samples. Those who have been in contact with social services specify the need for financial support as the most common reason (70.5 per cent), which is consistent with the findings from 2002. Of those who have been in contact with the social security office, 46.7 per cent consider the assistance they have received either bad or very bad, while 31.1 per cent consider the assistance they have received either good or very good. Although the proportion of those displeased is considerably higher here than for NAV/the National Insurance Service, once again it is difficult to interpret what is actually behind these figures. The allocation and disbursement of social benefit also involve a larger degree of discretion than other benefits, which may increase the risk that misunderstanding and dissatisfaction may arise in the relationship between consumer and department. People who receive social benefit are very often marginalised from the outset. It is thus difficult to judge what meaning the HIV diagnosis may have had in such a context.

## Breach of confidentiality

On the topic of welfare services, the respondents were asked the following question: 'If any of the staff at NAV/the National Insurance Service or social services know you have HIV, are you afraid that the duty of confidentiality may be violated?' In 2002 (Fangen et al. 2002) nearly half those questioned expressed such a fear (45 per cent). In our study, well over half of those who have been open about the diagnosis toward NAV/national insurance offices or social security offices feel such concern (more precisely, 58.7 per cent). Compared to the Danish figures, this is high; there 28 per cent expressed such a fear (Carstensen and Dahl 2007). It is disturbing that such a large proportion feel uncertain that their rights in connection with confidentiality are observed in their encounters with such a big, important service as NAV.

At the same time, *more* people respond 'they do not know I have HIV' now than did so in 2002 (9.7 per cent compared with 5 per cent in the 2002 sample). In comparison to the Danish figures, however, there are a larger proportion in Norway who are open about the diagnosis in their encounters with the welfare system – in Denmark, 20 per cent had not informed the Social Services Department of the diagnosis (Carstensen and Dahl 2007).

Observation of the duty of confidentiality in contact with the workplace, health system and departments of state was a theme of several of the interviews. For many people with HIV, it is very important to have control over who knows about the HIV status and whom one has told about it. That HIV status is entered into records and the like can be perceived as sinister, because one must have faith that this information will be kept in confidence. At the same time, in dealings with the health system and public offices, it is also important that information about HIV status be given, for instance in connection with the right to have expenses covered for health support and access to services – but there are two sides to the picture with which we are presented. On the one hand, there are informants who find it awkward to have their HIV status stored. On the other hand, there are informants who get tired of always having to tell the welfare system they have HIV. This applies particularly when people have to state this information in situations where they find it uncomfortable to say it – for example, at the counter of a NAV office or a doctor's office. This does not directly involve breach of confidentiality, but people with HIV are put in situations where they are 'forced' to bring up their HIV status when it is not comfortable.

I had a skin growth that was not malignant. You're not supposed to pay for that. [I] still have to explain that they should put that code down. What code? [...] When I come to reception, they say I have to pay for this and that. Then I have to say I'm not supposed to pay. In the end, I say I have HIV. There are people standing right beside me, you know. But I can't say I have an immunodeficiency disorder, you see.

The devil gets into me. It puts them right in their place but it happens so damned many times.

Such situations are felt to breach confidentiality, because people with HIV find they have to talk about their HIV status when they meet with public services and when others are present. These situations bear witness to the fact that staff in public services who meet people with HIV in open office environments do not always competent or understanding enough for HIV status not to be announced to other listeners, unless those with HIV themselves bring up the matter. One of the informants had had such an experience upon admission to hospital, when she had just embarked on a relationship, had fallen ill and had with her her sweetheart who did not know about her HIV status:

Because we went to the hospital, where there was an elderly nurse who came up, while my sweetheart sat holding my hand, and said, 'Was it you who had the blood infection?' I looked at my sweetheart. 'What was that?' And, you know, that was really unprofessional. You experiences things like that, and when you've experienced it a few times you get a bit... you know... because you do encounter an unfathomable lack of awareness.

## Refugees and asylum seekers

A report on the 'Bridge-Building Project' of the Danish HIV organisation Hiv-Danmark describes a complicated dialogue between health staff and HIV-positive people from immigrant backgrounds. There is a lot that people with HIV feel they cannot discuss with the staff (Hiv-Danmark 2004). People who have contracted the infection before coming to Norway make up a relatively large proportion of those diagnosed with HIV (see Table 2.1). A substantial number of these people are refugees and asylum seekers. Fafo's previous study of living conditions (Fangen et al. 2002) revealed a number of criticisms toward the asylum reception centres, about poor knowledge, prejudice and problems with confidentiality. We therefore put a few questions of our own to people who have come to Norway as refugees or asylum seekers in the last five years. There are 27 people who answered these questions.

Testing in the context of arrival or at asylum reception centres has been a controversial measure. Two-thirds of those who responded say they were tested in the context of coming to Norway. Norwegian policy is for testing to be voluntary but several of the informants queried this and said there was a kind of voluntary compulsion. We therefore asked whether they felt the test was voluntary. There are 20 people who an-



swered this question. Two-thirds of them say they felt the text was voluntary. The fact that one-third felt that a voluntary test was not voluntary may be regarded as a little alarming. Slightly more than half of those who answered, however, say the information they received in connection with the testing was good or very good.

The last question we asked was how the respondents felt the staff at asylum reception centres dealt with questions connected with HIV-Aids. So few people answered these questions that it is not possible to deduce anything from them. The only answer that may perhaps be mentioned is the one where seven out of eight respondents agree with a statement to the effect that there was no mention of HIV-Aids. Granted that very few people answered here, and that it is therefore not possible to draw clear conclusions, there may nonetheless be cause to ask whether the asylum reception centres make HIV a taboo topic.

Clear conclusions cannot be drawn from the very limited material we have when it comes to encounters between people with HIV and asylum reception centres and asylum authorities, but a couple of issues emerge that presumably ought to be studied further: the perception of testing as voluntary or otherwise, and whether there is a need for greater awareness of how HIV-Aids is dealt with in asylum reception centres.



## **PART IV ATTITUDES TOWARD OTHER PEOPLE**

In this part of the report, we will take up questions connected to social life, family and networks. This also means questions about openness, support, discrimination and stigma. As mentioned by way of an introduction, a bipartite picture emerges. On the one hand, there are those who do not want their HIV status to mark their lives to any considerable extent. On the other hand, there are a group of people with HIV who fill life with content connected to having HIV. Between these two extremes, of course, there are also many of the informants and respondents.

One of the informants came forward with the following reflections on attitudes toward HIV-negative people and toward having HIV:

The openness that is needed is for HIV-negative people to start talking about HIV. [...] What I try to throw light on is HIV and Aids as a cause, but they still don't see it. They see this poor woman who was so unlucky to get HIV and how well she manages. They don't see that HIV *is* here. That's what I've tried to express. They just see this face. [...] HIV doesn't have a face. It's a damned little virus, and if it does have a face, it isn't mine at any rate.



## 12 Openness and isolation

In Fafo's previous study of living conditions (Fangen et al. 2002), the authors express their surprise at the fact that, almost twenty years after the discovery of HIV, there is still little openness about HIV status among people with HIV in Norway. Almost eight years have gone by since that study, the medicines have significantly improved and what people with HIV expect it to mean for them to have contracted the infection has changed – but openness about HIV status still seems very limited. The Danish study of living conditions (Carstensen and Dahl 2007) reveals that one in three HIV-positive Danes is afraid people will find out about the diagnosis. In their Aksept user study, Fuglestad and Lauritzen (2004a and 2004b) also discuss the question of openness, and conclude that openness is very limited and that there is a great deal of loneliness connected with having HIV.

Table 12.1 How long did it take you to tell someone else for the first time that you have HIV? Percentages. (N=238)

Straight away	54.6
0–1 year	25.6
1–2 years	8.0
2–3 years	1.3
3–5 years	2.5
More than 5 years	8.0
Total	100.0

It emerges from Table 12.1 that a little more than half the respondents who have told someone they have HIV told others of their HIV status as soon as they found out about it and around 80 per cent did so during the first year. In addition to those who have not told anyone about their HIV status (see Table 12.2), there are thus a substantial group who waited more than a year before telling anyone else about the diagnosis. Being diagnosed with HIV leads to a life crisis. Being able to talk about this life crisis only to the doctor who has made the diagnosis may be regarded as a significant additional burden.

Table 12.2 reveals that only 8 per cent have not told anyone they have HIV. That means almost everyone – over 90 per cent – have told someone they have HIV.

Table 12.2 How many people have you told you have HIV (health care personnel not included)? Percentages. (N=249)

Have not told anyone	8.4
1–2 people	14.5
3–5 people	18.5
6–10 people	20.1
More than 10 people	38.6
Total	100

Several informants say being open has not been without its complications but that a process of change has taken place along the way. One spoke as follows:

In retrospect, I've seen that the fact that I chose to be open and to take part in public information work together with the county doctor's resource group was clearly 'help for self-help,' of the very highest order. I can't say I threw myself into the public information work and sorted everything out for myself in that short time, because I didn't. It was something that happened as I went along – with regard to things I talked about at all the seminars and conferences, from time to time I noticed that, in my communication, I was putting things into words that I'd not put into words for myself. I've never regretted that choice to be open. In that way I was able to think of this as an illness. Why on earth should I not say who I am and what kind of diagnosis I've been given?! Should I be driven out – tattooed with a distinguishing mark?! That was so wrong! The driving force was anger and injustice.

However, there are 61 per cent who either have not told anyone or have told fewer than ten people. This suggests a majority of people with HIV tell a very select group of people they have the infection, and that it can feel lonely:

It's a lonely life. I choose not to discuss it with people – even those who know. I have no partner, you know – do nothing to get one. I've no desire to tell anyone I'm HIV positive. Yes, it's a shame, and that is how it's going to be, but it's not so much a reduction in quality of life with regard to health as with regard to well-being in general.

Many of the informants say this leads to a rather complicated existence. It is by no means easy to maintain an overview of who knows and who does not. Others describe the feeling of not being able to be completely honest in particular situations as unpleasant. The following quotation provides an insight into the complicated life 'partial openness' can involve:

I've chosen not to be 100 per cent open about this, you know, but kind of partly open, and there's been a process, and of course I've been open with my children – I

owe it to them, you know. Also, for security reasons, we're a big family, so there's one of my siblings I've informed, and I have a few friends I've informed as well – and under work conditions, there's always one person who knows about it. It's kind of security-related, so I'm making up a system for this – in case I should fall ill. So what seems stupid to me is that it's turned me into a liar, you know – I'm not a particularly secretive person, and suddenly I have to be, and I don't think it's nice. [...] There's doubtless an element of cowardice about it – there is – but there's also a little common sense to it, because the consequences of being open are not in proportion to what you get back. My view is that I'm open to the extent that it's good for me [...]. But I think it's a shame I have to lie about it.

Another quotation describes the more social complications that can arise from a lack of openness:

My uncle works at a hospital. [...] I had a cold and a sore throat. So he wondered why that was. Why I was so ill so often. [...] He said, 'Can't you just come to the office? Then I can take a blood sample.' But I'll never do that, you know. He still fusses about it – I can't get away from such fuss. It stresses me out. Every time I see him, I think, 'Oh no, he's going to bring it up again. What shall I say now?'

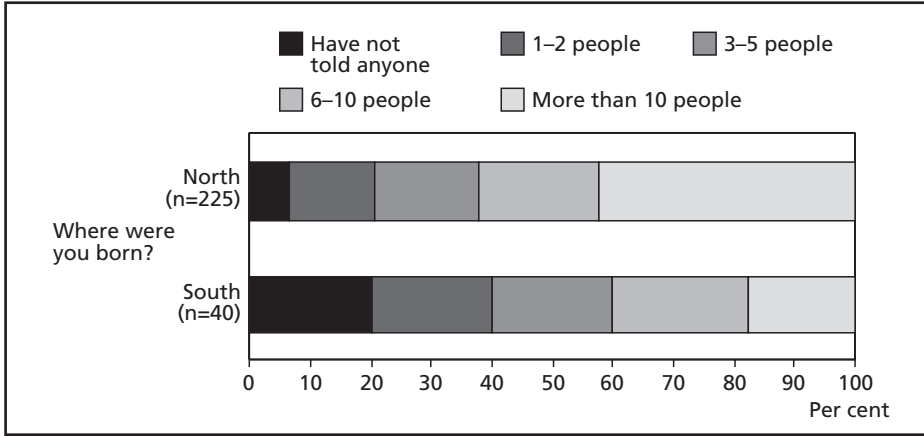
Whom people with HIV open up to is a result of various personal strategies. One strategy for them can be to opt for openness in settings with other people with HIV or in contexts where they know that those they are together with have connections with HIV-positive communities. Another kind of setting can be one where the individual knows that those he/she is open with have a duty of confidentiality, either formally or informally. This means the person chooses to restrict openness to rather enclosed settings. The following quotation describes this:

But that stuff about my being open is only about these HIV pockets – HivNorway, Gay & Lesbian Health Norway, Aksept and so on. [...] For me, then, it's about moving between these pockets. I can be openly HIV positive, but in enclosed groups, as I see it.

Some of the immigrant communities are described as difficult as far as openness is concerned. Immigrant informants in particular talk about the difficulties of being open in immigrant communities. Several say they are not open with people from their own homelands, but only with Norwegians.

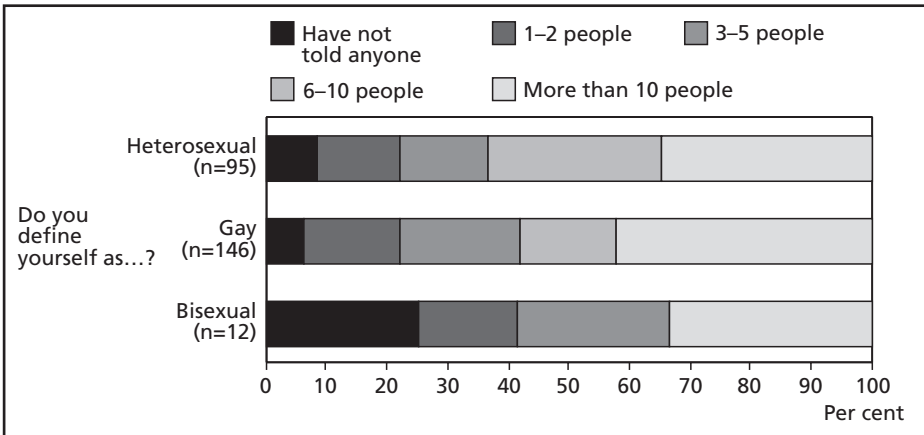
The people from the country I come from don't know. I'm not going to tell them about it, either. They're also friends of my brothers and sisters, you see – so I can't tell them. My siblings may also suffer because of it, you know. We have to think about a lot of things. We can't just think about ourselves. We have to think about the whole family, so it's pretty hard.

Figure 12.1 How many people have you told you have HIV? By native country. (N=265)



We can see from Figure 12.1 that there is a difference between the North and South groups. Of those born in the South, 82 per cent have either not told anyone they have HIV or told fewer than ten people. Of those from the North, 57 per cent are in a similar situation. In the South group, as many as one-fifth have not told anyone they have HIV. In both groups, however, a clear majority of the respondents have told fewer than ten people about their HIV status. In the South group, the majority have told fewer than six people they have HIV. In other words, we can see there is less openness about HIV status among people from countries in the South than among people from countries in the North in our sample. All the same, there are grounds for pointing out that even in the most open group, openness is very limited. The trend is the same among those born in the South, only more pronounced.

Figure 12.2 How many people have you told you have HIV? By sexual orientation. Percentages. (N=258)



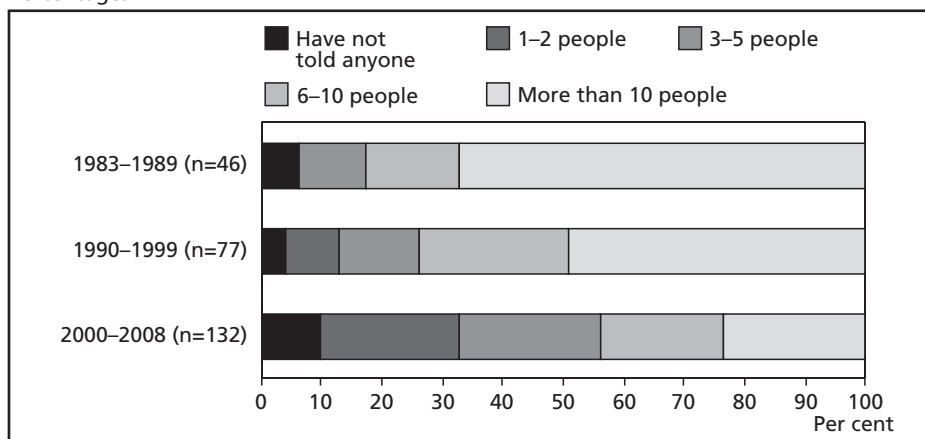


Sexual orientation is also a dimension that can influence the degree of openness. Gay informants say that it is difficult to be open in gay circles and that a new phase of 'coming out' in life can be difficult. We have therefore compared homosexuals, heterosexuals and bisexuals. Here, in contrast to a number of the other analyses, we have used informants' own definitions of sexual orientation as categories. This is because here we are most concerned with milieu affiliation and believe identity to be the best indicator.

We can clearly see from Figure 12.2 that those who define themselves as gay are open toward more people than those who define themselves as heterosexuals. Biphiles represent the group with the least openness. This is not surprising, because bisexuality is stigmatised and little recognised as a sexual orientation. However, it is necessary to make the proviso that the group is small and one must therefore interpret this figure with caution.

We have also looked at whether the time of diagnosis may be considered to have any bearing on *whether* and *to how many people* one will have talked about the HIV diagnosis. Figure 12.3 shows the distribution for this question.

Figure 12.3 Time of diagnosis and how many people have talked about the HIV diagnosis. Percentages.



We can see the following from the chart: to have told more than ten people about the diagnosis is clearly most common among those who were diagnosed in the 1980s (67.4 per cent). In the same way, we see that among those who were diagnosed in the 1990s, it is more common to have told 6-10 people (24.7 per cent) and more than 10 people (49.3 per cent) than, for example, 1-2 people (9.1 per cent). When it comes to those who were diagnosed in the 2000-2008 period, Figure 12.3 does not show any pattern; here it is as common to have informed 1-2 people as to have informed more than 10 people. As far as the interpretation of Figure 12.3 is concerned, it would appear that

Table 12.3 Why have you not told your parents, siblings, children, friends or others that you have HIV? Multiple responses possible. Numbers and percentages. (N=176)

	Number	Percentage
I am afraid they will reject me	45	26
I know they will not accept it	34	19
They would be afraid for me	76	43
I am too ashamed	47	27
I am afraid	36	20
It just has not been like that	33	19
Other	59	34

the likelihood that one will have informed many people is greatest among those who were diagnosed longest ago.

We also asked why people had chosen not to tell people about their HIV status. This question was put to all those who talk of closed ‘niches’ in their lives.

Table 12.3 reveals that when we ask people the reason they have not told family or friends they have HIV, the commonest answer (43 per cent) is that ‘they would be afraid for me’. Fear of rejection and shame are the next two categories. The first category is expressive of a kind of consideration people have for those around them. They do not want to cause others any concern over how they themselves will be.

I choose people carefully. There are a couple of people I trust but I don’t think they’ll handle it – not in relation to myself but in relation to the fact that they’ll feel so sorry and concerned and the last thing I need is sympathy and to be patted on the shoulder and ‘poor you’ – then you’re kind of not my friend any more. They can say it when I call and ask for it, because it does happen that I do that – when it suits me.

The two other categories, however, are connected to stigma in a completely different way and are expressive of a fear of others’ reactions on the one hand and people’s own sense of something they do not want to acknowledge on the other hand.

Another question that says something about the respondents’ relations with those around them is the question about the feeling of being isolated. Among the respondents, there seems to be an overrepresentation of people who are active in the HIV area through contact with organisations and networks such as HivNorway, Aksept and Homopositiv, a Norwegian organisation for gay men with HIV. (See Chapter 3 on who the respondents are.) In spite of this, there are a large group who say they feel isolated.

Table 12.4 reveals almost half feel isolated to a lesser or greater extent. Some of the other questions in the questionnaire give an indication of how people with HIV

Table 12.4 To what extent have you as someone with HIV found any of the following... to a lesser or greater extent? Numbers and percentages. (N=262)

	Number	Percentage
That you feel isolated	126	48
That you have less contact with family and friends	90	35
That you meet with less physical intimacy	99	39
That others are afraid of you and keep their physical distance	60	24
That you feel infectious and keep your physical distance from others	97	38
That you get more care and attention from other people	50	20
That you have got better at taken decisions about your life	142	56
That you contemplate being able to live a long life in a different way	151	58
That you are anxious about your health in the future	173	66

themselves look upon the cause of any isolation. People have been asked questions about the feeling that others are afraid and keep their distance and whether they themselves feel infectious and keep their distance from other people. It turns out only 24 per cent say they find that others to a lesser or greater extent keep their distance from them, whereas 38 per cent to a lesser or greater extent themselves feel they are infectious and therefore keep their distance from others. In other words, where people feel they are isolated or have less physical contact, more attribute this to themselves than to others. If we compare this with the answers in Table 12.3 about shame and rejection, there would seem to be a self-confirming pattern in the relationship between people with HIV and those around them.

This gives us an interesting perspective on the concept of stigma. This is a concept that people almost always apply in the description of the social consequences of the HIV epidemic (see for example UNAIDS 2008). The term ‘stigma’ as Goffman (1972) explained it describes a process of interplay between individuals and those around them. Our figures indicate that individuals with HIV themselves actively contribute to this stigmatisation process. One informant who has long lived with the diagnosis is thoroughly convinced of this:

I warn HIV-positive people against our stigmatising ourselves. We can have a tendency to do that. To underestimate people and be certain of the response from those around us in advance is no good. I think a great many people who become involved in situations with people close to them and are allowed to know what kind of illness they’ve contracted will have a feeling of gratitude and say, ‘Thank you for your trust – because you’re telling me this, I may at least be able to offer support in time of need.’

The qualitative interviews indicate that, for many, having a virus in their blood is connected with a feeling of being dirty and infectious. This feeling seems to have more to do with a psychological reaction to stigma than a careful consideration of how infectious they actually are. One of the informants says the following:

Because of the diagnosis, you become isolated and don't want to meet people. [...] When you're open about your diagnosis, you fall ill from the stigma.

In two short sentences, this describes how people with HIV can become isolated. Further, it can lead to the creation of a vicious circle, so that, by and by, they themselves do not want to meet people. In addition, it describes the notion that openness leads to stigma, which in turn makes people with HIV ill. To understand better how these processes happen, we also asked what kinds of reaction the respondents have had to being open about their HIV status.

Table 12.5 What kinds of reaction have you met with from those around you in the last five years when you have talked about the fact that you have HIV? Numbers and percentages.

	Number	Percentage
I have predominantly met with positive reaction	118	53.4
I have predominantly met with negative reaction	5	2.3
Reaction has been mixed	72	32.6
Don't know	26	11.8
Total	221	100.0

In Table 12.5 we see a slightly more positive picture. In fact only 2.3 per cent say they have predominantly met with negative reaction. One may say this is a very small proportion, not least when we view it in connection with the figures we have discussed above with regard to stigma and isolation – but at the same time, about one-third have experienced mixed reaction, and a relatively large group do not know. There are also a relatively large group who did not answer the question. Thus, in total, no more than a little over half the respondents report predominantly positive reaction.

Several of the informants describe being open as strenuous. They say it marks their relations with other people, as openness causes them to be unduly linked to being diagnosed HIV positive in their encounters with other people.

I've always been of the opinion that no one really cares whether I've got HIV or not. For me, it was ten years before I told my mother about it. And the reason I didn't talk about it was that I really didn't see any reason to talk about it. It was only when the medicines arrived that I told her about it. Then I at least knew she'd understand I wasn't just going to die.

This informant describes how being associated with HIV also means one is associated with death. This informant has also gone from being secretive to being more open about HIV status. The two following quotations describe the reverse process. Both say they would probably be less open today – one because he feels alone as someone openly HIV positive, the other because he finds people are afraid.

It must be possible to be open. I'm tired of making a stand and being the only one who's open – being the outward face. People think I'm the only one, whereas there are loads of people around me. It's tiresome. I'd think again as far as being open is concerned. But doubtless that's because I'm the only one.

I was open with everyone to start with – told everyone in prison. Everyone there got to know about it. It wasn't a conscious choice – I didn't think about it. [I] felt so stigmatised and judged already that having HIV wasn't so important. I don't know whether I'd say it today. The treatment you get – you notice that people are afraid of you, you know. It's like TB in the old days.

We have also seen that openness among the respondents is limited. There is more openness among HIV-positive people from the North than among those from the South. There is more openness among homosexuals than among heterosexuals. The secrecy seems to be due to anxiety, though few report predominantly negative reaction to being open. The limited openness is a stress factor in many people's lives and many struggle to maintain an overview of who knows and who does not know among the people around them.

Most things stop me short since I've locked myself up in my own home – I only feel safe there. If I go into an office, or anywhere, my shoulders tense up, I get totally up-tight, I can't relax – then I come home and lock the door and think about myself.



## 13 Friends and networks

According to Barstad (2009), the Norwegian population have a large number of friends in comparison to other countries. According to Statistics Norway's study of living conditions (*ibid.*), about 10 per cent of the population lack intimate friends. People with HIV would seem to come out of this worse than the population in general.

In the chapter on openness, we saw from Table 12.4 that nearly half have experienced feelings of isolation. As many as 35 per cent of the respondents say they have had less contact with family and friends because of HIV. This may be viewed as an indication of loneliness among people with HIV.

Table 13.1 When did you last see one of your friends? Numbers and percentages.

	Number	Percentage
Today or yesterday	145	54.5
2–7 days ago	84	31.6
8–29 days ago	18	6.8
1–12 months ago	15	5.6
Not in the last 12 months	4	1.5
Total	266	100.0

When we ask directly about contact with friends, however, the picture becomes less clear. Of the respondents, 86 per cent have been in contact with friends during the previous week. There remain a small group who have very little contact with friends. For these individuals, this is obviously a problem, but this aspect – of a group of lonely individuals – does not make up the big picture of the respondent group. The combination of limited openness and relatively frequent contact with friends sets the problem of openness further in relief, as this may indicate that many people's openness is limited even with respect to people they count as friends, and that they feel isolated even though they have contact with friends.

I've got bad nerves and social anxiety that have built up over such a long time. I find it difficult – [I] don't know what to talk about, I get uptight, I get worn out from meeting people, feel tired all the time.

To understand better how the friendships work, we also asked whether the respondents had anyone to whom they could talk in confidence. Although the question is not exactly the same as in the study of living conditions (Barstad 2009), it would nonetheless seem that the proportion of people without intimate friends is significantly higher among people with HIV than among the general population.

Table 13.2 Do you have anyone close to you to whom you can talk in confidence? Numbers and percentages.

	Number	Percentage
Yes	214	80.8
No	51	19.2
Total	265	100.0

The majority, four out of five HIV-positive people in the sample, have someone close they can talk to in confidence. However, we also find that one in five do *not*. This picture proves more problematic when we go farther and ask whether they think they can get support when they need it.

Table 13.3 Is it easy or difficult for you to get help from immediate family, relatives or friends if you need support in a psychologically difficult situation? Numbers and percentages.

	Number	Percentage
Difficult	44	16.6
Both	86	32.5
Easy	105	39.6
Not sure	30	11.3
Total	265	100.0

From Table 13.3, we can see that only 40 per cent say that it is easy to get help from family or friends in a psychologically difficult situation. Here, then, a more problematic relationship with family and friends emerges. In other words, it would seem that the positive factor here is that many people with HIV have friends, and contact with them, but the negative side of this is that they doubt their friends will be forthcoming when they need them to be. The picture that begins to emerge is thus very complicated. Many have contact with friends and have people they can talk to openly but some are not really confident they can get support when they need it.



Table 13.4 To whom would you turn first of all if you had personal problems? Multiple responses possible. Percentages. (N=265)

Friends	46
Spouse, partner, cohabitant, boyfriend/ girlfriend	38
Doctor at department of infectious medi- cine	23
My regular doctor	17
Other family members	12
Nurse at department of infectious medicine	12
Parents, parents-in-law	11
Psychologist	9
HIV-Aids organisation	8
Children	4
Other	3
Grandparents	2
Priest or religious guide	1
Nobody	3
Don't know	3

Only 2 per cent did not answer the question, and in all, 6 per cent answered either 'don't know' or 'none'. In other words, most people have someone they can turn to with their own personal problems. Friends come top of the list, not family. At the same time, there are a rather large group who specify professional contacts, such as doctors, nurses and psychologists.

This slightly complicated picture of relations with friends is probably behind one of the findings in the qualitative part of the study. Many of the informants set great store by contact with other people who have HIV. Their explanation for this is that they can relax in such contexts, as illustrated by the following statement among others:

You see, I feel it's easier to have contact with other HIV-positive people in general. In a way, you can let your hair down. I'm not saying I don't have contact with HIV-negative people, because obviously I do have contact with HIV-negative people, but when you take part in these things that are only for people with HIV, you even notice people's shoulders relax, because then you don't have this little spectre in the background, lying in wait.

Those quoted say quite clearly that they need this contact. In the following quotation, the informant says she should have understood this sooner and that she tries to communicate this experience to others.

So for me, then, it's made a lot of difference. And I'm convinced of that. And when I talk or chat with other people, I say, 'At some point or other you'll need to have contact with others.' It's the same for cancer patients, you know – they need other cancer patients to talk to. You can live with it for two, three, four years, but at some time or other, you have to. The sooner, the better, then, I say. I wish I'd realised that sooner.

The next quotation brings an additional element to our understanding of social life. Some of the groups HIV hits hardest have other burdens that are also involved in limiting social life. The sum of these burdens can be rather heavy.

When you come off drugs and you've got HIV, it's hard to be sociable. How much dare I say? How much should I say? When should I say it? There are so many who judge you for what you've been – it's so difficult getting to know people. I don't like it when they ask what I've done in the past and so on.

In summary, one may say that many people with HIV seem to be quite sociable but that a significant group are also lonely. Only a minority think it is easy to get support from family and friends, and there are a significant group for whom the most important people in terms of support are professional helpers. Contact with friends who have HIV is important for many.

## **Social life and the reactions of those around**

The 2008 attitude study (Mandal et al. 2008) showed that a significant proportion of the public lacked knowledge of HIV and modes of infection. Notions that one can contract HIV by kissing or by drinking from the same glass as someone with HIV can cause reactions toward HIV-positive people that are perceived to be stigmatising and offensive. One of the informants offers the following simple description of this:

There are many who don't like to go to the toilet if I go there.

### **Gay circles**

Gay men who were interviewed talk of circles that are both inclusive and judgemental. The previous study of HIV and living conditions (Fangen et al. 2002) revealed that many people with HIV felt that defamation and a strong demand for success characterised gay circles. However, it is common to suppose that gay circles have the most knowledge and thus the greatest capacity to deal with people who have HIV. Among

the informants in this study, several are in fact critical of gay circles. In particular, people state that these circles can be exacting and demand a lot as regards success. The following quotation illustrates this well:

I suppose I feel we HIV-positive people are like a fly in the ointment for HIV-negative people. That really they'd prefer us out of the way, because we're a kind of threat and we oughtn't to be there. I think most of them would, really [...] I don't think much of the problem is about the sexual aspect. We talk about homos and so on – we're quite brutal with one another, you know. You have to be successful in every possible way, you have to look good, with good finances, be entertaining, be smart and all that. Once you've got HIV, you don't fit in.

The following quotation clearly illustrates the ambiguity of the perceptions people with HIV have of gay circles. It describes a feeling of both security and pain in encounters with these circles.

You know, HIV's been a lot closer to home in the gay community, so it's been debated and taken up much more. Since that's the community I move in, it's the community I feel most secure in, but at the same time, the community where it hurts most when you're criticised. After all, no one can hurt you as much as those you're fond of – those close to you. And there have been intense discussions, for instance on Gaysir<sup>8</sup>, but I think maybe it's wrong to say discussion is generally manifested elsewhere. But that's what you read and that's how you think, and so I've really felt excluded.

Using the Internet to make contact with other people – be they gay, people with HIV or both – is a phenomenon that characterises the everyday life of the individual much more than it did in 2001–2. Gaysir seems to be the most important website for gay men in Norway. Gaysir seems to be a way to meet other people in a place where it is easier for people to talk about their HIV status. For several informants, this has been an important arena. At the same time, this same arena has been a place where people can potentially encounter negative attitudes and reaction from other users:

I got a comment on Gaysir from an HIV-positive Norwegian – he said people from Asia mess around a lot or [...] I couldn't quite figure out what he meant, you know. Or I did figure it out, you know – little by little. He meant it was no surprise I'd got HIV, because I was from Asia. I thought, 'What is this? So, you can also get comments like this, then.'

Websites are both forums where it is easier for people to talk about their HIV status and forums where quite odious attitudes can easily surface – of rather a racist nature,

<sup>8</sup> Gaysir is a website for homophiles: <http://www.gaysir.no>

for example. Gay men from immigrant backgrounds who have HIV are not a large group in Norwegian society but they are there. The threefold stigma they encounter can be quite difficult to handle. This is a group that for many reasons has not been very conspicuous but should probably receive more attention in future.

### **Immigrants**

The informants from immigrant backgrounds paint a gloomy picture of the prospect of being open in the ethnic communities of which they are part. Immigrants with HIV also say other HIV-positive communities have little understanding of their situation – but establishing good relations among immigrants who have HIV is also problematic. This can be because minority ethnic communities are very diverse, because inadequate openness in these communities spreads to HIV-positive people themselves or because distrust is caused between them.

But if you come from a minority background, it's worse. You don't have anywhere to go if the society or community you've been part of rejects you. Then there's only Aksept and HivNorway. It's good but there are different people there. The ones who're gay don't want to talk to the ones who're hetero. The ones who're hetero are also... you know. There aren't many who understand. Relations aren't good. [...] We think there are so many of us who have HIV and come from minority backgrounds, but they don't trust one another.

One of the informants describes the isolation that accompanies this lack of trust as follows:

Several times I've thought I can't take any more... I don't have a social life. I just sit in prison at home, you know.

Trust is an essential part of social capital (see for example Rothstein 2004). The combination of isolation and lack of trust described may therefore be viewed as a significant strain on living conditions.

I'm thinking of moving now. I find the situation very difficult and don't know whether I can stick it out much longer. I feel really isolated. 'I move with my head down in this town.'

## 14 Participation in organisations

Participation in organisations and networks of other kinds is often an important provision for people with HIV. There it is possible for them to meet other people and have the option of talking together and sharing experiences and perceptions. Especially in view of the fact that we find that many people with HIV are not open about the diagnosis with family and friends to any great extent, it is evident that having some arena or other in which to be open will be very important to many and it may even be the only context in which they are open (cf. Carstensen and Dahl 2007). The organisations are also in many cases important sources of information on various types of user-oriented service. Through the qualitative interviews, we have gained some understanding of the fact that organisations of this kind and the provisions they represent often function as useful channels of information, where people with HIV can exchange information about experiences connected with rights, health services and what kinds of follow-up provision there are.

We asked the correspondents about contact with networks and organisations. There are a multitude of these organisations and they offer a very broad variety of provisions. Aksept, which the Oslo Church City Mission runs, offers provision of psychosocial support but also represents an environment where people can get to know others with HIV. The Trondheim, Bergen and Stavanger Church City Missions conduct some operations of the same kind, but on a more limited scale. HivNorway is an interest organisation but it also engages in public information and has its own services at the same time – such as legal advice – aimed at HIV-positive people and their relations. Gay & Lesbian Health Norway primarily pursues preventive work aimed at gay circles. Some of the networks are primarily Internet-based groups, others arrange social gatherings for groups of people with HIV. Anyway, on this basis, we have employed participation in organisations and networks as an expression of various kinds of strategy connected to having HIV.

Table 14.1 shows the degree of affiliation to organisations, networks and support provisions among the respondents, but general conclusions cannot be drawn about organisational affiliation among the whole population. The recruitment plan we followed means we probably ended up with a sample that is more active in organisational contexts than is typical for the group of HIV-positive people as a whole. In the Danish sample, 41 per cent responded that they had never taken advantage of the HIV organisations' provision of counselling and support (Carstensen and Dahl 2007). This

Table 14.1 Are you part of any organisation or network for people with HIV, or do you have contact with other networks or support services? Multiple responses possible. Numbers and percentages. (N=267)

	Number	Percentage
HivNorway	97	36
Aksept	88	33
Homopositiv	20	7
Networks	30	11
Gay & Lesbian Health Norway	15	6
Live with HIV/CCM* Stavanger, Bergen and Trondheim	11	4
Social Medical Centre in Tromsø	9	3
Other	11	4
None	112	42

\* Church City Mission foundation

is very much in harmony with our sample, where 41.3 per cent say they are not part of/in contact with any network or organisation.

In this question, it was possible to tick several options. Just under half give more than one response. In other words, most of the people who specify a network or organisation have contact with several organisations or networks – 1.8 on average.

One interpretation of this finding is that the respondents represent an either-or pattern – either they are quite insular about having contracted HIV and about their knowledge of it or they have extensive networks related to the fact that they have HIV. There is reason to believe this gives us a picture of the situation among HIV-positive people in general. The finding is also consistent with descriptions we have obtained from people well acquainted with HIV-positive communities and networks.

When we check whether there are differences between the groups, we find there is some overrepresentation of people born in the South among those who do not have contact with any network or organisation, but there does not seem to be a very big difference between the groups (41 per cent of those born in the North, and 48 per cent of those born in the South, have no contact with networks or the like).

Granted that there are no big differences between the groups, we can nonetheless see that, in relative terms, in comparison with other infection groups, more of those who have contracted the infection homosexually are involved with networks. Norwegian homosexuals are relatively well represented when it comes to 'other' and 'networks', which are the generic categories. This means that here people have probably picked out groups on Gaysir, for example. In addition to the general networks, homosexuals also have their own – Homopositiv, for example. Surprisingly few report that they have contact with Gay & Lesbian Health Norway. There are actually more who report that they have contact with Homopositiv. As one might expect, homosexually infected

ethnic Norwegians entirely dominate the group made up of people who report that they have had contact with Gay & Lesbian Health Norway.

Fuglestad and Lauritzen (2004a and 2004b) conducted a user study at Aksept that showed that a relatively large number of those who take advantage of Aksept have contracted the infection recently. Upon dividing up the respondents who report that they take advantage of Aksept according to whether they were born in the North or in the South, and by infection group, we find that representation for most of the groups is around 30 per cent. In other words, the figures show there is relatively little difference between the groups when it comes to the proportion who take advantage of Aksept. Norwegians, Africans and Asians are somewhat overrepresented among those who take advantage of Aksept. As far as infection groups are concerned, too, the distribution is quite even, although, in relative terms, there are somewhat more people who take advantage of Aksept among those infected homosexually and among those infected by hypodermic needles. Some of the figures here are low, but the overall impression is nevertheless that the various groups are quite evenly represented.

HivNorway is the organisation that has contact with the biggest group of respondents. Presumably this is in part a result of one of the imbalances in the sample, but it may also be viewed as a result of the fact that this is the organisation that has contact with the most HIV-positive people. When it comes to the relative distribution of members among the various groups, however, we can see that HivNorway has a rather broad spread across different groups. As far as modes of infection are concerned, those infected homosexually have more representatives than other groups, but again we can see that there are no big differences in the relative distribution, which ranges from 25 per cent (drug users) to 44 per cent (people born in the South). Thus, in the same way as with Aksept, we get a picture of a rather composite group of members and users.

## **How pleased are HIV-positive people with the organisations and networks?**

The informant interviews reveal positive mention of many of the organisational networks and support provisions for people with HIV. This applies to HivNorway, Gay & Lesbian Health Norway, Aksept and the Church City Mission's provisions in Stavanger, Trondheim and Bergen, along with the Social Medical Centre in Tromsø. However, the statements point in many directions and, among the informants and respondents, there is more criticism of the biggest organisations, including HivNorway and Aksept. One of the informants describes the barrier engaging with organisations involves:

Today, I've got quite involved. Had you told me a little over a year ago that I'd be sitting here with you and talking now, and everything else I've been involved with, I'd have laughed my head off. But once I got past that, I understood the value of it, you see, and that it wasn't so dangerous. I didn't expose myself to such enormous risk by taking part in this, especially because it was only HIV-positive people who took part in these events. I remember it was very important that it was only HIV-positive people. Because if it's only HIV-positive people, and they're the ones who're there, then there's much much less chance the tittle-tattle will go any further, you know.

The peace of mind of being in a context where everyone has HIV seems to be something positive. This also emerges from the following quotation, which also describes some of the things about such environments that can be perceived as problematic:

Again, it's a good provision for us, where we can meet and talk to others who are like-minded. [...] I don't think many people identify with everyone who goes there. It's sort of a bit two-sided, because I don't want to be a person who's got something against drug addicts, for example. I think, in a way, many people don't want to go there, because there's really a lot of focus on tragedy. That's the reason I don't go there, a bit, because I've no desire to join some morbid club. I've no desire to join a club where people bring one another down, but I absolutely do think it's a very good provision, though I see no reason for me to go there.

There are others who say there are barriers of this kind to their participating: this applies not least to the descriptions of Aksept. There are also several informants who make critical remarks about HivNorway. The following quotation encompasses most of the points that come up.

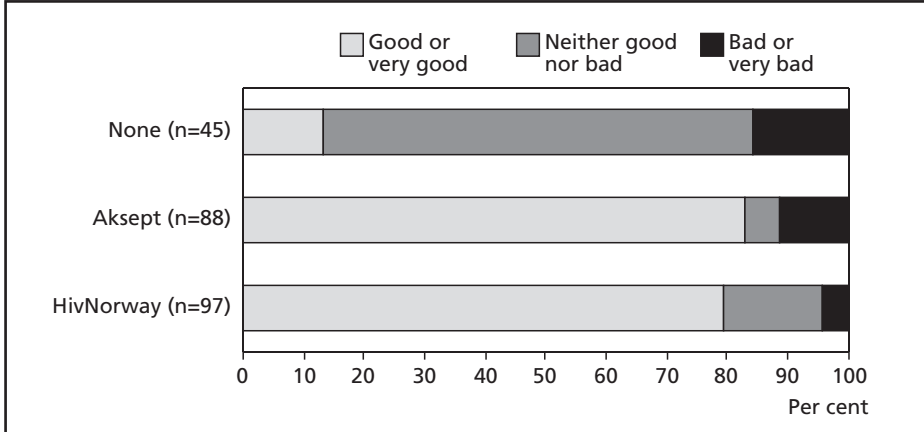
I tried dabbling with HivNorway, [...] but I got angry with them because they didn't want to listen to us HIV-positive people, so I left the organisation. [...] It's the only organisation in the Nordic countries that doesn't have an article about improving the quality of life of HIV-positive people. It's also the only organisation that doesn't require you to be HIV positive to get involved, so really they don't know whether they've got a single member who's HIV positive. Another thing is that support members or HIV-negative people have equal member status. According to their articles, then, the whole committee can be HIV negative. It says the head of the committee should ideally be HIV positive, but that doesn't mean he is.

In the questionnaire study, we asked the respondents to describe their experiences of contact with organisations and networks. Figure 14.1 represents the results of this.

From Figure 14.1, we can see how those who report that they are involved with HivNorway or have contact with Aksept, as well as those who have no connection to networks or organisations, respond to the question about their experiences of contact



Figure 14.1 How would you describe your experience of contact with the organisations or networks? By affiliation.



with them. Not surprisingly, we find that a large proportion of those who are not involved in organisations or networks respond ‘neither good nor bad’. The respondents who report that they take advantage of Aksept or have connections to HivNorway generally give positive assessments of them. About eight out of ten answer ‘good’ or ‘very good’. Views are somewhat more polarised among those who take advantage of Aksept than among those who take advantage of HivNorway – that is, there are a few more people who answer ‘very good’ or ‘very bad’. However, one cannot deduce much from this difference, since there is a big overlap between these two groups – around half are repetitions. All the same, it must be emphasised that we did not ask the respondents to rate the individual organisations. As regards both those who have contact with Aksept and those who have contact with HivNorway, the fact is that they have contact with an average of about two organisations each. The picture that emerges, however, is that those who are members of or have connections to networks and organisations are pleased or very pleased with their contact with them.

In summary, one may say that there seems to be a polarisation when it comes to contact with networks and organisations. On the one hand, there are a large group who do not have contact with any. On the other hand, a slightly larger group have contact with several networks and organisations. Most of the respondents who have such contact are pleased with the provision. This last fact may be the result of a positive selection but the figures are so clear that they indicate that those who have contact with organisations are in fact quite pleased with the contact.



# 15 Family, relationships and sexuality

## Family

Support and back-up from family and friends play an important role in daily life for many people, not least when serious health problems afflict them. As emerges from Table 15.1 below, almost one in two respondents (48 per cent) is married or in cohabitation or has a boyfriend/girlfriend.

Table 15.1 Respondents' civil status. Percentages. (N=247)

Married with person of opposite sex	13.4
Partner of person of same sex	14.2
Cohabiting with person of same sex	6.1
Cohabiting with person of opposite sex	5.7
Divorced/separated	9.3
Widowed	3.2
Unmarried/not cohabiting, with boyfriend/girlfriend	8.9
Unmarried/not cohabiting, without boyfriend/girlfriend	39.3
Total	100.0

In most cases, the partner or boyfriend/girlfriend is described as supportive – but there are also exceptions. One of the informants, for example, says the following of his relationship with his wife:

She got really afraid when I became HIV positive. Then she got really afraid for our daughter. And at home, too, if she hurts herself and grazes herself then I'm not allowed. Even if she knows it won't happen, because I haven't got open wounds or whatever, she says, 'No, you just keep away.' Such conflicts do come up. [...] As far as one's own child is concerned, one does change a little. When my daughter wants to kiss me, she gets uneasy about it as well. I say it's not some droplet infection, you know. We don't talk about it that much, not unless we have to. If we start talking about it at home then everything goes quiet – there's only sadness then.

The interviews revealed examples of people with HIV who stay in relationships because, for various reasons, they feel they have to out of consideration for their partners. This can apply, for example, to bisexual men who end up living double lives although their wives know what is happening because they have found out about the HIV infection – and, although there is a high divorce rate in Norway, the informants talk of situations and environments where it is very difficult to break free of marriage, even if a given individual might like to do so.

Several of those who live alone reveal they have big problems getting established in relationships, on account of the fear of rejection:

I've had several people interested in me but have kept them away. I can't handle it – I can't handle being rejected.

For me, it's very difficult to believe or have faith that HIV doesn't matter. In practice it's almost a taboo topic because you're afraid of rejection and the reaction and then people protect themselves from ending up in such situations. It's easiest – people choose the easiest solution.

What I think about is whether they've got enough strength to live with someone who's openly HIV positive. Having enough strength to live with someone who has HIV is one thing but living with someone the whole district knows has HIV is something else. That wasn't something I thought about when I opened up...

At the same time, one informant said she knew of three women with HIV who had all found HIV-negative men who had accepted the situation and all three were in intimate relationships or living with these men.

Family, however, consists of more than partners and boyfriends/girlfriends. We also asked about relationships with siblings and parents. Table 15.2 represents the responses.

Table 15.2 How would you describe your relationship with your parents and your siblings? Percentages.

	Parents	Siblings
Very good	31.7	37.9
Good	29.4	28.7
Neither good nor bad	9.9	14.9
Bad	4.2	4.6
Very bad	1.9	6.5
None of my parents/siblings is alive	22.9	7.3
Total	100.0	100.0
N	262	261

From Table 15.2, we get the same picture – that many people have good relationships with their parents and siblings. At the same time, there are a considerable group who experience difficult relationships. More people have good relationships with their siblings than with their parents but the two pictures are not directly comparable since more people have siblings who are alive than parents.

If we look at openness toward parents and siblings, we find that fewer people are open about their HIV status than say they have positive relationships with these same people.

Table 15.3 Have you told any of the following you have HIV? Numbers and percentages. (N=235)

	Number	Percentage
Parents	108	46.0
Siblings	132	56.2

From Table 15.3, we can see once again that it is difficult for some people with HIV to be open about their HIV status even with people they are close to and with whom they say they have good relationships.

My parents aren't about to disown me but I am afraid they can't handle it – [I] am afraid it will be like: 'Poor, poor you – such an unequalled tragedy.' Which they'll never get over. They're quite elderly people and I don't hold it against them. It'll be a burden both for them and for me and I don't think I can bear it myself.

In some cases, openness actually causes problems.

My sisters are a bit panicky when they come to my place. I can see it and feel it, so it's not nice having visits like that. I mean, when they come visiting, they bring coffee in a flask and their own cups.

They're comparatively nice, they call me, they talk to me, but they've got their own lives, you know. They come round once in a while, they haven't abandoned me – they're nice enough, my family. I'm the one backing away.

Some informants mention that it is unfortunate there is no provision for relatives where a person can get help dealing with the fact that someone in the family has contracted HIV. The HIV organisations do not do much work with respect to families but instead focus on HIV-positive people themselves, and the same is true of the health system. One informant talks of a daughter who very much wants to participate and contribute to attitudinal work on HIV, but the informant reports that it is not easy:

She's said she'd have liked to be more involved in HIV work but she feels that HivNorway is only for HIV-positive people and not for relatives. She's been a member for several years [...], but doesn't feel there's any room for her there. She'd have liked to be informing people about HIV herself – someone who could help other relatives – because it's a hard job being a relative.

Only half the respondents are open with their parents and siblings. However, most of the informants are open with their families and a few have very positive stories to tell:

I think what underlies a great deal of the security I've felt and the fact that things have been OK for me, comparatively speaking – it's because I got immediate support from home. I've had the family behind me, constantly, all the way. That's been the key. I've been able to talk about everything.

However, several also tell stories about uncomfortable situations with friends and family, where one is not included in the same way, for fear of infections:

They invited all their friends to come and then they went to the jacuzzi together. We've always had mutual girlfriends – we do today. These girlfriends get invited along with the siblings, with nieces and nephews – I've never been invited. She asked me once whether I could bathe in the same water, which surprised me, but I think in a way it's all right that she asked – so I said I could, but all the same, she's never invited me. I've pointed it out to her.

## Children

Of the respondents, 27 per cent have children, and half of these 27 per cent have children under 18. Of those who do have children, 62 per cent say they have custody of some of the children. Only 7.5 per cent of the respondents say they want to have children with their partners. As many have had children since finding out they have HIV. This means some of the respondents have grown-up children, roughly as big a group have children under 18, and, in addition, we find there are also a group who have had children since being diagnosed.

About one-third of the respondents who have children have told their children about their HIV diagnosis. Several of the heterosexual informants have children. It is often difficult to tell one's own children about the infection, and those who have not yet told them about it say they dread the day they will have to tell them.

He doesn't know. I've thought about saying it from time to time but why should I do that? What does everyone think when they hear about HIV? They think it's a

death sentence. Why should I let him think I'm mortally ill? What I've done – I've taught him how to use plasters, to be careful with blood. I've taught him to be careful about uncleanliness, because many people we associate with could have bad immune defences, I often say. I've taught him about immune defences, about viruses, and he knows what HIV is as well – we've looked at it in children's books about the virus. So I think that, when the day comes, it'll be easy to tell him what's wrong.

However, several of those who have already talked about the diagnosis mention that it has brought them closer to their children. The children are also an incentive for them to live with the diagnosis, in order to survive to be present in the children's lives.

If I hadn't been responsible for a child, I'd probably not be sitting here today and have lived the life I have done. The fact that I was responsible and dealt with it from day one – that's saved me. It's given life meaning – one must. I can't lie down. Many is the day I've wanted to lie down, and maybe some days I've got no drive, but I don't think I have any choice, because there's no one else who'll do it.

For some of the informants, the fact that, in Norway, people with HIV cannot get help to have children is painful. The informants from immigrant backgrounds in particular draw attention to this as something very difficult, because within many immigrant communities there is also the pressure to start a family. The fact that one cannot have children makes it difficult to conceal the diagnosis.

As the doctor said it, I thought, 'Well, never mind – I'm only HIV positive, after all. I can still have children for all that.' [...] But when I found out you can't get help to have children, it dawned on me. That was the only hope my wife had – because I have to think about my wife as well. [...] She got really dejected then. [...] I've told her I've got HIV – I did that straight away. [...] She took it really badly – she'd been thinking about children all along.

However, there are a considerable group – 7.4 per cent – who have had children since finding out they have HIV.

Table 15.4 shows that those of the respondents who have had children since being diagnosed have predominantly met with positive reaction. However, being asked to

Table 15.4 Reaction of those around them to the fact that they, being HIV positive, had children. Numbers and percentages.

	Number	Percentage
Got a lot of support and back-up	12	75
Encountered much negative reaction	1	7
Were asked to abort	3	23
People behaved the same way they usually do	9	56

have an abortion represents quite a prominent response, even if only three people are concerned.

Of the respondents, 12 per cent state that they are open with their children. This is about half of those who have children. In relative terms, somewhat fewer people seem to have told those of their children who are under 18 that they have HIV than have told those of their children who are over 18.

## Sexuality and sexual life

In the main, HIV spreads sexually, and much of the stigma surrounding the HIV epidemic is connected to this fact. It is therefore important to know something about how having HIV affects sexual practices and sexual life. The informants have varying degrees of need for active sex lives and we find much the same variation when it comes to the extent to which they do in fact have active sex lives. Several informants say they no longer have sex lives. Several reasons are given. For some, their partners' fears of infection are so great that they stop having sex. Others report the opposite: although their partners have relatively straightforward attitudes toward having sex, they themselves find it difficult because they are afraid of infecting those in question. Here the Penal Code is a complicating factor.

*My wife and I don't have sex. That's something new. Even if you can protect yourself, we haven't, because she kind of doesn't want to, so it causes a lot of problems, you know. [...] But you know, I feel it's my fault that she doesn't get enough sex or that I can't satisfy her. So I feel really bad.*

*Sex came to an end. You feel you're unclean inside – that you've got something deadly. I was about 30 when I contracted the infection. [...] I have been interested in some people since, as well, but I haven't dared.*

*The biggest change has been my sex life – I don't have one. I don't dare become fond of anyone, because I'm afraid of infecting other people.*

*The loss I feel is more about having a life partner and a close confidante I can share life with. The sexual side is important as well, but only a part of the whole.*

This series of quotations indicates that several of the informants no longer have sex. As we shall see again in the analysis of the questionnaire data, however, by no means everyone has stopped having a sex life. The following quotation gives a slightly different picture. Here is someone who found that sexual life got easier:

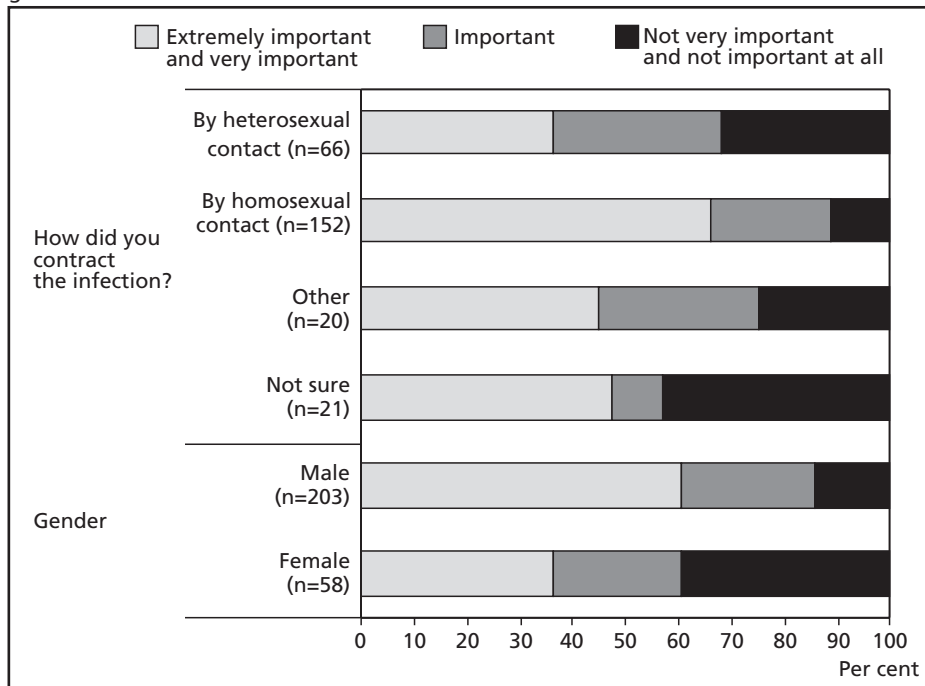


What I remember, in addition to the slightly tragic part and the shock and things like that – there was also a sense of freedom. A feeling that I didn't need to worry about all that stuff any more then, finally, and in this way, my sex life changed to some extent. A great many people either go that way or go down to the basement and stop having sex. I chose to have sex. I felt that – though my sex life didn't change that much, it did at least make it easier, or I rid myself of that worry. There was kind of a sense of freedom. Since then I've felt that I've nothing to fear, but it's hard to explain. Because, in a way, it does affect your sexual life, but when you've had HIV as long as I have – my sexual partners know where they've got me. We've got our ways of having sex, so it's clear that HIV affects your sex life. But I've had a lot of time to adjust to it – so for me, then, it's totally normal now.

In the questionnaire, we asked questions about how important sexual life was for each of the individuals and whether they were worried about infecting other people, and we asked them to specify their positions on a number of statements about changes in sexual life connected to the HIV diagnosis.

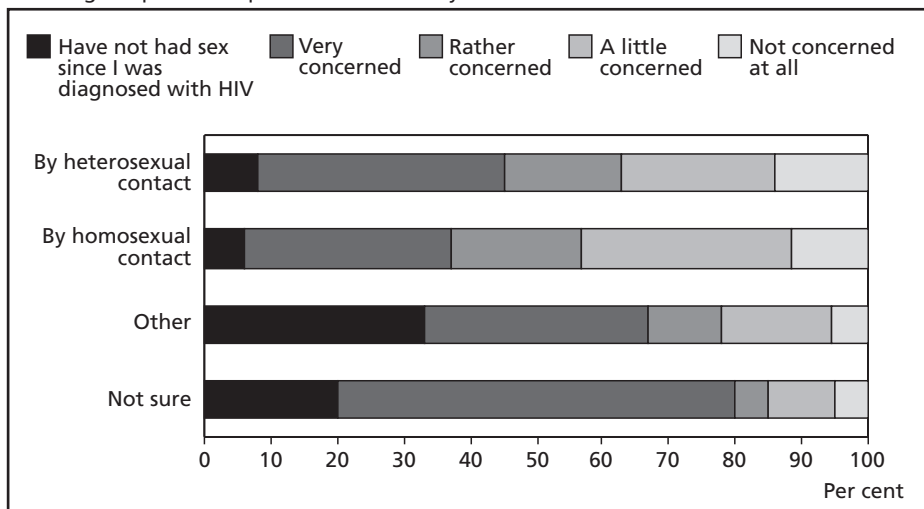
In the analysis, we have placed the main emphasis on whether there are differences between the various infection groups as far as these aspects of sexuality and sexual life are concerned. We see from Figure 15.1 that there is a big difference between hetero-

Figure 15.1 How important is it to you to have a good sex life? By mode of infection and gender.



sexually and homosexually infected people as regards how important they think it is to have good sex lives. We see the same pattern when we divide the respondents up according to gender. Thus the explanation for this difference could just as well be connected to the gender dimension as to modes of infection or sexual orientation.

Figure 15.2 If you have sex with a person who does not have HIV, how concerned are you about infecting the person in question with HIV? By mode of infection.



We can see from Figure 15.2 that there are marginal differences between different infection groups when it comes to the fear of passing HIV onto HIV-negative sexual partners. Somewhat more than half the respondents, whether homosexually or heterosexually infected, are rather or very worried about infecting other people. Those who have contracted the infection in other ways, or are not sure how they contracted it, stand apart – but it is not surprising that those who have not themselves contracted the infection sexually are less worried about sexual infection.

Table 15.5 presents response distributions for a number of statements dealing with how sexual life has changed since the diagnosis. The figures that emerge may be seen as quite dramatic. Almost nine out of ten people say sexual life has changed. Three out of four say they have fewer partners and slightly fewer than two out of three say it has become harder to find regular partners. There are 37 per cent who say they choose partners who have HIV and one-third say their HIV status means they no longer dare to have sex. So we can see that a great many people say sexual life has become more difficult. In Fafø's previous study of living conditions (Fangen et al. 2002), one-half said HIV had meant that they no longer dared to have sex – a significantly higher proportion, in other words, than in our data.

Table 15.5 Here are some statements about your sexual life since you were diagnosed with HIV. To what extent do you agree with these statements (completely agree or rather agree)? Numbers and percentages.

	Number	Percentage
My sex life has changed	220	87
I have fewer partners	180	76
More difficult to find regular partners	145	60
I am afraid to have sex	134	55
I choose partners who have HIV	84	37
I dare not have sex any more	80	33

In order to find out a little more about changes in sexual life, we have looked at whether there are differences between the infection groups in question. There do not seem to be any big differences. Along one axis, however, there is a difference – namely age. Table 15.6 shows, for example, that the proportion of those who report that they have fewer partners increases with age.

Table 15.6 Those who completely or rather agree with statement 'You have fewer partners'. By age. Numbers and percentages.

Age	Number	Percentage
18–29	11	65
30–39	28	65
40–49	73	75
50–64	58	87
65 and over	9	90
Total	179	77

In all the age groups, a high proportion of people say they have fewer partners since the HIV diagnosis. On the basis of the figures in Table 15.6, however, one may ask whether age is as important a cause of change in sexual life as the HIV diagnosis or perhaps even more important.

People with HIV who returned the questionnaire say it is important to have good sex lives. Many are worried about infecting other people and there is a clear decrease in sexual activity, which the respondents directly link to having HIV. This raises an important question: what needs to be done to provide for the best and safest sexual practice possible in this group?

In both Denmark and Australia, more people feel that contracting HIV has had a negative impact on their sex lives. There are, however, differences between the groups. It is those infected heterosexually who make the biggest changes (Grierson et al. 2006,

Carstensen and Dahl 2007). In our material, the picture is somewhat different – there do not seem to be big differences between the groups as far as changes in sexual activity are concerned.

## The Penal Code

During the course of the work on this study of living conditions, §155 of the Penal Code was high up on the agenda of HIV politics. This section makes it a criminal offence to infect other people or expose them to the threat of infection (Mandal et al. 2008). Section 155 came up as a big problem in the qualitative interviews. People with HIV are afraid of infecting other people and the Penal Code exacerbates this fear.

And it's also connected to the judgements there have been since §155 that have scared the living shit out of me, and which also made me more scared while I was poorly. I thought, 'Dear God, what'd happen if it now turned out that...?' After all, there have been accidents, as I call them, in our relationship during the twelve years we've been together. But he's very calm and collected. 'It's not that dangerous, you know,' he says. Then I say, 'But let me tell you, if I should get very poorly and feel I maybe have to take a break then people will think it's all over, and then I can get convicted for it,' but then he says it'll never happen. 'But you don't know that, do you?' I say to him. One never knows what people think, after all, or what they say or believe. It's been a bit problematic. That's also the reason I've taken a little break from my relationship. He's HIV negative, you see. I hope he still is.

A large proportion of the informants in the qualitative interviews drew attention to the Penal Code as a problem, sometimes before they were asked. However, the picture is a little more nuanced when we look at what answers the respondents gave in the questionnaire study.

Table 15.7 Do the provisions of the Penal Code disturb you? Numbers and percentages.

	Number	Percentage
No, I never think about that	83	35.2
Yes, they occasionally disturb me	61	25.8
Yes, they often disturb me	55	23.3
Don't know	37	15.7
Total	236	100.0

As Table 15.7 reveals, around half report that the Penal Code disturbs them, but there are also a relatively large group who respond 'don't know' and around one-third who say they never think about it. Though the questionnaire study and the in-depth interviews point in the same direction as far as the problems connected to §155 of the Penal Code are concerned, it seems the findings from the in-depth interviews are more negative than the findings from the questionnaire study.

An important argument in the debate on the Penal Code is that it will help to prevent infection. Because, in the main, HIV spreads sexually, we therefore asked whether the provisions of the Penal Code had any influence on the respondents' sexual lives. Table 15.8 represents the response distributions.

We can see that very few people say they have more unsafe sex as a result of the section – but we can see that more than half say the section has had an impact on their sex lives. Most also say that it has influenced their behaviour in a 'preventive' direction – less and safer sex. The question, though, is whether the costs are in proportion to the preventive effect. The Penal Code is described as a strain on the quality of life of people who have HIV – as something that exacerbates the anxiety of sexual life and has a negative impact on life with one's partner. One of the informants describes this as follows:

Table 15.8 Have the provisions of the Penal Code had an impact on your sexual life? Multiple responses possible. Numbers and percentages. (N=260)

	Number	Percentage
Yes, I have less unsafe safe	26	10
Yes, I have fewer partners	38	15
Yes, I have stopped having sex	39	15
Yes, I always tell my sexual partners I have HIV	58	22
Yes, I sometimes tell my sexual partners I have HIV	27	10
No, the Penal Code has not had any significance	81	31
Yes, I have more unsafe sex or more sexual partners	6	2
Don't know	27	10

When I stood up in the courtroom as a witness, and he sat on the bench – the man who'd infected me – and insisted we'd used condoms all the time, while I stood there insisting we'd twice had unprotected sex, I thought, 'Once I walk out of that door, the situation turns around completely – I'm no longer a victim then, I'm a criminal then, because if the man I'm in a relationship with goes into town now and has sex with anyone' – because it's what the man who infected me said, not knowing how many people I'd had sex with, you know – 'and contracts the infec-

tion, then he'll know I've got HIV.' Then he can do the same thing I've done – go to the police, report me and say the same things I said, while I'd sit there saying the same things as the man who infected me said, and I'd be found guilty. Court cases in Norway have shown as much – I'd be found guilty and he'd be believed. That's how the law works.

Another says this:

It's very awkward having safe sex – not entirely in relation to the fact that the person mustn't get infected, but in relation to what can be done to you if the person finds out about it and if you don't say it but rather protect yourself. Sex has become this whole big really complicated thing. It's really stupid – really limiting.

Although the questionnaire study suggests the Penal Code may play a part in causing HIV-positive people to have less and safer sex, it does not seem to bring any substantial reduction in the risk of infection. The law is felt to be stigmatising. One of the positive findings of the 2008 attitude study (Mandal et al. 2008) was that 98 per cent said they agreed that everyone had a responsibility to prevent infection. The Penal Code places the responsibility with people who have HIV and they perceive this lack of mutual responsibility as a problem.

I suppose I found it easier to be daring before and to get into a situation that might lead to my meeting someone, which might result in a sexual relationship. There have been ups and downs too, of course – I've had periods of self-imposed isolation in relation to my own sexuality, you see. You know, actually I must admit that §155 really affects me, more than I've thought.

# 16 Perspectives on life

## Living with HIV

There are a number of books in which individuals convey powerful impressions of what it is like to live with HIV. One of the more recent Norwegian contributions is John Galt's book (2008) *Døden ved min side* ('*Death by My Side*'). Several of these contributions describe a powerful existential process connected to being diagnosed with HIV. In addition, several of the contributions have levelled criticism at various authorities' handling of the HIV situation.

Let us end the chapters about the arenas of living conditions with a series of quotations describing how some of the informants tackle HIV in daily life.

It's changed my life in several ways. When I came to Norway, I was very much ready for school. I was going to study to a higher level, but when I found out I had HIV, I thought I only had ten years left, you know. So I said, 'Ten years – I can forget it, then.' So I just don't think about education. That's what changed my life.

It was really hard. When I suddenly had HIV. I found out about it suddenly, you see. OK, what'll happen next month? Will there be hepatitis? Or what'll happen the month after that? Will it be cancer? Can it lead to things like that? That's how I've started thinking. But after all, it doesn't happen, you know.

It plays a big part, because I'm thankful for each day I get. I've become happier in my life. You can't take it for granted, kind of. That's the difference. I'm thankful for what I have, because I really have a lot.

But I can only try to account for the stages when I got really poorly, and when, by chance, I ended up in hospital, and that was the first time I had contact with HIV doctors. Because, you see, there wasn't any point getting in contact with these doctors when there weren't any medicines. But then came the medicines, you see. When I got them, for the first time I felt myself getting better, but I hadn't noticed I was poorly. And when I got much better physically, these thoughts came back. What the hell do I do now? Maybe now I'm going to grow old. So then I had to think things over, you see. And then I entered this new stage in my life where I kind of spent time clearing up the mess I'd made before.

I think the reason I haven't handled HIV that well is because I know I've got no one to blame but myself, so I have to take the responsibility now that I should've taken then. I also think there's a connection. I think it used to be something you were exposed to much more. Whereas now people are maybe a bit more aware of their own responsibilities and handle it differently.

In the time right after I got infected, I was struck by a kind of feeling of emptiness, in the sense that I felt I was the only person in the world who had HIV. There was no one to talk to.

Why do I get to live so long? Even other people who had the same virus as me have been dead for many years. Why me? Am I alive to torment myself? Or to give myself another chance? It's hit me many times. But there are days I don't want to stand up and just want to disappear.

One thing these quotations have in common is that they describe the duality of having HIV in the period since the advent of the anti-virals. Many find they have to regain both their perspective on life and their spirits. There is actually a lot of support and encouragement to be had along the way. At the same time, there are many hard battles. Many start thinking about what it is going to be like to grow old with HIV.

## **Growing old with HIV**

Medicines mean people can live for a long time with HIV. More than half the respondents in the sample (58 per cent) say they contemplate being able to live long lives in a different way. However, two-thirds also say they are anxious about their health in the future.

For many of the informants, being able to see a future for oneself is a positive thing – but for some it involves some clearance work, because they have left things to their own devices in the belief that they would die early on. For some, it is also hard to have lived with a diagnosis for a long time, to have seen many friends die of HIV-Aids and to go on living themselves. There is coming to be a significant group of older people with HIV. Among the respondents, 33 per cent are over 50. We could see beforehand that this was a problem on which more light must be thrown. We therefore asked the respondents about their thoughts on the future. This issue also arose in the qualitative interviews. The following quotations describe slightly different aspects of this perspective on life.

It's strange when you don't expect to grow old. Although we have the medicines, we don't know everything about the side effects. The medicines have saved many



people but people mustn't think it's just about taking medicine – that it's not that dangerous. It's an awful disease – it is.

Some are uncertain what it will be like to grow old with HIV and how well their bodies will stand up to the medicine in the long term.

I've had some strange feeling of sorrow or other that kind of gets the upper hand for occasional spells – this suffocating kind of feeling of sorrow. I'm not afraid of death per se, but I'm really uneasy about the process of getting there, because I've seen far too many people in situations in hospital where they've not been given respect or had a dignified passing.

Another insecurity is connected to the fear of loneliness.

I have thought about it. But it's the same for others as well, you know. Loneliness and getting ill – seriously ill for a long time. I have a lot of thoughts about religion and euthanasia and palliative care and pain. I'm putting it off. I take one day at a time.

Others still are most absorbed in the fact that they have discovered a new lust for life upon realising that they may live for a long time:

Now I'm thinking far into the future. That's something different than I was doing half a year ago. Back then I wasn't thinking so very far into the future. Back then it was more uncertain. Back then I hadn't got all my counts stabilised. As soon as I get them stabilised, I get my second wind again – the old spark comes back again for some strange reason or other. I don't know where it hides itself away but it hides itself away occasionally and then suddenly it bursts into flower again.

Another primarily expresses gratitude for the fact that he has lived a long life.

Most of us must feel fortunate one way or another, you know. I mean, it's not as if I feel unfortunate in any way. Having HIV is like that. I got it when I was 18. That is to say, in many ways, I don't have any frame of reference other than being HIV positive. Really I've always been HIV positive. Because I talk to people now who've recently been infected and they talk about what it was like before they were HIV positive. For me, being HIV positive has really just been my whole life, because I got it so early on. There are many people who ask things like: 'Would you have done things differently in your life?' But I can't put it any other way than to say this is my life, I'm in charge of it, I'm glad about what I've experienced in life and what I've been part of.

So we can see that there will be more old people with HIV. This will challenge health services. This is perhaps as true for psychosocial as for physiological provision.

## The 'be happy' game?

In summary, the chapters on openness, relationships and social life point in the direction of a polarisation among people with HIV. Many are fine and have good lives. At the same time, many have serious problems connected to their HIV status. For some, the HIV diagnosis has brought increased social capital, but for a significant group, the diagnosis has meant a significant reduction in social capital.

Upon analysis of the qualitative interviews, a picture emerges that is a little diffuse. There are several who say they are fine. At the same time, there is something incongruous about these accounts. On the one hand, the informants describe rather difficult and strained situations in life, but at regular intervals they come back with statements to the effect that they are fine. It is natural to ask whether, given the new medicines, people are allowed to say they have problems. One must be thankful that one has survived. Is it perhaps the case that though people with HIV think life is problematic, they nonetheless spend a lot of time and energy convincing themselves and those around them that really they are fine?

There seems to be a difference between the various groups of people who have contracted the infection as regards what stance they take on the question of responsibility and guilt. It would seem that gay men take the blame for contracting the infection upon themselves more than the other groups. This may suggest there is still an element of guilt and innocence in the way people think about those who have contracted the infection.

It is important to stress that there are also informants who say convincingly that HIV has brought positive change to their lives, as the following statements illustrate:

I'm really thankful, because HIV has been an unbelievable teacher. It's made me a more secure and richer person, emotionally and mentally.

Many times I've said, 'Thank heavens!' I've been able to experience a whole lot of good things, experienced a lot for better and worse, but have not wanted to be rid of it – I mean that with all my heart!

In the beginning when I joined the HIV community, I'd often say HIV had given me my entrance ticket to a community I'd never have got into otherwise. I've met some unbelievably nice people there.

## **PART V SUMMARY AND RECOMMENDATIONS**

The report was prefaced with an account of the polarisation in the material upon which this study is based. In comparison to the situation in 2001–2, which was the last time Fafo presented a study of living conditions among people with HIV, there is progress as regards physiological and physical factors. On the other hand, there does not seem to be such big change when it comes to the psychosocial problems. Notwithstanding all the limitations of the material, there nonetheless seems to be a change when it comes to the choice of personal strategies among people with HIV. Especially among those who have contracted the infection recently, there are a group who do not seem to want HIV to play a big part in their lives. Many, however, encounter attitudes and ignorance in society that are felt to be a strain irrespective of personal strategy. It must also be emphasised that there are many who do not report any such burden. For some, the strain seems primarily to relate to their own fear of others' reactions more than to their real reactions.

People with HIV make up a multifarious and composite group. Gay men – whether Norwegians or immigrants – heterosexual men and women – whether from countries in the North or from countries in the South – and drug users are quite different groups, with varying social challenges.

### **Gay men**

This group make up approximately 30 per cent to 40 per cent of the population and 58 per cent of the respondents in the questionnaire study. Gay men are thus overrepresented among the respondents. The group consists only of men, and most of them were born in Norway. In the last few years, one has seen an increase in new infections among gay men (Norwegian Institute of Public Health 2008). It is this group that does best as regards several of the living condition indicators that this study has mapped out.

It is striking that the proportion of people who report that they have financial problems is also high in this group of respondents. Among the informants too, there is the perception that the HIV diagnosis has led to financial problems.

The group made up of people who have contracted the infection homosexually are also the group who are most open about their HIV status. However, even in this group a large proportion of people limit their openness to a small group of people close to them. Several of the informants who define themselves as being gay also say contracting HIV meant a new process of 'coming out'. Furthermore, as far as health is concerned, this group stands apart by making more use of psychologists' services than the other groups do.

Gay men describe the gay community as both inclusive and judgemental. The informants say these circles demand a lot as regards success. Many actively use the Internet and say it is a place where it is easier to talk about one's HIV status. However, HIV-positive homosexuals from immigrant backgrounds, for example, say they can encounter substantial prejudice on such websites.

## **Women and men who contract the infection heterosexually**

This group makes up a little under half of those registered HIV positive. Two-thirds of them have contracted the infection before coming to Norway and thus it is natural to assume that they come from immigrant backgrounds. Some of those infected heterosexually who have contracted the infection in Norway also represent immigrant communities. The high proportion of people from immigrant backgrounds also leaves its mark on the living conditions of this group. Women from immigrant backgrounds, not least, come out relatively badly as far as material living conditions are concerned.

People from immigrant backgrounds who have HIV, both men and women, report that it is difficult to be open within their own ethnic groups. Several, for example, report that they can be open only with Norwegian friends. It is a struggle to maintain an overview of whom one can be open with and with whom one cannot. In the questionnaire study too, this is the group that emerges as least open. Some of the questions in the questionnaire study – more precisely, those regarding relations with the asylum authorities – were only put to people who had come to Norway during the previous five years. Around one-third say they did not feel that the HIV test was voluntary, and comparatively many say HIV-Aids was not discussed at the asylum reception centres.

Only one in five of the respondents is in a long-term heterosexual relationship. Several of the informants shy away from entering into relationships. Several are disconsolate because they cannot get help to have children, and many wish for such provision.

### **The gender dimension**

Of those who returned the questionnaire, 210 are men and 59 are women (2 did not specify their sex). In other words, 75 per cent of the respondents are men. Among the informants, two out of five, i.e. 40 per cent, are women. In our material, in other words, there is not an even distribution of women and men. This makes reliable analysis of gender differences difficult.

However, there are some clear differences between women and men when it comes to income and finances and attitudes toward sexuality, which means it is reasonable to state that gender is of importance as far as these factors are concerned. Women generally have lower incomes and worse finances and are less concerned about having optimum sex lives. They claim that sex is not so important any more – intimacy and closeness are more important.

As far as relationships with family and friends are concerned, too, it seems women set more store on these relationships. Support from and intimacy with family and friends also seem to be very important to their mental health.

### **Drug users**

This group of people infected by hypodermic needles now makes up only about 10 per cent of those who have been diagnosed and are living with HIV in Norway. The number of new infections is also relatively low. This is a group that is heavily under-represented among the respondents in the questionnaire study. It is therefore difficult to use the data from this study to give an account of this group's particular needs. We know this is a group that generally comes out badly as regards various living condition indicators. Therefore, greater participation in the questionnaire study from this group would probably have resulted in lower scores on several of the living condition indicators.

### **Overall**

As mentioned, the group of people with HIV comprises various subgroups, several of which are marginalised along various dimensions. This applies, for example, to gay men, people from immigrant backgrounds and drug users. Women make up the largest group among those who have contracted the infection before coming to Norway. Above, we have taken up some of the areas in which it is most obvious that the groups differ from

one another. Nonetheless, given how different these groups are, it is remarkable that they seem to have many challenges and problems in common.

As far as material living conditions are concerned, we can see that a relatively large proportion of people in our material receive disability benefit. In a way, this is probably not surprising, since the study looks at a group whose health is compromised. It would seem people with HIV used to receive disability benefit more or less 'automatically', but today this has changed. However, a few findings suggest some of the people with HIV who receive disability benefit might, for example, have coped with and profited by working part-time. There are also some who say they need adjustments in the workplace but that this is not followed up. Implementing the 'welfare to work' policy in practice and creating an inclusive world of work that also encompasses people who have HIV would thus appear to be a challenge.

Several of the informants and a high proportion of the respondents report financial problems. This latter proportion is so large that the group's level of income alone cannot account for it.

The workplace also represents a challenge as far as openness is concerned. The attitude study (Mandal et al. 2008) revealed that there was scepticism among the population about working with HIV-positive people. Few of the respondents who work are open, and a relatively high number of those who are open have subsequently encountered negative reaction. A few informants say they have encountered discrimination or persecution in the workplace.

It therefore seems openness is limited among both the respondents and the informants. However, among networks, friends and family, there is no indication of such openness problems as we saw in the arena of working life. On the contrary, several of the informants say they have received a great deal of support from family and friends and that this has been crucial to their mental health.

The most positive part of what it is like to have HIV in Norway in 2008–9 relates to the physiological health issues. The medicines are improving, the side effects are becoming less extensive and many people experience improvement in relation to health. However, there are still challenges for the machinery of public service when it comes to knowledge of and attitudes toward HIV. This particularly applies to the generalists, be they regular doctors or caseworkers at NAV/social services. In relation to these authorities, there are reports of inadequate knowledge of HIV, and insight into the mental and social aspects linked to having HIV also seems limited. The finding is thus of some interest that, among those who contracted the infection long ago, there is a tendency for HIV specialists (for example, doctors at the polyclinics) to have taken on roles whereby they not only attend to what is purely HIV-related but may also assist in other ways.

The variable that most clearly influences openness is the time of diagnosis. The longer a person has known he or she has HIV, the more likely it is that he/she chooses

to be open. The fear of openness seems to be connected more to HIV-positive people's own fear of stigmatisation and their own notions as to what openness will lead to than to actual experience of rejection due to HIV status.

The proportion of people who have contact with networks, organisations and psychosocial support authorities is roughly the same in all the groups. Many have contact with several organisations/networks. A large proportion make positive statements when it comes to the help and follow-up they have received from various organisations. However, there are also critical voices, and these appear primarily to be concerned with two things: one is the fact that the organisations and networks focus on misery too much, the other – which particularly relates to HivNorway – is that HIV-positive people themselves have too little influence within the organisations.

Sexuality is a problem that concerns many people, and several informants report problems connected to this. Among the informants, §155 of the Penal Code emerges as a significant problem. It plays a part in worsening the quality of life and causes problems in amorous relationships, and with respect to daring to embark on new relationships. This is a little less clear among the respondents, even if more than half say the Penal Code worries them.

On the basis of the findings made in this study, we will finish with a brief list of some of the challenges we think it is important to look at more closely in the future in order to be better able to provide for HIV-positive people to be able to take part in working life and society on an equal footing with everyone else. They are:

- Attitudes, arrangements and information at work
- Awareness of HIV in generalist services (regular doctors and NAV)
- The potential for openness in general, and especially in immigrant communities
- All the groups report limited openness. Even in gay circles it seems to be a challenge to create an environment where people with HIV can be open without experiencing negative feedback.
- §155 of the Penal Code
- The need for psychosocial follow-up – not least for guidance as far as financial affairs and financial problems are concerned. This is also a question of access to those providing professional help, such as psychologists.
- We achieved a very low response rate in the questionnaire study. This may also be seen as a finding and may be an expression of the diminished accessibility of the group made up of people with HIV. For some, this may be a result of better provision of treatment – for others, it may unfortunately mean they live an isolated existence.

The contrast – between, on the one hand, improved prospects of being able to live longer on the individual level and, on the other hand, the knowledge, attitudes and reactions among other people – has been an important point of departure for this study of living conditions. It is a positive thing that medical progress has improved the prospects among people with HIV of living long lives, but it does not seem that the reactions and attitudes people with HIV meet with in society have moved in the same way. There is still some way to go.



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# Appendix 1 Questionnaire

<b>Study on the living conditions of persons with HIV and AIDS in Norway.</b>	<b>Fafo</b>

Fafo (Institute for Labour and Social Research) in conjunction with HIV Norway is conducting a study on the living conditions of HIV positive persons. The study is financially backed by the Directorate of Health. Synovate (formerly MMI) is responsible for the practical implementation of the questionnaire-based study.

It is important for us to collect answers from as many HIV diagnosed persons as possible. We would therefore kindly ask you to complete this questionnaire. The data collection will occur in the time frame xx.-xx., and you should only complete the questionnaire once.

The objective of the project is to examine different questions related to the living conditions of HIV positive persons. For example, the project will examine how HIV positive persons perceive their health situation, work, residence, finances, and their relationship with family and friends, as well as their experiences with government offices and the support system. Through this knowledge, it will be possible to work towards improving the living conditions and support for HIV positive persons.

The questionnaire will be distributed to HIV positive persons at hospitals, institutions and organisations. We would also encourage you to pass on a questionnaire to any other HIV positive persons you may know. The questionnaire may seem large, because it includes many aspects of being HIV positive. Some of the questions may also seem personal, but we need this information to get a complete overview of the living conditions, and to understand the connection between different factors. By answering the questionnaire, you will contribute towards an increased understanding of the financial and social consequences of living with HIV.

The questionnaire is completely anonymous, and your identity will be kept secret from those who will be working with this project. Since the questionnaire is anonymous, it will not be possible to link information in the questionnaire with information about each individual from other sources. Information about health is confidential, and the researchers will treat the information confidentially. The collected data will not be made available to other parties than those involved directly with the project. It will also not be possible to identify single individuals in the reports.

Participation involves completing the questionnaire and returning it in the enclosed return envelope. The questionnaire should only be completed if you are HIV positive. You may end up receiving more than one questionnaire, but we only want one completed questionnaire per person. Participation is voluntary. Participation has no consequence for any future follow-up from the health authorities. Nobody will know who has participated in the study.

A report from the project will be published in the first half of 2009. The project will be completed within 1/1/2010. At that time, the questionnaires will be destroyed.

If you have questions about the project, you can contact project manager and researcher Arne Backer Grønningsæter at Fafo: Postboks 2947 Tøyen, 0608 Oslo. Telephone: 22 08 87 15. E-mail [arne.groenningsaeter@fafo.no](mailto:arne.groenningsaeter@fafo.no)

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Use a pen when completing the questionnaire, and check the square for the option you feel is the most suitable. Otherwise follow the instructions in the questionnaire. The arrow (=>) next to an option means that you should proceed to the question indicated by the number behind the arrow. Return the completed questionnaire in the enclosed envelope as soon as possible.

**BACKGROUND INFORMATION**

First we would like to ask you some general questions.

**1 Gender**  
 Male .....  1  
 Female .....  2

**2 How old are you?**  
 18-29 .....  1  
 30-39 .....  2  
 40-49 .....  3  
 50-64 .....  4  
 65 or older .....  5

**3 Where were you born?**  
 Norway .....  1  
 Other country in Europe .....  2  
 Africa .....  3  
 North-America / Australia / New Zealand .....  4  
 Central- America/ South-America .....  5  
 Asia .....  6

**4 How long have you lived in Norway?**  
 WRITE DOWN HOW MANY YEARS  1

**5 Where were your parents born?**  
 ONE ANSWER PER COLUMN

	A Mother was born in:	B Father was born in:
Norway .....	<input type="checkbox"/> 1	<input type="checkbox"/> 1
Other country in Europe ...	<input type="checkbox"/> 2	<input type="checkbox"/> 2
Africa .....	<input type="checkbox"/> 3	<input type="checkbox"/> 3
North-America / Australia / New Zealand .....	<input type="checkbox"/> 4	<input type="checkbox"/> 4
Latin-America / South-America .....	<input type="checkbox"/> 5	<input type="checkbox"/> 5
Asia .....	<input type="checkbox"/> 6	<input type="checkbox"/> 6

**6 What is your highest level of completed education?**  
 Primary and lower secondary school .....  1  
 Upper secondary school .....  2  
 University or college .....  3  
 Not completed primary school .....  4

**HEALTH SITUATION AND HIV**

We will now ask you some questions about your HIV infection and the care you are receiving.

**7 When were you diagnosed as HIV positive?**  
 WRITE DOWN THE YEAR  1

**8 How were you infected with HIV?**  
 Heterosexual contact .....  1  
 Homosexual contact .....  2  
 Street drug injection .....  3  
 Buying or selling sexual services .....  4  
 Blood transfusion / blood products .....  5  
 From mother to child .....  6  
 Other .....  7  
 Not sure .....  8

**9 Have you developed physical symptoms as a result of being HIV positive?**  
 Yes .....  1  
 No .....  2  
 Not sure .....  3

**10 Do you receive antiretroviral treatment for your HIV infection?**  
 Yes .....  1  
 No ..... ( => 12 )  2  
 Not sure ..... ( => 12 )  3

GO TO QUESTION 12 IF YOU ANSWERED "NO" OR "NOT SURE" AT QUESTION 10

<b>11 How much do you agree or disagree with the following statements about how this drug treatment affects your everyday life?</b>						
<b>ONE ANSWER PER LINE</b>						
	Completely agree	Partially agree	Neither agree nor disagree	Partially disagree	Completely disagree	
	1	2	3	4	5	
It improves my general well-being .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
It worsens my general well-being .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
It relieves pain .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3
It gives me bothersome side-effects .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
It reduces the frequency of infections .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5
It reduces my physical ability to perform .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6
It makes it more difficult to visit others .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7
It limits my social participation .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
It is difficult to manage taking drugs regularly .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9
I am worried about possible side-effects of the drugs .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10

**OTHER QUESTIONS ABOUT YOUR PHYSICAL AND MENTAL HEALTH**

Here are some questions about how you view your health, both related to your HIV and other potential health problems.

**FOR EVERYONE**

**12 How do you view your health in general?**

Very good .....  1

Good .....  2

Neither good nor bad .....  3

Bad .....  4

Very bad .....  5

**13 As a result of being HIV positive, how many days in the past 14 days have you been...**

**WRITE DOWN THE NUMBER OF DAYS ON EACH LINE**

Fully active .....

Less active, but not bedridden .....

Partially bedridden at home .....

Completely bedridden at home .....

Bedridden at a healthcare institution .....

**14 We would like to know how you have been doing lately. How much of the time in the past 14 days have you experienced any of the following?**

**ONE ANSWER PER LINE**

	All of the time	A lot of the time	Some of the time	None of the time	
	1	2	3	4	
Felt refreshed and energetic .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Been happy and satisfied .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Been bothered by nervousness and anxiety .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3
Been bothered by fear or worrying .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Felt helpless about the future .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5
Been down and depressed .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6
Been worried and unsettled .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7

**15 In the past 12 months, have you used sedatives, sleeping pills, antidepressants or similar?**

Yes .....  1

No .....  2



**16** Do you do any of the following to improve your general health and condition?  
**MULTIPLE ANSWERS POSSIBLE**

Try to eat healthier .....  01.  
 Exercise .....  02.  
 Try to smoke less .....  03.  
 Quit smoking .....  04.  
 Trying to reduce alcohol intake .....  05.  
 Quit drinking .....  06.  
 Trying to reduce drug use .....  07.  
 Quit using drugs .....  08.  
 Taking dietary and vitamin supplements .....  09.  
 Nothing in particular .....  10.

**17** Not related to your HIV, have you been diagnosed with any other chronic diseases or injuries by a doctor?

- Injury related to an accident .....  1.
- Muscle / joint condition .....  2.
- Heart or vascular diseases (for example high blood pressure / angina / infarction) .....  3.
- Respiratory conditions (for example asthma) . .....  4.
- Mental or psychological disorders / problems . .....  5.
- Metabolism disorders .....  6.
- Nervous system disorders or conditions affecting the senses (for example hearing condition or epilepsy) .....  7.
- Other conditions .....  8.
- No, none .....  9.

**DENTAL HEALTH**

**18** Has your dental health worsened since you were diagnosed with HIV?  
 Yes .....  1  
 No .....  2

**19** Are you aware of your rights when it comes to dental care and your HIV diagnosis?  
 Yes .....  1  
 No .....  2

**20** Does your dentist know that you are HIV positive?  
 Yes .....  1  
 No .....  2 ( ⇒ 23 )

GO TO QUESTION 23 IF YOUR DENTIST DOES NOT KNOW THAT YOU ARE HIV POSITIVE

**21** Does your dentist treat you differently after learning of your HIV diagnosis?  
 Yes, better .....  1  
 Yes, worse .....  2  
 No, the same as before the diagnosis become known .....  3

**22** Does your dentist help you with the reimbursement programs that exist?  
 Yes .....  1  
 No .....  2

**CONTACT WITH HEALTH SERVICES**

All HIV positive persons have the need for contact with health services. We would therefore like to ask you about your experiences with the health personnel.

FOR EVERYONE

**23** How many times have you been in contact with the following health services in the past 12 months?  
**ONE ANSWER PER LINE**

	0 times	1-2 times	3-5 times	6 times or more	
Your family doctor (fastlege) or other general practitioner ....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	1
Privately specialist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Psychologist .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3
Hospital or outpatient clinic (without being admitted) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Admitted to a hospital or nursing facility .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5





**24** All in all, do you feel that knowing about your HIV diagnosis has changed the way you are treated by the health services mentioned above? (Family doctor (fastlege), specialist, psychologist, hospital, nursing facility)  
**MULTIPLE ANSWERS POSSIBLE**

- Yes, I am taken more seriously .....  1.
- Yes, I feel better cared for .....  2.
- Yes, I feel they treat me as very contagious ...  3.
- No, I feel they treat me about the same as before .....  4.
- No, none of these health services know that I am HIV positive .....  5.
- Other .....  6.

**25** Do you have a family doctor (fastlege) or medical clinic that you go to when you need medical help?  
**MULTIPLE ANSWERS POSSIBLE**

- Yes, a family doctor (fastlege) .....  1.
- Yes, a medical clinic .....  2.
- Yes, an occupational health service (bedriftshelsetjeneste) or student health service .....  3.
- No .....  4. (⇒ 28)

GO TO QUESTION 28 IF YOU DO NOT HAVE A FAMILY DOCTOR OR MEDICAL CLINIC

**26** When you want to reach your family doctor or medical clinic, do you usually get a hold of them when you call them during the day?

Yes .....  1  
 No .....  2

**27** Does your family doctor (fastlege) know that you are HIV positive?

Yes .....  1  
 No .....  2  
 Not sure .....  3

FOR EVERYONE

**28** Do you have a need for more information about any of the following, or are you satisfied with the information you are currently receiving?  
**ONE ANSWER PER LINE**

	Have a need	Satisfied	
	1	2	
Contagious behaviour .....	<input type="checkbox"/>	<input type="checkbox"/>	1
Safer sex .....	<input type="checkbox"/>	<input type="checkbox"/>	2
Drug use and side-effects .....	<input type="checkbox"/>	<input type="checkbox"/>	3
Diet .....	<input type="checkbox"/>	<input type="checkbox"/>	4
Alternative medicine .....	<input type="checkbox"/>	<input type="checkbox"/>	5

**29** How satisfied or dissatisfied are you overall with the information you have received about your treatment from hospitals, outpatient clinics and your family doctor?  
**ONE ANSWER PER LINE**

	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Fairly dissatisfied	Very dissatisfied	
	1	2	3	4	5	
Information from hospitals .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Information from outpatient clinics ..	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Information from your family doctor .	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3

**30** How satisfied or dissatisfied are you overall with the treatment and follow-up you have received from hospitals, outpatient clinics and your family doctor?  
**ONE ANSWER PER LINE**

	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Fairly dissatisfied	Very dissatisfied	
	1	2	3	4	5	
treatment and follow up from hospitals .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
treatment and follow up from outpatient clinics .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
treatment and follow up from your family doctor .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3

**31** Have you had the need for any of the following types of services related to being HIV positive?  
**ONE ANSWER PER LINE**

	Have not had the need	Have had some need	Have had a large need	
	1	2	3	
Physical therapy/physiotherapy .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
Recuperation stays or similar .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
Psychological counselling / treatment .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3
Occupational therapy (ergoterapi) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
Support groups for HIV positive persons .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5
Conversations with a social worker .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6
Drug assisted rehabilitation (methadone or subutex) .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7

**32** Have you received offers for any of the following types of services?  
**MULTIPLE ANSWERS POSSIBLE**

- Physical therapy/physiotherapy .....  1.
- Recuperation stays or similar .....  2.
- Psychological counselling / treatment .....  3.
- Occupational therapy (ergoterapi) .....  4.
- Support groups for HIV positive persons .....  5.
- Conversations with a social worker .....  6.
- Drug assisted rehabilitation (methadone or subutex) .....  7.
- No, none of the above .....  8.

**33** How satisfied or dissatisfied are you overall with the support and rehabilitation services you have used?

Very satisfied .....  1  
 Fairly satisfied .....  2  
 Neither satisfied nor dissatisfied .....  3  
 Fairly dissatisfied .....  4  
 Very dissatisfied .....  5  
 Have not used any such services .....  6

**34** Have you used any of the following because you are HIV positive?  
**MULTIPLE ANSWERS POSSIBLE**

- Special diet .....  01.
- Relaxation techniques .....  02.
- Meditation or yoga .....  03.
- Vitamin therapy .....  04.
- Herbal therapy .....  05.
- Acupuncture .....  06.
- Natural medicine .....  07.
- Hypnosis .....  08.
- Healing .....  09.
- Homeopathic medicine .....  10.
- Aromatherapy .....  11.
- Other .....  12.
- None of the above .....  13.

**CONTACT WITH WELFARE SERVICES**

Many also have contact with other parts of the support system. For example NAV/Trygdekontoret (The Norwegian Labour and Welfare Administration / the National Insurance Office), or social services / the social welfare office. We would therefore like to know how HIV positive persons experience this contact.

**35** In the past 12 months, have you been in contact with NAV/Trygdekontoret?

Yes .....  1  
 No .....  2 (⇒ 38)

GO TO QUESTION 38 IF YOU HAVE NOT BEEN IN CONTACT WITH NAV/TRYGDKONTORET

**36** What was the contact with NAV/Trygdekontoret about?  
**MULTIPLE ANSWERS POSSIBLE**

- Information about rights .....  1.
- Help to complete application forms .....  2.
- Conversation with a caseworker .....  3.
- Medical evaluation .....  4.
- Other .....  5.

**37** How would you describe the help you received from NAV/Trygdekontoret?

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5

**FOR EVERYONE**

**38** In the past 12 months, have you been in contact with municipal social services / the social welfare office?

Yes .....  1  
 No .....  2 (⇒ 41)

GO TO QUESTION 41 IF YOU HAVE NOT BEEN IN CONTACT WITH MUNICIPAL SOCIAL SERVICES / THE SOCIAL WELFARE OFFICE

**39** What was the contact with social services / the social welfare office about?  
**MULTIPLE ANSWERS POSSIBLE**

- Information about rights .....  1.
- Financial assistance .....  2.
- Help to complete forms .....  3.
- Conversation with a case worker .....  4.
- Conversation with a drug / psychiatric counsellor .....  5.
- Conversation with a legal consultant .....  6.
- Other .....  7.

**40** How would you describe the help you received from social services / the social welfare office?

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5

+

FOR EVERYONE

**41** If any of the employees at NAV/Trygdekontoret, know that you are HIV positive, are you worried that confidentiality might be compromised?

Yes .....  1  
 No .....  2  
 They do not know that I am HIV positive .....  3  
 Not relevant / no contact .....  4

**42** Have you received financial or material assistance from other parties than the ones already mentioned?

MULTIPLE ANSWERS POSSIBLE

Yes, from Hiv-fondet .....  1.  
 Yes, from voluntary organisations .....  2.  
 Yes, from family .....  3.  
 Yes, from friends .....  4.  
 Yes, from others .....  5.  
 No, I have not received additional assistance .....  6.

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QUESTION 43-47 SHOULD ONLY BE ANSWERED BY PERSONS WHO HAVE ARRIVED IN NORWAY AS REFUGEES OR ASYLUM SEEKERS SINCE 2001. OTHERS SHOULD PROCEED TO QUESTION 48

IF YOU ARRIVED IN NORWAY AS A REFUGEE

**43** Many refugees and asylum seekers learn that they are HIV positive when they come to Norway. We would therefore like to know how this situation was experienced.

Were you HIV tested when you came to Norway?

Yes .....  1  
 No .....  2 (⇒ 46)

GO TO QUESTION 46 IF YOU WERE NOT HIV TESTED WHEN YOU CAME TO NORWAY

**45** Did you feel that the test was voluntary?

Yes .....  1  
 No .....  2

**44** How would you evaluate the information you received in connection with the HIV testing?

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5  
 I was not given any information .....  6

**46** If you have lived at a refugee reception centre (asylmottak), how would you evaluate the health care you received in general while you resided at the refugee reception centre?

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5  
 I have not lived at a refugee reception centre (asylmottak) ..... (⇒ 48)  6

GO TO QUESTION 48 IF YOU HAVE NOT LIVED AT A REFUGEE RECEPTION CENTRE (ASYLMOTTAK)

IF YOU CAME TO NORWAY AS A REFUGEE AND HAVE LIVED AT A REFUGEE RECEPTION CENTRE (ASYLMOTTAK)

**47** How would you describe the employees at the refugee reception centre (asylmottak) when it comes to their handling of questions related to HIV / AIDS?

ONE ANSWER PER LINE

	Completely agree	Partially agree	Neither agree nor disagree	Partially disagree	Completely disagree
	1	2	3	4	5
• There was no talk about it .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• It was handled in a good manner .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• It was handled in a discrete manner .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• It was handled in a discriminating and prejudiced manner .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

1  
2  
3  
4

+

**FAMILY**

**Support from family and friends plays an important role in the everyday lives of many people, both in general, and when suffering from a serious illness. Here are some questions about your friends and family.**

FOR EVERYONE

**48 Are you currently...**

Married to a person of the opposite gender .....  1  
 Partner with a person of the same gender .....  2  
 Cohabiting with a person of the same gender ....  3  
 Cohabiting with a person of the opposite gender .  4  
 Divorced / separated .....  5  
 Widow or widower .....  6  
 Single / not married or cohabiting, but have a girlfriend / boyfriend .....  7  
 Single / not married or cohabiting, and do not have a girlfriend / boyfriend .....  8

**49 Do you define yourself as a...**

Heterosexual .....  1  
 Homosexual .....  2  
 Bisexual .....  3  
 Transsexual .....  4  
 Unsure .....  5

**50 Do you have children of your own?**

Yes .....  1  
 No .....  2 (⇒ 54)

GO TO QUESTION 54 IF YOU DO NOT HAVE CHILDREN OF YOUR OWN

**51 Are any of these children under the age of 18?**

Yes .....  1  
 No .....  2

**52 Are you completely or partially responsible for the care of any of these children?**

Yes .....  1  
 No .....  2

**53 Has your relationship with your children changed as a result of being HIV positive?**

Our relationship has gotten better .....  1  
 Our relationship has gotten worse .....  2  
 Our relationship is the same as before .....  3

FOR EVERYONE

**54 Some people want to have children. Which of the following descriptions is the most suitable for you?**

MULTIPLE ANSWERS POSSIBLE

- I want to have children with my partner .....  1.
- I feel that I do know enough about the possibilities of having children .....  2.
- I miss information about the possibilities of having children .....  3.
- I could use this kind of information in the future .....  4.
- None of these descriptions are suitable / not relevant .....  5.

**55 Have you had children since you learned that you are HIV positive?**

Yes .....  1  
 No .....  2 (⇒ 57)

IF THE ANSWER IS "NO", GO TO QUESTION 57

**56 What were the reactions from your surroundings to you having children after you became HIV positive?**

SELECT HOW WELL THE STATEMENTS ARE SUITABLE

	Completely suitable 1	Partially suitable 2	Slightly suitable 3	Not at all suitable 4
• I received a lot of support and backing .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I received many negative reactions .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I was asked to have an abortion .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• People acted the way they normally do when someone is pregnant or have children .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

FOR EVERYONE

**57 How would you describe your relationship with your parents?**

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5  
 I have no living parents .....  6

**58 How would you describe your relationship with your siblings?**

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5  
 I have no living siblings .....  6

## FRIENDS AND NETWORK

**59** When did you last see one of your friends?

Today or yesterday .....  1

2-7 days ago .....  2

8-29 days ago .....  3

1-12 months ago .....  4

Not in the past 12 months .....  5

**60** Do you have anyone you are close to that you can talk to in confidence?

Yes .....  1

No .....  2

**61** Is it easy or difficult for you to get help from family, relatives or friends if you should need support in a psychologically challenging situation?

Difficult .....  1

Both difficult and easy .....  2

Easy .....  3

Not sure .....  4

**62** Who would you primarily turn to if you had personal problems?

Spouse / partner / cohabitant / girlfriend / boyfriend .....  01

Children .....  02

Parents / in-laws .....  03

Grandparents .....  04

Other family members .....  05

Friends .....  06

Your family doctor (fastlege) .....  07

Doctor in the department of infectious diseases (infeksjonsavdelingen) .....  08

Nurse in the department of infectious diseases (infeksjonsavdelingen) .....  09

Psychologist .....  10

HIV / AIDS organisation .....  11

Minister or other religious leader .....  12

Others .....  13

Nobody .....  14

Don't know .....  15

## YOUR SOCIAL LIFE AND REACTIONS FROM SURROUNDINGS

Here are some questions about telling others that you are HIV positive, as well as the reactions from your surroundings to you being HIV positive.

**63** How many people have you told that you are HIV positive (not including health personnel)?

1-2 persons .....  1

3-5 persons .....  2

6-10 persons .....  3

More than 10 persons .....  4

I have not told anyone ..... (⇒ 67)  5

GO TO QUESTION 67 IF YOU HAVEN'T TOLD ANYONE

**64** What kind of reactions have you received in the past 5 years from your surroundings when telling someone that you are HIV positive?

I have received a vast majority of positive reactions .....  1

I have received a vast majority of negative reactions .....  2

The reactions have been mixed .....  3

Don't know .....  4

**65** How long did it take before you told someone for the first time that you are HIV positive?

Immediately .....  1

0-1 years .....  2

1-2 years .....  3

2-3 years .....  4

3-5 years .....  5

More than 5 years .....  6

**66** Have you told any of the following persons that you are HIV positive?

Parents .....  1.

Siblings .....  2.

Own children .....  3.

Friends .....  4.

Others .....  5.

GO TO QUESTION 68 IF YOU SELECTED ALL THE OPTIONS IN QUESTION 66

**67** Why have you not told your parents, siblings, children, friends or others that you are HIV positive?

MULTIPLE ANSWERS POSSIBLE

I am worried they would reject me .....  1.

I know they would not accept it .....  2.

They would become afraid of me .....  3.

I am too shameful .....  4.

I am afraid .....  5.

It just did not turn out that way .....  6.

Other .....  7.



FOR EVERYONE

**68** As a result of health problems, do you have difficulty with any of the following?  
 MULTIPLE ANSWERS POSSIBLE

Participating in organisational work .....  1.  
 Visiting relatives or friends .....  2.  
 Grocery shopping .....  3.  
 Managing your personal hygiene .....  4.  
 Participating in spare time activities .....  5.  
 Performing lighter physical activity .....  6.  
 None of the above .....  7.

**69** To what degree have you, as a result of being HIV positive, experienced any of the following?  
 ONE ANSWER PER LINE

	To a high degree	To some degree	To a little degree	To no degree	Not sure	
	1	2	3	4	5	
• That you feel isolated .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	1
• That you have less contact with family and friends .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	2
• That you receive less physical affection .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	3
• That others are afraid of you and keep you physically at a distance .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	4
• That you feel you are contagious and keep yourself physically at a distance from others .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	5
• That you get more care and attention from other people .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	6
• That you have gotten better at making decisions about your life .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	7
• That you plan your life differently to be able to live a long life with HIV .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	8
• That you are worried about your future health .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9

**70** In the past 5 years, have you experienced been discriminated against because of your HIV status?  
 MULTIPLE ANSWERS POSSIBLE

At work .....  1.  
 At educational institution .....  2.  
 In connection with spare time activities .....  3.  
 In other situations .....  4.  
 No .....  5.  
 Don't know .....  6.

**71** Are you a member of any organisation or network for HIV positive persons, or do you have contact with other networks or support services?  
 MULTIPLE ANSWERS POSSIBLE

Yes, network .....  01.  
 Yes, HIV Norway .....  02.  
 Yes, Helseutvalget (Gay & Lesbian Health Norway) .....  03.  
 Yes, Homopositiv .....  04.  
 Yes, Aksept .....  05.  
 Yes, Leve med HIV (Living with HIV) - Kirkens Bymisjon (The Church City Mission) in Rogaland .  06.  
 Yes, Leve med HIV (Living with HIV) - Kirkens Bymisjon (The Church City Mission) in Trondheim  07.  
 Yes, Kirkens Bymisjon (The Church City Mission) in Bergen .....  08.  
 Yes, Sosialmedisinsk Senter (Social-Medical Centre) in Tromsø .....  09.  
 Yes, other .....  10.  
 No, none .....  11.

**72** How would you describe your experiences from your contact with these organisations or networks?

Very good .....  1  
 Good .....  2  
 Neither good nor bad .....  3  
 Bad .....  4  
 Very bad .....  5



**WORKING LIFE**

**Work is an important venue for social participation and living conditions. We would therefore like to ask you some questions about your work.**

**73 What is your main source of income?**  
**ONLY ONE ANSWER**

Paid work .....  01  
 Unemployment benefits (unemployment compensation) / course compensation .....  02  
 Sick pay / sickness allowance .....  03  
 Rehabilitation benefits .....  04  
 Social benefits .....  05  
 Qualification program allowance .....  06  
 Introduction program allowance .....  07  
 Disability pension (permanent or temporary) .....  08  
 Old age pension .....  09  
 Student loans .....  10  
 Other .....  11

**74 When you were diagnosed with HIV, were you...**  
**ONLY ONE ANSWER**

Employed .....  01  
 Unemployed / looking for work .....  02  
 On rehabilitation .....  03  
 Participating in a qualification program .....  04  
 Participating in an introduction program .....  05  
 Receiving social benefits .....  06  
 A student / in school .....  07  
 A homemaker / stay at home parent .....  08  
 Retired .....  09  
 Disabled .....  10  
 On long term sick leave .....  11  
 Other .....  12

**75 How many hours did you normally work per week when you were diagnosed as HIV positive? If this varied, estimate the average number of hours per week.**

\*

WRITE DOWN THE NUMBER OF HOURS  .

FOR EVERYONE

**76 Are you currently...**  
**ONLY ONE ANSWER**

Employed .....  01.  
 Unemployed / looking for work .....  02.  
 On rehabilitation .....  03.  
 Participating in a qualification program .....  04.  
 Participating in an introduction program .....  05.  
 Receiving social benefits .....  06.  
 A student / in school .....  07.  
 A homemaker / stay at home parent .....  08.  
 Retired .....  09.  
 Disabled .....  10.  
 On long term sick leave .....  11.  
 Other .....  12.

QUESTIONS 77-84 SHOULD BE ANSWERED IF YOU CHECKED "EMPLOYED" AT QUESTION 76. OTHERS, GO TO QUESTION 85.

**77 How many hours do you currently work per week?**  
**If this varies, estimate the average number of hours per week.**

\*

WRITE DOWN THE NUMBER OF HOURS  .

**78 If there have been changes relating to your work (degree of employment, number of work hours or similar), to what degree is this a result of being HIV positive?**

\*

There has not been any change .....  1  
 The changes are largely related to my HIV diagnosis .....  2  
 The changes are somewhat related to my HIV diagnosis .....  3  
 The changes are not related to my HIV diagnosis .....  4

**79 What is your employment status?**

\*

Permanently hired employee .....  1  
 Temporarily hired employee .....  2  
 Substitute or relief staff .....  3  
 Other .....  4  
 Not employed .....  5

**80 Have you told anyone you work with that you are HIV positive?**

\*

Yes .....  1  
 No .....  2 (⇒ 82)

<b>81 To what degree have you experienced any of the following after telling your colleagues that you are HIV positive?</b>					
<b>ONE LINE PER ANSWER</b>					
	To a high degree	To some degree	To a little degree	To no degree	Not sure / not relevant
• That your colleagues have distanced themselves or become more reserved or careful in their relationship with you .....	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
• That it has become easier for you to relate to your colleagues after you told them you are HIV positive .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• That it has reduced your future earning potential .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• That this knowledge has contributed towards greater closeness and understanding among your colleagues ...	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• That it has reduced your professional development / opportunities .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• That it has affected your authority or area of responsibility negatively .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• That you have experienced positive reactions from your colleagues .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>ANSWER THE FOLLOWING QUESTION ONLY IF YOU ANSWERED NO TO QUESTION 80</b>					
<b>82 What is the reason you have not told anyone you work with that you are HIV positive?</b>					
<b>MULTIPLE ANSWERS POSSIBLE</b>					
*					
I am worried that it would reduce my career opportunities .....	<input type="checkbox"/>	1.			
I am worried about being socially excluded .....	<input type="checkbox"/>	2.			
I am worried about losing my job .....	<input type="checkbox"/>	3.			
I consider this a private matter .....	<input type="checkbox"/>	4.			
I do not want any special treatment .....	<input type="checkbox"/>	5.			
Other .....	<input type="checkbox"/>	6.			
I work alone .....	<input type="checkbox"/>	7.			
The diagnosis does not affect the work .....	<input type="checkbox"/>	8.			
<b>83 Have you had the need for adjustments in your work situation as a result of being HIV positive?</b>					
<b>MULTIPLE ANSWERS POSSIBLE</b>					
• Yes, I have had the need to change the number of hours I work .....	<input type="checkbox"/>	1.			
• Yes, I have had the need for fewer tasks to reduce physical strain .....	<input type="checkbox"/>	2.			
• Yes, I have had the need for fewer tasks to reduce mental strain .....	<input type="checkbox"/>	3.			
• Yes, I have had the need for guidance and counselling relating to my work situation .....	<input type="checkbox"/>	4.			
• No, I have not had the need for any adjustments in my work situation .....	<input type="checkbox"/>	5.			
<b>84 Have these needs been given consideration in your place of work?</b>					
Yes .....					
No .....					
<b>FOR EVERYONE</b>					
<b>85 Let us assume that your ability to work would be 100% at its best. How many percent would you consider your current ability to work?</b>					
<b>Write for example 50 for 50%. Write 0 if you are not able to work at all.</b>					
Your ability to work in % .....					
<b>86 After you learned of your HIV diagnosis, have you been on doctor prescribed sick leave because of health problems related to your HIV?</b>					
Yes, I have been on sick leave .....					
No, I have not been on sick leave .....					
<b>87 After you learned of your HIV diagnosis, have you been on doctor prescribed sick leave because of other conditions not related to your HIV?</b>					
• Yes, I have been on sick leave because of other conditions after I received the diagnosis .....					
• No, I have not been on sick leave because of other conditions after I received the diagnosis .....					



## LIVING SITUATION, FINANCES, ETC

Here are some questions about your residence and finances. These are basic questions to understand people's living conditions.

**88** Where in Norway do you currently reside?

Oslo/Akershus .....  1  
 Hedmark, Oppland, Østfold .....  2  
 Aust-Agder, Buskerud, Telemark, Vest-Agder .....  3  
 Hordaland, Rogaland, Sogn og Fjordane .....  4  
 Møre og Romsdal, Sør-Trøndelag, Nord-Trøndelag .....  5  
 Nordland, Troms, Finnmark .....  6

**89** Where in Norway is your legally registered residence?

Oslo/Akershus .....  1  
 Hedmark, Oppland, Østfold .....  2  
 Aust-Agder, Buskerud, Telemark, Vest-Agder .....  3  
 Hordaland, Rogaland, Sogn og Fjordane .....  4  
 Møre og Romsdal, Sør-Trøndelag, Nord-Trøndelag .....  5  
 Nordland, Troms, Finnmark .....  6

**90** Do you currently have a permanent residence?

Ja ..... ( ⇒ 92 )  1  
 Nei .....  2

GO TO QUESTION 92 IF YOU HAVE A PERMANENT RESIDENCE

**91** Where are you currently living?

With friends .....  1  
 In a borrowed house /apartment .....  2  
 In a hotel / apartment hotel .....  3  
 At a hostel .....  4  
 At a refugee reception centre .....  5  
 At an institution .....  6  
 Other .....  7

FOR EVERYONE

**92** Does your residence have...

- A toilet .....  1.
- A bath or shower .....  2.
- A kitchen at least 6 square meters or larger ..  3.
- More than one room in addition to the kitchen .....  4.
- A hot water connection .....  5.
- Central heat or electrical heaters as a source of heat .....  6.
- A balcony / patio or yard .....  7.

**93** Is your residence adapted to your practical needs in a manner that is appropriate to your current health situation?

Yes .....  1  
 No .....  2

**94** What was your gross income in 2007? With gross income, we mean your income before taxes and deductions. Pensions, disability or social benefits are considered income.

Up to NOK 100,000 .....  01  
 NOK 100, - 199,000 .....  02  
 NOK 200, - 299,000 .....  03  
 NOK 300, - 399,000 .....  04  
 NOK 400, - 499,000 .....  05  
 NOK 500, - 599,000 .....  06  
 NOK 600, - 799,000 .....  07  
 NOK 800,000 - less than 1 million .....  08  
 NOK 1 million or more .....  09  
 Don't know .....  10

**95** In the past year, has your household had occasional difficulty managing living expenses such as food, transportation, housing and similar?

Yes, often .....  1  
 Yes, once in a while .....  2  
 Yes, occasionally .....  3  
 No, never .....  4

**96** Were you in a financial situation for most of the year where you would be able to handle an unexpected bill of 5000 NOK, for example a dental or repair bill, or similar?

Yes .....  1  
 No .....  2

**97** Has being HIV positive had any impact on your financial situation?  
 MULTIPLE ANSWERS POSSIBLE

- Yes, it has resulted in lower income .....  1.
- Yes, it has resulted in poorer management of finances .....  2.
- Yes, it has resulted in better management of finances .....  3.
- I have had to go on disability .....  4.
- Other .....  5.
- No, it has not resulted in any changes .....  6.

**98** Has your HIV status had consequences for your ability to get life insurance, pension schemes or private health insurance?  
 MULTIPLE ANSWERS POSSIBLE

No .....  1.  
 Yes, life insurance .....  2.  
 Yes, pension schemes .....  3.  
 Yes private health insurance / accident insurance .....  4.  
 Not relevant for me .....  5.

**SEXUALITY AND SEX LIFE**

Here are some questions about sexuality and your sex life. Some of these questions may be considered quite personal. However, sexuality is important for many when it comes to quality of life. When it comes to HIV, this is intensified because HIV is a sexually transmitted disease.

**99** How important is it for you to have a good sex life?

Extremely important .....  1  
 Very important .....  2  
 Important .....  3  
 Not particularly important .....  4  
 Not at all important .....  5

**100** If you have sex with a person who is not HIV positive, how worried are you about infecting that person with HIV?

Very worried .....  1  
 Fairly worried .....  2  
 Slightly worried .....  3  
 Not at all worried .....  4  
 I have not had sex since I learned that I was HIV positive .....  5

**101** Here are some statements about your sex life after you were diagnosed with HIV. How much do you agree or disagree with each of these statements?

ONE ANSWER PER LINE	Completely agree	Partially agree	Neither agree nor disagree	Slightly disagree	Partially disagree
	1	2	3	4	5
• Your sex life has changed .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• You have fewer partners .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• You have a more difficult time finding a steady partner or girlfriend / boyfriend .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• You choose HIV positive partners .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• You have become afraid of having sex .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• You no longer dare to have sex .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**THE CRIMINAL CODE**

There have been a lot of discussion about how the criminal code regarding transfer of infectious diseases (§155) works when it comes to HIV. We therefore need specific information about how each individual perceives this.

**102** Have you received information about the criminal code on transfer of infectious diseases?

Yes .....  1  
 No .....  2

**104** Does the criminal code worry you?

No, I never think about it .....  1  
 Yes, it worries me every once in a while .....  2  
 Yes, it worries me often .....  3  
 Don't know .....  4

**103** Has the criminal code affected your sex life in any way?

• No, the criminal code has not had any implication .....  1  
 • Yes, I have less unprotected sex .....  2  
 • Yes, I have fewer partners .....  3  
 • Yes, I have stopped having sex .....  4  
 • Yes, I always tell my sexual partners that I am HIV positive .....  5  
 • Yes, I sometimes tell my sexual partners that I am HIV positive .....  6  
 • Yes, I have more unprotected sex or more sexual partners .....  7  
 • Don't know .....  8

**Thank you for your help. Please return the questionnaire in the enclosed envelope as soon as possible. The envelope is addressed and postage is already paid.**

## Appendix 2 Interview guide

### Introduction

Presentation of project

### The following background information should be recorded:

Interview started (d.m.y – time): \_\_\_\_\_

Interviewer:

Sex of informant:

Age group: 18–29 ( ) 30–39 ( ) 40–49 ( ) 50–64 ( ) 65+ ( )

The informant was born in:

Norway

the rest of Europe

Africa

North America/Australia/New Zealand

Central or South America

Asia

The informant now lives in (county):

Oslo/Akershus

Hedmark, Oppland, Østfold

Aust-Agder, Buskerud, Vestfold, Telemark, Vest-Agder

Hordaland, Rogaland, Sogn and Fjordane

Møre and Romsdal, Sør-Trøndelag, Nord-Trøndelag

Nordland, Troms, Finnmark

Town/country?

Civil status:

Education: Primary school ( ) Secondary school ( ) University and/or college ( ) Did not complete primary school ( )

How did you contract the infection?

**The interview itself follows:**

Tell your story from the time you were diagnosed with HIV until today

- How did you react when you were given the diagnosis?
- How has your life changed since you were given the diagnosis?
- Were there any new changes when you started on medicine?
- Can you elaborate on how your life has changed?

How would you describe

- your relationships with family?
- your social situation?
- your financial situation?
- your workplace?

**Secondary questions in case the respondents themselves do not start talking**

(The general approach must be to get the informants to tell their stories, starting from the time of the HIV diagnosis. The following topics are intended as an aide-memoire/ checklist to ensure the most important themes are covered)

- Reactions in daily life
- Participation in working life/time management in daily life
- (possible effects of the HIV infection on your substance use)
- Finances
- Accommodation and living standards
- Perspectives on the future
- Social participation and integration
- Quality of life
- Sexuality and sexual health
- Health situation
- How is your health now? Medicines, treatment
- Contact with and experience of the health service
- Contact with and experience of other public services



# Living with HIV in Norway – 2009

This report is the main report forming part of Fafo's wider project on living conditions among people with HIV in Norway, conducted in 2008–2009. In 2008 Fafo published a report in two parts: an attitude survey carried out among the population and a knowledge update. The findings of the attitude study provide an important framework for the interpretation of many of the findings presented in this report. The knowledge update was a first step in the work of studying the living conditions of people with HIV. The conditions for people with HIV have changed a lot the last decade. The anti-viral medicines that appeared in 1997 have steadily improved. In spite of the successes as far as medical progress is concerned, there does not seem to have been any corresponding progress when it comes to openness, knowledge and attitudes in society. One of the goals of the study is therefore to find out how the tension between individual prospects on the one hand and knowledge, attitudes and stigmatisation on the other hand affects the living conditions of people with HIV.

A description of the living conditions of people with HIV in Norway is a story of which there are at least two versions. One version of this story is about people diagnosed with HIV who for various reasons want this to be as small a part of their lives as possible. The other version of the story is about people who give a completely different place in their lives over to having HIV. For many of them, being HIV positive becomes an identity and is linked to activities and procedures that take up quite a lot of their lives and their time.

The report finds that 70 per cent of the respondents declare being in good or very good physical health, and 80 per cent consider that medical treatment contributes positively to their health levels. However, the report also finds that there exist several challenges linked to openness and stigmatisation. One arena standing out in particular is the workplace as it presents challenges associated with attitudes towards people with HIV, and the dissemination of and access to information about rights and adaptation to ensure that people with HIV can participate in the workplace.

The project was conducted in collaboration with HivNorway, and was commissioned by the Norwegian Directorate of Health.

HivNor<sup>ge</sup>



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