



NORDIC HIV TREATMENT QUALITY SURVEY REPORT

2019 – 2020

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This is a Survey Report written by the Board of HIV-Nordic in 2020, finalized in 2021.

We want to thank Nordic Welfare Center, Nordens Välfärdscenter (NVC) for funding to conduct the survey and all people living with HIV and volunteers in the Nordic countries for their participation.

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HIV-NORDIC

The Nordic Treatment Quality Survey was conducted by HIV-Nordic and the member organizations of HIV-Nordic. HIV-Nordic is the cooperative body of the Nordic organizations by and for people living with HIV (PLHIV). All patient-led NGO's in the Nordic countries can join HIV-Nordic. All member organizations have representation in the board of HIV-Nordic. At the time of the survey HIV-Nordic had five member organizations: Hiv-Denmark, HivNorway, HivFinland, HIV-Sweden and Hiv-Iceland.

The main purpose of HIV-Nordic is to uphold awareness around the development of human rights issues for PLHIV in the Nordic region. We share best practices, and develop new projects, and collaborate with different stakeholders in the field of HIV.

THE AIM OF THE SURVEY

The aim of The Nordic Treatment Quality Survey 2019 was to study the impact that changes in treatment regimens have, on treatment adherence and on patient involvement and patient-physician trust, among people living with HIV in the Nordic countries. The survey aimed to get information about the current situation of HIV-treatment in the Nordic countries and how it affects the patients receiving HIV treatment.

The survey results were collected between August and December 2019 and it was conducted using the Webropol survey and reporting tool. Potential respondents were encouraged to engage directly on collaborating organizations' websites and via social media. The questionnaire could be answered in English, Swedish, Norwegian, Danish and Finnish. A total amount of 436 responses was received.

The survey represents community-based research. Community-based research is becoming increasingly important as communities are being required to take greater ownership and control over decisions affecting the health of the people in the communities. Community-based research must have a high degree of relevance to the community. The participatory nature of community-based research assists in the uptake of knowledge for both communities and policy makers.

Having the results of this project is something Nordic HIV-organizations can use in their advocacy activities to promote rights and to improve patient involvement and treatment adherence, which are important factors for the wellbeing and the quality of life of people living with HIV. It gives important new knowledge that can be used by decision and policy makers as a support for well informed decisions regarding future treatment pricing and recommendations on HIV-medication.

The survey was funded by Nordic Welfare Center, Nordens Välfärdscenter (NVC).

The survey questions are represented in Annex 1.

COUNTRY CONTEXT AT THE TIME OF THE SURVEY

This background gives an overview of each country prior to the survey and explains what prompted us to conduct a survey on treatment and care. Also, to be noted, this survey is done right before the global Covid-19 pandemic.

In the spring 2019 in Finland, the main clinic for infectious diseases in Helsinki had moved from a very cozy old building to the main hospital. The clinic had been in an old “home-like” building since the beginning of the HIV epidemic in Helsinki and Finland. This probably played a big role in why a feeling of things changing emerged and why there was an uncertainty of whether it was good or bad or a bit of both. People felt that there was no longer as much time as before at an HIV-doctor's appointment. There was also a feeling that doctors started suggesting changes in treatment more often and money started playing a much bigger role in treatment decisions than before. As Finland is a geographically big country (like Sweden and Norway), people in smaller hospital districts are not always necessarily experiencing the same things as in bigger hospitals.

In Norway, in 2016, the Norwegian National Assembly adopted the Prioritization Report. In short, this means that the financial responsibility for medicines was transferred to the health trusts, and tender processes were initiated to achieve competitive prices. Under the slogan “More health for the money” a list of prioritized treatments was to be made for the doctors to choose from.

For PLHIV it was frustrating to have decisions made on their behalf without their wishes being heard. There were a number of factors in this process that HivNorway was critical towards including a severe side effect profile in the winner of the tender. The guidelines from Sykehusinnkjøp did not take into sufficient account how many changes of treatment regime each patient had been through in the past, which was rectified in the autumn of 2019. A new tender for HIV drugs was carried out and an important principle was accepted: it is medically inadvisable to frequently change PLHIVs treatment regimen. This second tender would be valid for three years as opposed to the first, one-year tender.

It is crucial that the trust between doctor and patient is maintained and that they together can choose the treatment that is in the patient's best interest. HivNorway believed these tender processes to have had a negative impact on the doctor-patient-relationship, and HivNorway received several inquiries from PLHIV who felt forced to change treatments, without the patient's view having been taken into account. Some were worried they would have to keep fighting to stay on the treatment they experienced as good for them at every consultation. There was a need for knowledge on how this situation and these tenders actually affected the doctor-patient relationship. In the other Nordic countries PLHIV also experienced that prices and saving costs were arguments for changing their HIV treatment.

In 2013 the Swedish health agency 'Smittskyddsinstitutet', after 2014 referred to as 'Folkhälsomyndigheten' launched the report 'Contagiousness and treatment of HIV infection' stating that it was a very low risk transmitting HIV while well treated. This changed the guidelines of initiating HIV treatment on people living with HIV. However, in 2016 the Swedish government decided to cut the national fundings, both in prevention and for people living with HIV.

In 2018 the cost for treating people living with HIV also changed from being nationally funded to be a part of the clinics' cost. This made an impact and a discussion on whether everyone would receive generics or not. Meanwhile at the time, 98 % of the diagnosed with HIV were on medication and 98 % of those were well treated. The overall satisfactory treatment results opened the possibility to less frequent appointments, and for many patients once a year check-ups and appointments became the norm. In some Swedish regions, patients have also been encouraged to seek general, non-HIV related care at primary care units, instead of first going to the infectious disease clinics. The changes in funding, coupled with the shift in regard to appointments and where to seek care spurred questions about how people living with HIV were to be affected.

In Denmark, the Rehpa-center at the University of Southern Denmark did research on people who had been living with HIV for many years. The result was clear: many of them suffered from multiple diagnoses, side effects, loneliness and feeling of stigmatisation. A simple demographic exercise proves that this is a growing group of people and needs to be an important focus for the Hiv-Denmark. This is a challenge that also needs to be addressed publicly at a time where public focus on HIV in Denmark as in most other countries is decreasing.

RESULTS

The results of this project are comprehensive. They covered the individual experiences of the respondents as well the similarities and differences across the Nordic countries. They especially took into consideration the experiences of receiving and getting care.

This report is a general report on Nordic level written by the Board of HIV-Nordic.

There is also a lot of country-specific data gathered in this survey. Due to limited resources the country-specific information cannot be represented in this report.

Organizations who participated in this survey can, and have already used more disaggregated data in their own contexts.

BACKGROUND

In the recent years some of the Nordic countries have decided that medicines supplied through the hospitals shall be subject to a tender in order to reduce costs. This new procedure also applies to lifelong antiretroviral treatments (ART) used for HIV infection. Hospitals are obliged to prioritize those medicines that win the tender each year. As the tender is based on cost, there is a risk that the patient's wellbeing and their quality of life are no longer considered in full extent for the choice of treatment and this may cause challenges and problems for people living with HIV. In some Nordic countries changes in national subsidies and pricing of new and older HIV-treatments, and the introduction of generics, is a new challenge for both patients and prescribers. This development brings forth new challenges regarding both maintaining and increasing patient involvement, patient centered care model, and treatment adherence as well as patient-doctor-trust.

HIV is a chronic disease with many specific characteristics that acquire a high level of expertise to reach and maintain successful treatment. HIV is also still a contagious disease, although we today know that people living with HIV, whose treatment has brought their viral load to an undetectable level, do not transmit HIV to any other person. Living with HIV remains a constant challenge. One of the challenges is the complex and changing treatment regimen and adherence to it. Adherence to treatment is recognized as the essence of a successful HIV treatment.

A positive patient experience is associated with improved clinical outcomes

Patients' experiences with care, particularly communication with providers, correlate with adherence to medical advice and treatment plans. This is especially true among patients with chronic conditions, where a strong commitment from patients to work with their providers is essential for achieving positive results. Patients with better care experiences often have better health outcomes. If patients are satisfied with clinician-patient interactions, they are likely to be more compliant with their treatment plan, to understand their role in the recovery process, and to follow through with the recommended treatment. A growing body of evidence links a doctor-patient relationship defined by effective communication with improved HIV outcomes.

Adherence

When facing a situation where the costs of medication is the reason for changing medication it can be detrimental to the relationship between the patient and the care-giver and affect the

adherence. There is also a risk of side-effects not yet known, as the generic medicines have not yet been studied to a greater extent. Medication side effects are one of the most consistent predictors of incomplete adherence. Although adherence to one medication often predicts adherence to another medication, differential adherence is not uncommon and may be related to differences in dosing schedule and/ or differences in actual or perceived side effects. Changes in treatment regimens where treatments are switched between different active substances can have grave long-term effects on health. Studies also show that adherence goes beyond "complying with" the medical instructions, it also depends on how much of an active role the patient plays in the choice to adhere.

Quality of life

A good quality of life is crucial for people living with HIV as it helps to deal with the disease and associated problems and thus a good quality of life should be the goal of all HIV treatment. When people have a feeling of control and empowerment, quality of life improves. For people with HIV, that means controlling the impact of the disease on the psychological, social, and physical aspects of their daily lives. Controlling HIV means a lifetime of medication. It also means managing the stigma that still today is related to HIV. This, and the long-term nature of the disease, presents a number of quality-of-life issues and health complications. Therefore individualized HIV treatment should be prioritized to ensure the best possible treatment.

GENERAL QUESTIONS

The general questions in the survey covered respondents' country of residence, age, gender and language. Respondents were also asked when they had been diagnosed with HIV and for how long they had been on HIV medication.

In which country are you receiving your HIV medication?

Respondents were from Denmark 34 %, Norway 34 %, Finland 18 %, Sweden 12 % and Iceland 2 %. In their respective countries 70 % of the respondents receive their treatment in the capital area or main HIV treatment and care provider in their country, 23 % in another big city and 7 % in smaller places or in the countryside.

Your Gender

The majority, 77 % of the respondents identified themselves as male. 22 % identified as female and 1 % non-binary, other or preferred not to say.

Your Age

Most of the respondents (62 %) were aged between 40 and 59 years. Another 23 % were 60 years or more, and 15 % of the respondents were between 20 and 39 years old.

Nearly a third of the respondents (31 %) were diagnosed with HIV more than 20 years ago. Majority of the respondents (87 %) had been on treatment for more than 3 years. Nearly half of the respondents had been on treatment for more than 10 years.

There were also some country-specific differences in the responses. From Sweden there were on average younger respondents than from other countries. From Finland there were on average more respondents who identified themselves as women. And from Denmark there were more respondents who identified themselves as men, who have been living with HIV more than 20 years and been on treatment for more than 15 years.

When were you diagnosed with HIV?

We had quite a lot answers from people who have been living with HIV for a long time.

Less than a year ago 1 %

1-3 years ago 9 %

4-6 years ago 13%

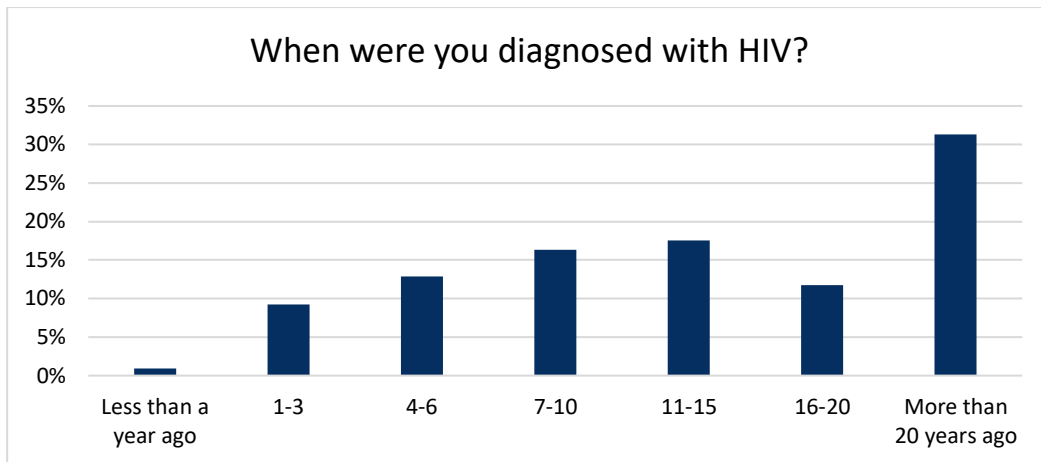
7-10 years ago 16%

11-15 years ago 18%

16-20 years ago 12%

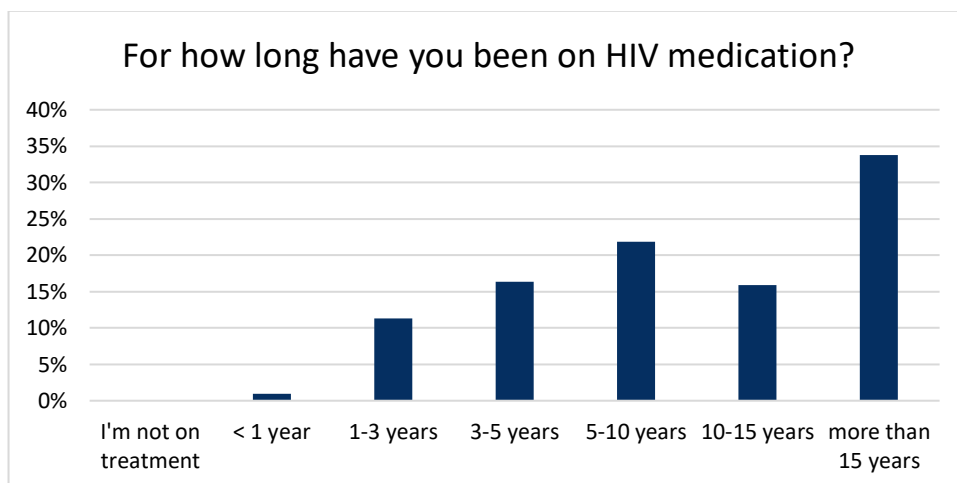
And 31% more than 20 years ago.

Please find a column on next page.



For how long have you been on HIV medication?

I'm not on treatment 0 % and less than one year < 1 %
 1-3 years 11 %
 3-5 years 16 %
 5-10 years 22 %
 10-15 years 16 %
 more than 15 years 34%



Language

Up to 94 % of the respondents were fluent in the local language. A proportion of 8 % of the respondents said they understand and can express themselves, and less than a percent said they understand most of things said to them, but have difficulties expressing themselves or they speak the language only a bit.

EXPERIENCED PATIENT-DOCTOR RELATIONSHIP

Respondents were asked how their relationship with their doctor is today and how it was 2-3 years ago. There were some differences but not any remarkable changes when comparing the present moment and 2-3 years ago.

On average the respondents were satisfied with their patient-doctor relationship and found it easy and functional. On a scale from 1 to 10, with 1 being extremely difficult and dysfunctional relationship and 10 being extremely good, easy and functional relationship, the average was 8,5 both today and 2-3 years ago.

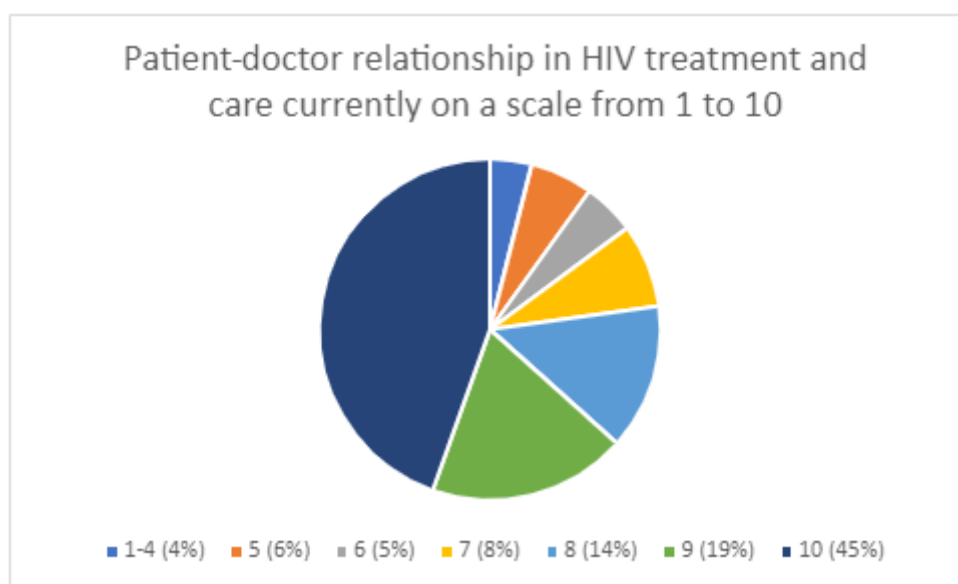
Today: 64 % were extremely or really satisfied with their patient-doctor relationship, giving either 9 or 10.

2-3 years ago: 63 % were extremely or really satisfied with their patient-doctor relationship, giving either 9 or 10.

The results about treatment today compared to treatment 2-3 years ago have remained almost the same for most respondents with a maximum of 0-3% fluctuation. 10% of the respondents answered with 5 or smaller, and it can be said that they were not satisfied with the patient-doctor relationship. 9% of the respondents answered with 5 or smaller to the treatment they had 2-3 years ago.

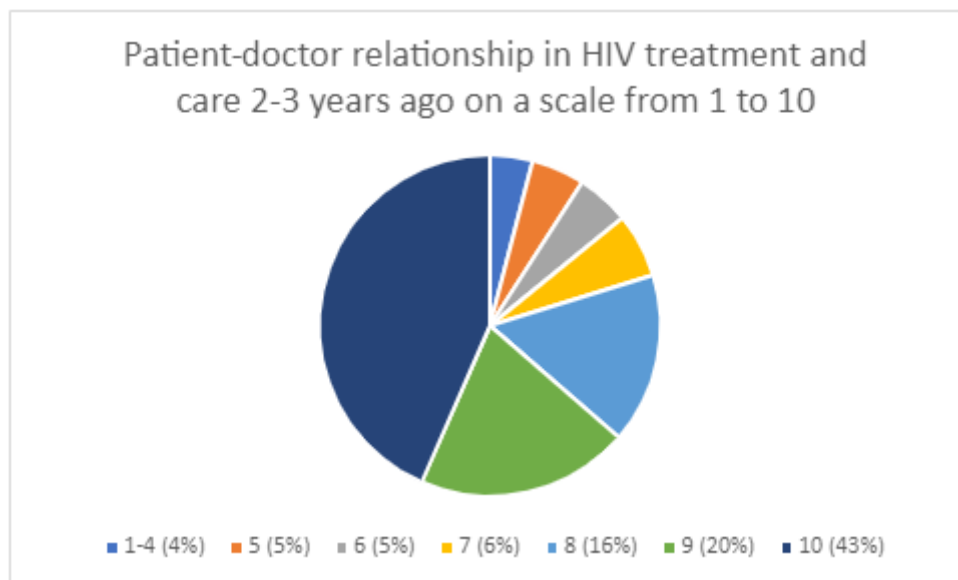
When asked about satisfaction with the current patient-doctor relationship, 32% of the respondents were for the most part satisfied. A proportion of 19% were partly satisfied with their relationship.

How would you describe your current patient/doctor relationship in your HIV treatment and care on a scale from 1 to 10? (10 extremely good ... 1 extremely difficult)



The majority (45%) of the respondents answered that their patient-doctor relationship in HIV treatment and care was currently on an extremely good level. 10% of the respondents answered that the relationship was difficult (5 or less).

How would you describe your patient-doctor relationship in your HIV treatment 2-3 years ago? (10 extremely good ... 1 extremely difficult)



The majority (43%) of the respondents answered that their patient-doctor relationship in HIV treatment and care was on an extremely good level also 2 to 3 years ago. 9% of the respondents answered that the relationship was difficult (5 or less).

How would you describe the changes in your patient-doctor relationship?

When asking to specify the changes in respondents' patient/doctor relationship, the majority of the open feedback respondents stated that there were no significant changes they wanted to emphasize. The theme that repeated often in open feedback was the challenges of having a different doctor every time. Some respondents also stated the feeling of their doctor having less time to talk to them than earlier.

“Can’t really talk about patient-doctor relationships because there are none. Everytime different doctor.”

“The doctor has less time to listen to me than before.”

“Less time, changing doctor and less personality in discussions.”

There was also positive feedback from the patient-doctor relationship.

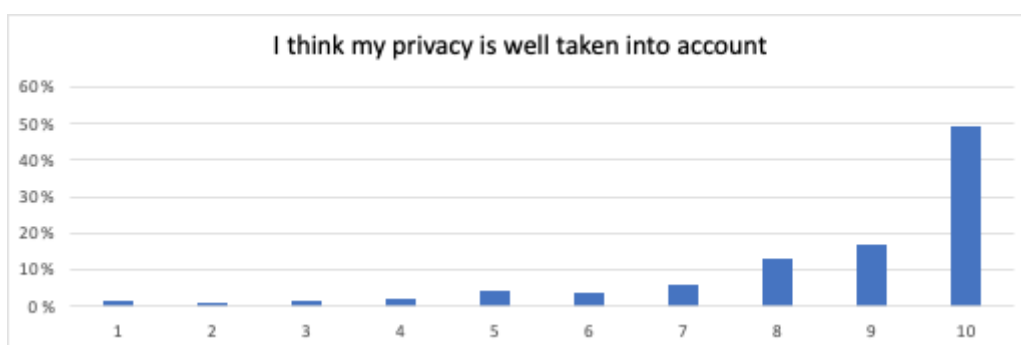
“No changes. Patient-doctor relationship has always been perfect.”

“Consistent and good.”

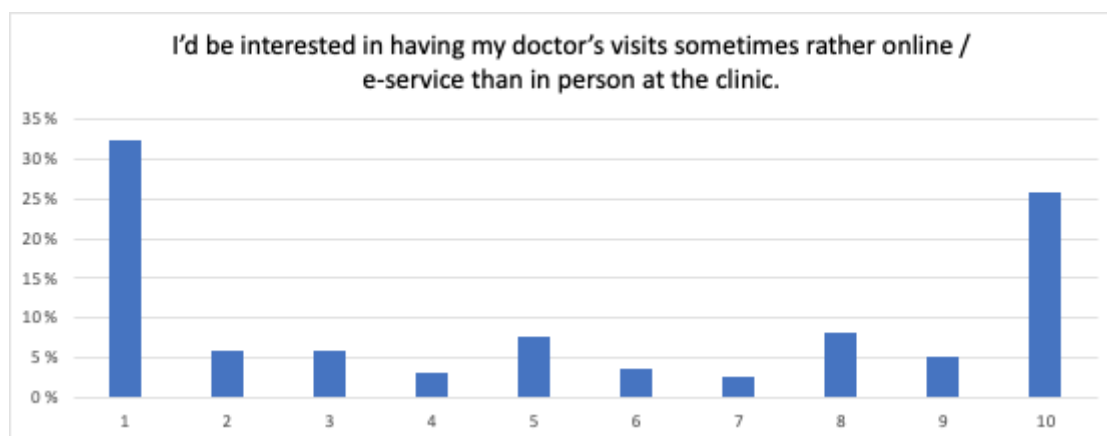
“Everytime different doctor but everyone has been very professional and good.”

HIV TREATMENT AND CARE

The respondents were given ten different statements about their HIV treatment and care and they were asked to evaluate them on a scale. The scale was from 1 (strongly disagree) to 10 (strongly agree).



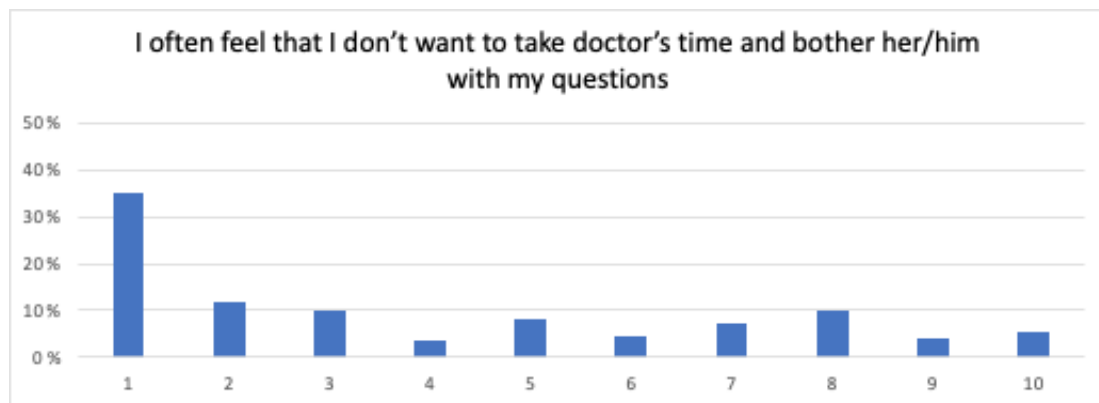
Respondents agreed that their privacy was taken into account (average being 9) and that they can trust that the appointment was confidential (average being 9).



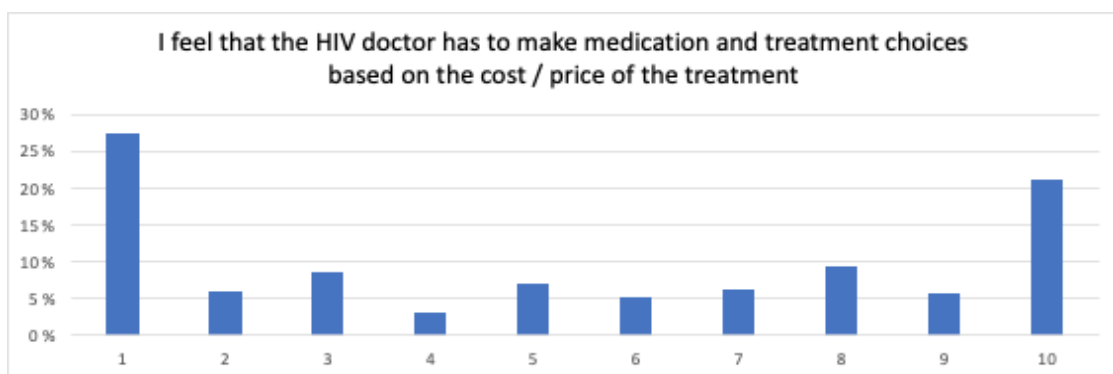
Some countries are planning to have every second or every third doctor's appointment online or via an email service instead of an appointment in person at the clinic. Therefore the respondents were asked whether they would be interested in using these online services in the future. There was a significant division between the respondents' opinions (median being exactly 5). Where 26 % of the respondents were strongly agreeing, 32% of the respondents were strongly disagreeing with being interested in using online services.



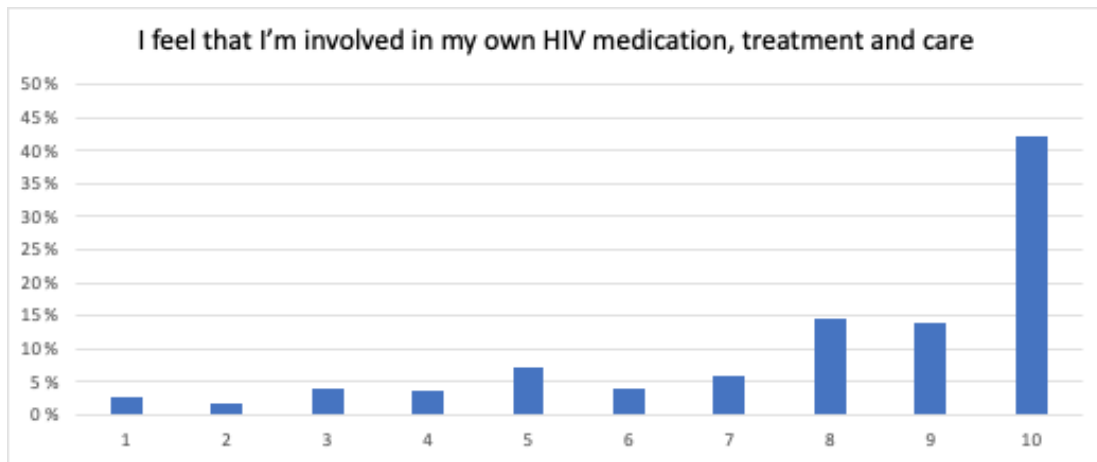
The majority of the respondents agree that they had been given ample time at their doctor's appointment (average being 8). Every fourth respondent evaluated their last appointment with a grade of 7 or 8 on having ample time. Less than 5 % of the respondents strongly disagreed with the statement and felt like they had not been given ample time.



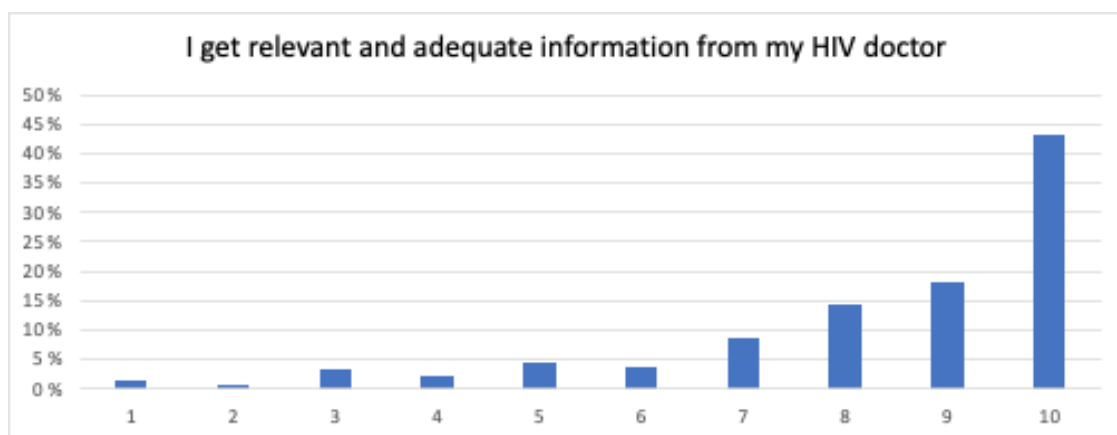
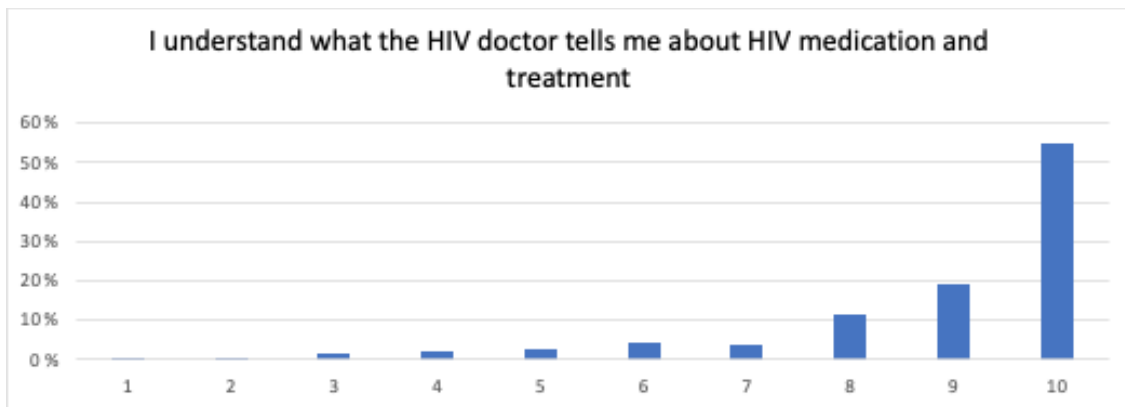
On average the respondents did not strongly agree with the statement about bothering their doctor, the average being 4. However a third (31%) of the respondents felt on some degree that they didn't want to take their doctor's time and bother their doctor with their questions.



There was a significant division between respondents feeling that the HIV medication they receive is strongly based on the costs of the treatment, median being 5. The dispersion was notable here also.



The respondents mainly agreed to the statement “I feel being involved in my own HIV medication, treatment and care”, average being 8.



On average the respondents felt that at their last appointment they understood everything their doctor told them about HIV medication and treatment (average being 9). The information given about the medication from their HIV doctor was also relevant and adequate in the respondents’ opinion (average being 8). There were only a few respondents strongly disagreeing with these statements.

TREATMENT

Regarding HIV treatment, the majority of the survey respondents take 1 to 2 pills every day (76 %). A proportion of 15 % take 3 pills every day and 9 % of the respondents take 4 or more pills every day. The majority of the respondents take HIV treatment pills once in a day, when 6 % take their medication 2 or more times a day.

The respondents were asked about changes in their HIV medication. Questions covered areas such as have the respondents experienced pressure to change their HIV medication or requested it themselves, and the reasons behind these actions. However, the survey did not cover the reasons why the respondents might have requested to change the medication themselves.

Over half (53 %) of the respondents answered that they had not suggested any changes for their treatment during the past 2 to 3 years. 31 % of the respondents had themselves requested the doctor to change their treatment and had succeeded in changing it as well. However a proportion of 7 % have requested a change without getting one. The reasons for not getting their treatment changed were not monitored by this survey.

A third (34 %) of the respondents responded that during the past 2 to 3 years their HIV doctor had suggested changing their HIV medication from one pill a day to more pills a day. 55 % did not experience these kinds of suggestions.

A majority of respondents (62 %) answered that their doctor had suggested changing their HIV medication. Respondents had the opportunity to choose up to three alternative reasons given by their doctor to change their HIV medication. The most common reasons were

- 1) cost efficiency, same effect but lower price (31%)
- 2) minimizing side effects (25%)
- 3) fewer pills (15%)
- 4) better treatment effects (14%)

Open feedback was gone through. This meant for example changing the HIV medication due to other health problems, for instance cardiological ones. Also reducing the number of pills was mentioned as a reason several times.

46% of the respondents had had no problems changing to the medication that was suggested for them. 12% of the respondents felt that they had no choice but to change the medication. 23% were not applicable. The main reason for the respondents to agree on changing the medication was to reduce the side effects (19%). Also 14% of the respondents felt like they had no choice. 13% answered that the reason was to save money for the healthcare system.

MEDICATION

Respondents were also asked specific questions about their medication. Questions were presented with statements of the medication, and the respondents were asked about the satisfaction of their current treatment. The majority (40 %) of the respondents stated that they don't mind taking more than one pill a day, as long as it is only once a day. However 20 % of the respondents stated that taking more than one pill a day was not something they would want to do.

Respondents were also highly interested in the possibility of changing the pills to an injectable treatment, as almost a half (48 %) were willing to change from pills to injection. 19 % of the respondents were not willing to change from pills to injection. Approximately 15 % of the respondents stated that changes in their HIV medication made it more difficult to adhere to medication. The majority (51 %) of the respondents however felt that changes in medication did not have such effects. 57 % of the respondents trust the effectiveness of their HIV medication, whereas 18 % were worried if their medication was still being effective before their HIV doctor's appointment.

Most of the respondents were satisfied with their current treatment (85 %). 10 % were not sure whether they were satisfied or not, and 5 % said that they were not satisfied. 15 % were also experiencing side effects on their current treatment and some (10 %) had experienced side effects on the beginning of the treatment. 23 % were not sure if they were experiencing side effects from the current HIV medication or from something else. 52 % didn't experience side effects at all.

The survey also asked about the change of medication from the original medicine to a generic one. 45% said that their medication has not been changed, 33% said yes, and 22% was not aware if their medication has been changed. This uncertainty was due to the unawareness of the concept of the generic medicine.

When asking if the respondents have experienced more side effects when changing from original medicine to generic one, the majority of the respondents felt that they have not experienced more and/or side effects from the generic HIV medication (27%). Also a significant number were not sure if they had experienced them at all (15%). 9 % said they have experienced a lot or some side effects from the change. 49 % answered not applicable.

CONCLUSIONS AND FURTHER DISCUSSIONS

The Nordic HIV Treatment Quality Survey is the first comprehensive survey on differences and similarities between the Nordic countries regarding HIV treatment. It enables comparisons between the Nordic countries and between individuals.

One of the main results that needs attention arising from the report was that the experience and treatment are not equal amongst the respondents. Exemplifying this was the significant division between respondents feeling that the HIV medication they receive is strongly based on the costs of the treatment.

HIV treatment experience is generally assumed to be good in the Nordic countries since provided in the world leading healthcare systems. At the same time, many living with HIV haven't disclosed their HIV-status to anyone else than their treating doctor, which makes them very reliant on the healthcare professionals that provide them their treatment and care. It is important therefore that people living with HIV get all the information they need at their doctor's appointments. Furthermore, it is also important that they feel heard and understood. Patient involvement is important for adherence to treatment as well as quality of life. This survey points out there are differences across the Nordic countries and between the individual respondents.

The report established a foundation for comparison in a longitudinal perspective, paving the way for future research. We need deeper insight on the shortcomings in the treatment and care to make people to feel empowered. We need to address and remove the barriers that prevent people living with HIV getting the best out of their care.

HIV-Nordic will continue the advocacy work for the rights of people living with HIV, and will continue to promote wellbeing and quality of life of people living with HIV in the Nordic countries.

Once more we would like to thank NVC for making this report possible. And thank you to all respondents and volunteers who helped us to make this survey and report to happen.