

# Living with HIV during COVID-19

- A report on how people living with HIV in the Nordics have experienced and been influenced by the COVID-19 pandemic



**NORDIC MEETUP**  
- living with HIV during COVID-19

**Date:** 4 September 2021

**Time:** 11:00 in Iceland  
13:00 in Sweden, Norway and Denmark  
14:00 in Finland

#mylifemyhivtreatment

Hiv-Norden  
HIV-SVERIGE  
HivNorway  
hiv DANMARK  
HIV ISLAND

Authored and published by:



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## HIV-NORDIC

The Living with HIV during COVID-19 project 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. At the time of the project HIV-Nordic had five member organizations: Hiv-Denmark, Hiv-Norway, Hiv-Finland, HIV-Sweden and Hiv-Iceland. All member organizations have representation in the board of HIV-Nordic. 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, develop and manage new projects, and collaborate with different stakeholders in the field of HIV.

## BACKGROUND TO THE PROJECT

In 2019, HIV-Nordic conducted a quantitative survey, aiming to research the experience of treatment and care for people living with HIV in the Nordics. The survey provided invaluable information, uncovering disparities as well as commonalities between people living with HIV in the Nordics. The survey encompassed treatment and care, a largely medical perspective of living with HIV. The results from the survey underlined the necessity for people living with HIV to be engaged in their clinical care as well as to be diligent and fight for their needs.

With the survey, HIV-Nordic identified a requisite to better understand support and psychosocial needs for people living with HIV in the Nordics. Following the onset of the COVID-19 pandemic, these aspects became increasingly critical as uncertainties and isolation became a concern on a societal level.

## THE AIM OF THE PROJECT

The aim of the Living with HIV during COVID-19 project was to shed light on how the COVID-19 pandemic influences and impacts people living with HIV in the Nordics. In addition, the project intended to complement and provide deeper insights to the results from the survey conducted in 2019.

The aim was also to empower people living with HIV in the Nordics. The project set out to meet this objective by providing a possibility to meet either in person or virtually, encouraging exchange and discussion between people living with HIV in the Nordics and people working for patient organizations. Furthermore it was found imperative to understand and document commonalities when it comes to social and psychological factors for people living with HIV in the Nordics during the pandemic, and to encourage sharing these directly between people living with HIV.

This project was conducted with the means of community-based research. As communities are being required to take greater ownership and control over decisions affecting the health of the people in question, community-based research and knowledge is becoming increasingly important. 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.

With the results of this project the Nordic HIV-organizations can engage in 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. The results further provide important new knowledge that can support policy makers in making well informed decisions.

## Country context

The Nordic countries are relatively sparsely populated and share cultural and historical traits. The number of people living with HIV is relatively low in an international context. The HIV treatment and care as well as the strategies around treating people with HIV is also fairly similar in all Nordic countries. The Nordic countries are, in an international perspective, rich and wealthy countries with advanced healthcare systems. However, the response and strategies when it comes to COVID-19 have been more nuanced.

When the pandemic entered the Nordics, a variation of governmental actions were taken to prevent COVID-19 from spreading. The means and the number of restrictions varied between governments in the Nordic countries. One common issue for people living with HIV in the Nordics was that COVID-19 treatment and care was given by the same clinics that were providing HIV treatment. The overflow of patients caused those clinics to close their doors or limit access to all but COVID-patients, and HIV treatment and care were no longer provided in the same way as before. The limited access to the clinics meant that new routines were established. Consultations had to be done by phone or digitally, laboratory tests were postponed or even forgotten, and prescriptions were in some cases renewed automatically. Before March 2020, digital consultation and digital dialogues between the clinics and HIV patients were not common in the Nordics, which caused a need for information about these new routines from people living with HIV. From people living with HIV, there was also an immediate urge to know if COVID-19 might result in more severe disease for people living with HIV.

Patient organizations were highly involved in distributing and sharing important information about COVID-19 and HIV. In the beginning of the COVID-19 pandemic, knowledge about COVID-19 and HIV was poor, but increased as time went by, and information about the interconnectedness of HIV and COVID was provided as soon as new knowledge was acquired. The cooperation between patient organizations and the clinics when it comes to distributing and sharing information was mixed, and could even vary within countries. There were also variations in how the healthcare systems and the clinics handled the vaccinations, for example in Denmark people living with HIV were included in the so called risk groups, whereas in Sweden they were not.

## Data acquisition

The data from this project have been gathered by group discussions. The main event in this project was a group discussion event, called the Nordic Meetup. The meetup was arranged on 4<sup>th</sup> September 2021 simultaneously in every Nordic country: Iceland, Sweden, Norway, Denmark, and Finland. The event was conducted as a hybrid meeting, meaning it was possible to join digitally directly from home or physically at a local organization. The local organizations then jointly, with the individual participants from home, connected to the group meeting online. The format was a fitting solution to follow all different pandemic related restrictions in the Nordic countries and at the same time provide ample options for participation.

In addition to the Nordic Meetup, all organizations had the opportunity to arrange smaller meetups for those who did not want or were not able to participate in the Nordic Meetup. All in all the project gathered 61 participants, with 55 joining the main event. Both the Nordic Meetup and the smaller meetups are reviewed in this report.

The discussions were conducted in English and local languages. At the Nordic Meetup, five different breakout groups were arranged, in which the discussions were conducted either in English, Swedish, Finnish, or Norwegian. There was also the opportunity to discuss in Danish or Icelandic, but the participants from both language groups decided to have the conversations in English.

A short background information online survey was conducted before the Nordic Meetup, in order to gather preliminary information of the participant's thoughts and feelings experienced during the pandemic. This step was initiated to get a better insight of the participants focal points and need for discussion. In addition it was also to gather information about the participants' backgrounds, e.g., age and gender, but none of these factors are used in this report.

## RESULTS

There were three main themes for discussion. The themes were developed in a process of feedback and informal discussions with people living with HIV in each member organization. The insights from these meetings and discussions were then brought together by Hiv-Nordic and compiled into three themes;

1. Information about HIV and COVID-19
2. Living with HIV during the pandemic
3. HIV treatment and care during the pandemic

### Information about HIV and COVID-19

The discussions revealed that the beginning of the pandemic was a time of uncertainty, confusion and anxiousness. This eased up over time as more studies and information were published and made available. In the first months of the pandemic there was no clear data or studies about whether people living with HIV were more susceptible to severe coronavirus infections. There was also uncertainty about any possible joint effects of HIV medication and coronavirus infection and/or vaccines. This caused concern and confusion, which affected the feelings and mental health of the participants.

One of the main questions the participants had in the beginning of the pandemic was whether people living with HIV belonged to risk groups for severe coronavirus disease. Later the participants also wondered whether they would be on the priority list for vaccinations. Participants also encountered concern from other people, who were worried that their HIV status made them more vulnerable, at-risk of contracting COVID-19 and experiencing serious illness.

Most of the participants reported that they got information about COVID-19 from the internet, patient organizations' websites, newspapers, and social media, and from their doctors and/or nurses. The amount of information was substantial, but there was also plenty of misinformation and vague facts everywhere, especially in the social media. Participants encountered for example intentional misrepresentation of information in various social media platforms. Some stated that their HIV status and the knowledge of viral infections that comes with it helped them to better understand the lack of information and confusion concerning COVID-19.

When it came to information about the interconnectedness between HIV **and** COVID-19, participants stated that the patient organisations were a key voice in distributing it. In most cases they obtained the information they needed quickly, and it was easy to comprehend. However, the participants felt that the information in question was found mainly in native languages, which caused a problem in understanding for people whose mother tongue was something else. Language might have caused vulnerability for example among migrants.

Information about the vaccines was harder to find and it caused worry among participants. It took longer for the information to come out from authorities and health institutions. But once the information was out, it was to the point and easy to understand.

## Living with HIV during the pandemic

Many participants emphasized that their experiences during the COVID-19 pandemic were likely close to everyone else's. Most said that their social lives were considerably affected, and they encountered a high level of isolation. This also had a negative effect on mental health for some participants. Some were scared to meet new people, and most participants experienced a need for alternative ways to connect with other people.

Some noted that the hysteria surrounding the COVID-19 pandemic, at least in the beginning, was familiar to what they had experienced in the early years of the HIV pandemic. The lack of knowledge and fear was

mimicking what they had to face themselves during the 80s and 90s. Some also stated that the events during the pandemic helped them to get a better view and understanding of the history of the HIV pandemic.

Feelings of loneliness and isolation were common, and many missed various social gatherings and their office or workplace. For those already feeling lonely and isolated because of their HIV status, these feelings became even stronger during the pandemic. Some of the participants said they benefited from the support system already present for people living with HIV to help them during the COVID-19 pandemic, such as counselling and support from patient organizations. This backs up the peer support activities and low threshold services the patient organizations have been organizing before and during the pandemic.

When talking about stigma, some said that they had become less forthcoming about their HIV status in social situations during the pandemic. The focus on transmittable diseases and viral infections around the world made it harder to be open about HIV. Some also stated that living with HIV during COVID-19 pandemic affected their view on HIV stigma and helped to get some perspective about its origin.

The discussions showed that not all effects on social life during the pandemic were negative. Some participants stated that they have slowed down their pace in life, which was experienced as a positive change. Family members have become closer connected with each other as they have spent more time at home together.

The participants wondered if other people could from here on understand the stigma around HIV better, as they themselves had to face these questions in their everyday life. For some participants this view sparked bitter feelings; that people can take chances or gamble with exposure to COVID-19 infection, but still fear HIV infection or people living with HIV without good cause. The fact that there are still people who refuse to understand that undetectable means untransmittable (U=U), felt frustrating among participants.

## HIV treatment and care during the pandemic

Due to the similar infectious nature of COVID-19 and HIV, resources were diverted from HIV treatment and care to fight COVID-19. However, most participants reported that their HIV treatment and care continued to at least function somewhat during the pandemic. Although some participants experienced postponed or even called off appointments, and some stated that their appointments were changed to online appointments. Staff from the infectious disease clinics were transferred to COVID-19 tracing or treatment, which meant there were less personnel than usual attending and caring for people living with HIV.

Some stated they were not called to their usual check-ups at all during the pandemic, which caused them concern. The worry about potentially being in a risk group increased as there were no physical doctors' appointments. The degree of worry also related to one's CD4 count and having underlying issues, such as asthma. Online appointments did not quite compensate for physical meetings with a doctor. For example,

changing one's medication without seeing their doctor caused greater stress. In this sense there was a gap between the needs of people living with HIV and the access to their treatment and care.

Physical follow-ups and treatment continued during the pandemic with various infection control measures, such as masks. Some participants had problems getting their ARVs from the pharmacy. The fear of getting infected made some participants stock more medications at home, and some were afraid of going to the pharmacy in the first place.

Participants felt that the new ways to keep in touch with the infectious disease clinics were mainly positive. They found it negative that even with the new mediums for contact, there was often too little personnel, and that they didn't have time to answer.

## CONCLUSIONS AND FURTHER DISCUSSION

Discussions during the Nordic Meetup and the smaller meetups indicate that people living with HIV are highly adaptable and resilient. The discussions show that there is a high level of trust within communities and towards healthcare systems in the Nordic countries, which has been constructed over the years. People feel that they have been well taken care of and will continue to be in the future.

The experiences from the past and over the history of the HIV pandemic helped the participants to adapt themselves to new and unpredictable situations. Not only did the participants get used to wearing masks and keeping a safe distance, but also working remotely, studying via new platforms, and seeing their doctor via e-appointments. The participants thought that as this will not be the last pandemic we will face, it feels comforting to know people can adjust themselves to an entirely new environment with relative ease.

The discussions covered forward looking viewpoints too. One particular learning point for the future is to ensure the accessibility and more inclusive language in communication. All information ought to be available in more than the native languages and it should be adapted and directed to various groups. The participants also agreed that people should continue the good habits they have learned throughout the pandemic, such as good hand hygiene and staying home at a low threshold when sick. Furthermore, the changes in how people work, for example more flexible working hours, and working from home, should continue.

As for how the patient organizations work, the participants agreed that they should use the experiences and the knowledge the pandemic has brought to continually work on spreading information about HIV and what it means to live with HIV in societies. The participants also stated that the stigma around COVID-19 with all its travel restrictions and vaccination bans can remind people living with HIV of the HIV pandemic's history. They felt that is a great spot to educate the public as others can be more open to understanding living with HIV. They mentioned that the momentum of the pandemic should be used to spark discussion and further destigmatize HIV through advocating and spreading information.



Overall, the patient organizations have been forced to engage with target groups in a new manner, develop practices to meet new needs and overall navigate in a challenging environment. With the Nordic Meetup initiative, people living with HIV have been directly included and provided a platform to raise their voices. In turn, the findings will help strengthen our organizations and increase the organizational capabilities for change and ability to work in tune with the target group, now and in the future.