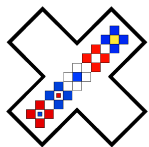


# HIV-Nordic

*Annual report 2021*



**Hiv-Norden**

Hiv-Norden - Samarbetsorganet för de nordiska paraplyorganisationerna för personer som lever med hiv, organization number 802408-2508.

HIV-Nordic - The co-operative body of the Nordic umbrella-organizations for people living with HIV (PLHIV).

## HIV-Nordic

### Annual report 2021

The Board of HIV-Nordic Annual report from 1. January - 31. December 2021.

### Members

HIV-Danmark (Denmark), HIV-Island (Iceland), HivNorge (Norway), HivFinland (Finland) and Hiv-Sverige (Sweden).

### The Board

The Board has consisted of 10 Directors, 2 from each member organization. The Board is elected for one year at the Annual Meeting:

|            |                   |         |
|------------|-------------------|---------|
| Chair      | Emanuel Karlström | Sweden  |
| Vice Chair | Nonni Mäkikärki   | Finland |
| Treasurer  | Sini Pasanen      | Finland |
| Director   | Einar Jónsson     | Iceland |
| Director   | Vacant            | Iceland |
| Director   | Helge Kvam        | Denmark |
| Director   | Michael Ovesen    | Denmark |
| Director   | Simon Blom        | Sweden  |
| Director   | Bente Bendiksen   | Norway  |
| Director   | Jacob Hermansen   | Norway  |

## The Operations

HIV-Nordic have in this period had 2 regular board meetings, one annual meeting and constituting meeting, a networking workshop/meeting in Malmö the 30th - 31st of October and 7 project meetings. In addition we have arranged a Nordic Meetup on the theme of Covid-19 and HIV in a hybrid format (online and physical participation) and a live web presentation of the results from the same project.

An online meeting was held Saturday the 20th of February. On this meeting the board decided to update our webpage and start uploading material to increase transparency and accessibility of our work. During this meeting there were lengthy discussions on COVID-19 and HIV, which prompted us to draft a project proposal on the topic. The country updates from this year's board meetings have been published online on our webpage [hiv-norden.org](http://hiv-norden.org) and an article summarizing the board meeting in Malmö has also been published on our webpage.

The HIV-Nordic annual meeting was held Sunday the 25th of April. Due to the COVID-19 pandemic the meeting was held online, and it was the first time the association has held an annual meeting online. The meeting also functioned as a kick-off for the COVID-19 and HIV project, as we two days prior to the meeting, received funding for the COVID-19 and HIV project.

As the COVID-19 situation improved and the travel restrictions were eased, the board held a physical board meeting in Malmö 30-31st of October. The agenda consisted of country updates from all countries, with a focus on how operating and ensuring accessibility to services during the pandemic. Secretary general of HivNorway joined virtually, to discuss PrEP injectables and the Fast Track Initiative and Anni Mattinen from HivFinland presented preliminary results from the COVID-19 and HIV project. On the agenda were also discussions on future projects, and link past and current projects into future initiatives and create a momentum for the advocacy points we choose to focus on.

Overall, the exchange of knowledge and experience through these meetings has been invaluable. All organizations in HIV-Nordic have faced challenges during the pandemic, some similar some different. To be able to discuss, compare and share best practices, and to bring this knowledge back home, has improved the way our organizations function and how we work with advocacy. The networking has also served to improve idea and resource sharing among our countries, especially for digital campaigns, as well as digital initiatives aimed to increase accessibility for people living with HIV.

There is also ongoing discussion and communications between our countries on a somewhat more informal basis. We have 39 posts in our private Facebook group thus far for the year 2021, with some 100+ comments, this interaction has for example led to HivNorway members joining events in Sweden, as we during the pandemic have shared and promoted activities between us in this group. It should also be noted that this is a direct effect due to these meetings and the funding we receive for our network activities.

From a social perspective, isolation and loneliness are issues that negatively affect people living with HIV even during normal, non-pandemic times. With our networking activities, learning up to the COVID-19 and HIV project, we have been able to reach out and offer people to partake and connect across the Nordic borders. Even for people who did not dare to participate because of stigma or fear, highlighting their issues and promoting wellbeing for people living with HIV during tough times has been appreciated. From a medical perspective, our dialogue during meetings and country updates have granted

understanding of how resources diverted from HIV to COVID-19 has affected those of us living with HIV. With this knowledge we are equipped with tools for advocacy to safeguard that these services are kept in place to ensure people living with HIV have at least a baseline level of standard of care, even during a pandemic. This goes in line with our aim to gather and retain knowledge of our board members and people living with HIV, to develop and spread this knowledge and to strengthen and grow the HIV -Nordic member organizations capacity. Exchanging experiences from the Nordic countries is a very important resource and process in the national advocacy work. The process helps member organizations to learn and tackle issues that are contrary to the human rights for people living with HIV.

The networking has made it possible to exchange digital tools, ideas and initiatives to improve our operations during the pandemic. Since we are working with a target group where many still feel stigmatized and are afraid to be open with their HIV status, there are specific challenges when for example creating events online, how to manage invitations or even if showing up on a digital event with your real name and video on, which would be the norm in other circumstances. Moreover, to continuously compare and share experiences from how our respective healthcare systems has handled people living with HIV has been very beneficial. For example, use of telemedicine, frequency of appointments and whether or not to include people living with HIV in risk groups. This information allows us to put forward the right questions in our dialogue with policy makers or use the information as arguments when applying for funding or resources to people living with HIV.

On our new website we have added an article with a summary and the country updates. The knowledge gained from the network meetings and the discussion around the COVID-19 and HIV project has also meant that we have gained a deeper understanding of the experiences of people living with HIV during the pandemic, and how we best can work to new meet newly arised needs stemming from the pandemic effects. Member organizations further share and report with both their boards, colleagues and with people living with HIV using their services, who in return give feedback to HIV-Nordic for new projects or arising issues that should be brought up on a Nordic level.

The activities have been fundamental to help all our member organizations as well as individual members to capacity build in an uncertain environment. The meetings have strengthened us both as individuals and organizations, the possibility to exchange knowledge equips us with energy, knowledge and sharp arguments for our advocacy. Sadly, it is also evident that there are still inequalities to address, we were reminded about medical and treatment issues in the Nordic HIV Treatment Quality Survey Report in 2020 and this year of the psychosocial challenges for people living with HIV through our COVID-19 and HIV project. We can also discern quite some gaps between people living fairly well with HIV and some doing not as well, this is a worrisome development in terms of equality and quality of life for people living with HIV as a group, as some people risk being left behind if their voices are not being heard. These points we bring with us in our work to influence policy makers, in our effort to increase equality, influence policy and create a fair and just society for people living with HIV.

With the restrictions, the activities and meetings have this year been extra important for all of us. This was also why the COVID-19 and HIV project was carried out with the aim to encourage participation and bring people together in a Nordic context. We wanted to extend the sense of community and knowledge sharing to a wider circle of people, utilizing

online meetings to create a Nordic platform for exchange worked well and might be a tool we use again in planned projects.

## **The Strategic Plan**

We aim to:

- 1) Strengthen our role as the collaboration body for PLHIV in the Nordic countries.
- 2) Develop collaboration in the Nordic countries between organizations working with HIV.
- 3) Develop new collaborations in the Baltic countries.
- 4) Empowering PLHIV.
- 5) Strengthen our information work.
- 6) Strengthen our advocacy work in the region.

## **Nordic HIV Treatment Quality Survey 2019**

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. The report was published on the HIV-Nordic website in 2021 and is available for downloading on [www.hiv-norden.org](http://www.hiv-norden.org).

## **The HIV-Nordic project: Living with HIV during COVID-19**

The Living with HIV during COVID-19 project was conducted by HIV-Nordic and the member organizations of HIV-Nordic and funded by Nordic Welfare Center. With the HIV Treatment Quality 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 this project was to shed light on how the COVID-19 pandemic impacts people living with HIV in the Nordics. In addition, the project intended to complement and provide deeper insights to the results from the HIV Treatment Quality survey.

The aim was also to empower people living with HIV in the Nordics by providing a possibility to meet, encouraging exchange and discussions between people living with HIV in the Nordics and people working for patient organizations. Furthermore, it was found imperative to understand and document commonalities in 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. 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.

## **MAIN FINDINGS**

The data from the project was gathered by group discussions and a short background information online survey. All together the project gathered 61 participants. The main group discussion, the Nordic MeetUp was arranged on 4th September 2021 simultaneously in every Nordic country. Due to the COVID-19 related restrictions, the event was a hybrid meeting, meaning it was possible to join digitally 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.

Developed from feedback from people living with HIV in the Nordic countries, the discussion points were information about HIV and COVID-19, living with HIV during the pandemic and HIV treatment and care during the pandemic.

### **Information about HIV and COVID-19**

The survey revealed uncertainty, confusion and anxiousness in the beginning of the pandemic. There were little data on the risk of severe coronavirus infections for people living with HIV, uncertainty about any possible joint effects of HIV medication and coronavirus infection and/or vaccines, and also if people living with HIV should be prioritized for the vaccine. This caused concern and confusion, which affected the feelings and mental health of the participants.

In the jungle of information and misinformation and vague facts, the patient organizations became the key voices in distributing comprehensive information on the interconnectedness between HIV and COVID-19. However, the participants addressed that information in other languages than Nordic and English were available late. Information about the vaccines took longer to come from the authorities and health institutions, causing worry among the participants. But once the information was out, it was to the point and easy to understand.

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.

### **Living with HIV during the pandemic**

Many participants emphasized that their experiences during the COVID-19 pandemic were likely close to everyone else's. Key words were isolation, feelings of loneliness, negative effect on mental health and need for alternative ways to socialize. For those already feeling lonely and isolated because of their HIV status, these feelings were increased. Some compared the hysteria surrounding the COVID-19 pandemic to what they had experienced in the early years of the HIV pandemic. 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.

The support system already present for people living with HIV was highlighted as beneficial, 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.

Other questions raised was if HIV related stigma would be better understood by the society, after having experienced stigma on COVID-19. 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**

People living with HIV in the Nordics mostly receive their treatment from the same clinics who provide treatment and care for COVID-19 patients. Even though resources were diverted from HIV treatment to treatment for COVID-19, most participants reported that their HIV treatment and care continued to at least function somewhat during the pandemic, though some participants experienced postponed or even called off appointments, and some had their appointments changed to online appointments. And some even had problems getting their treatment from the pharmacy. Online appointments did not quite compensate for physical meetings with a doctor. In this sense there was a gap between the needs of people living with HIV and the access to their treatment and care.

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.

### **FURTHER DISCUSSION**

The findings from the projects 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.

The experiences from the past and over the history of the HIV pandemic helped the participants to adapt themselves to new and unpredictable situations. 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 participants agreed that the patient organizations 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. And 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.

For more information and the entire report, please visit [www. hiv-norden.org](http://www.hiv-norden.org).



## Economy

HIV-Nordic relies on Nordic Welfare Center's support to operate. In 2021 HIV-Nordic was granted support for networking and a project. The fee for membership is collected from member organisations and in 2021 it was 5000 SEK per year.

### Financial Report January 1 – December 31 2021

#### INCOMES

|  |                       |
|--|-----------------------|
| MEMBER FEES                                | 20 085,70 SEK         |
| NORDIC WELFARE CENTER FOR NETWORK          | 30 000,00 SEK         |
| NORDIC WELFARE CENTER FOR COVID-19 PROJECT | 100 000,00 SEK        |
| <b>TOTAL INCOME</b>                        | <b>150 085,70 SEK</b> |

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#### EXPENDITURE

|                          |                       |
|--------------------------|-----------------------|
| BANK COSTS               | 618,00 SEK            |
| WEBPAGE COST             | 1 843,75 SEK          |
| NETWORKING and PROJECT   | 123 995,51 SEK        |
| <b>TOTAL EXPENDITURE</b> | <b>126 457,26 SEK</b> |

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|                          |                      |
|--------------------------|----------------------|
| <b>OUT GOING BALANCE</b> | <b>23 628,44 SEK</b> |
|--------------------------|----------------------|

## Virtual Annual Meeting, 26th of February 2022

|            |                   |         |
|------------|-------------------|---------|
| Chair      | Emanuel Karlström | Sweden  |
| Vice Chair | Nonni Mäkikärki   | Finland |
| Treasurer  | Sini Pasanen      | Finland |
| Director   | Einar Jónsson     | Iceland |
| Director   | Simon Blom        | Sweden  |
| Director   | Preben Sloth      | Denmark |
| Director   | Vacant            | Iceland |
| Director   | Bente Bendiksen   | Norway  |
| Director   | Jacob Hermansen   | Norway  |