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Nordic HIV Treatment
Quality Survey

Hiv-Nordic



HIV-Nordic

- HIV-Nordic is the co-operative body of the Nordic organizations for people living with HIV.
- HIV-Nordic was founded in 1995 and the organizations included in HIV-Nordic are Hiv-Denmark, HivNorway, HivFinland, HIV-Sweden and Hiv-Iceland.
- All patient-led NGOs in the Nordic countries can join HIV-Nordic.
- Sharing (best) practices, discussing situations in the Nordic countries and having small projects.

Why this survey?

- Privileged to get treatment and care from some of the best health systems in the world.
 - Many people not open about their HIV-status to anyone else than HIV-doctor and nurse.
- Many people dependent on the information provided by healthcare professionals.
- We had heard:
 - Changes in treatment and care in the past 2-3 years
 - Less time at doctor's appointment
 - "The service has been so good." But what it means when you've felt being involved in your care and treatment for 10-20 years and suddenly not anymore?
 - People haven't understood why their treatment (medication) has been changed.
- Patient participation is important for the treatment adherence, as well as for quality of life
 - Elements related to mental health and mental well being: Perceived self-efficacy, competence, subjective well-being...

Aim of this project and the survey

- To get information about HIV-treatment and care people have received during the past 2-3 years in the Nordic countries.
- Have people experienced any changes?
- To get data for our advocacy work
- To get information about the needs for more information, support, training, treatment literacy...
- Funding from Nordic Welfare Center

SURVEY



- October 2019 - December 2019.
- People born or who have lived for a long time in the Nordic countries.
 - Same expectations to health care
- Languages Finnish, Swedish, Norwegian, Danish and English.
- 435 responses
- www.hiv-norden.org/wp-content/uploads/2021/06/FINAL-REPORT-.pdf

SURVEY



- Care and treatment
 - Do people understand their treatment, do they feel they are understood, how people feel about the privacy and confidentiality at clinics...
- Medication
 - What kind of medication, side effects, are people forced to change medication, can they change medication, how many pills, how many times a day...?

Experienced patient / doctor relationship (n=435)

How would you describe your current patient-doctor relationship in your HIV treatment and care?

- 8,5
- People are satisfied with their patient-doctor relationship and find it easy and functional, 64% gave 9 or 10 on a scale 1-10.
- On a scale 1-10 average was 8,5, both today and 2-3 years ago.
- There are no markable changes when comparing today and 2-3 years ago.

How much do you agree with the following statements about your HIV treatment and care?

(Think about your last appointment)

Scale:

1 = Strongly disagree –
10 = Strongly agree

- I trust the confidentiality
 - 80% (9 or 10)
 - 89% (8, 9 or 10)
- I think my privacy is well taken into account
 - 66% (9 or 10)
 - 79% (8, 9 or 10)
- I feel that I'm involved in my own HIV medication, treatment and care
 - 55% (9 or 10)
 - 15% 8

- I feel that the HIV doctor has to make medication and treatment choices based on the cost / price of the treatment
 - Strongly disagree (1) 28% Strongly agree (10) 21%
- 54% strongly agree (10) that "I understand what the HIV doctor tells me about HIV medication and treatment"
 - 9 = 20%, 8 = 11%, 1-7 = 15%
- Before my HIV doctor's appointment, I'm worried if my HIV medication is still effective.
 - 47% strongly disagrees (1)
 - 18% agrees (8, 9 or 10)
- 20-25 % weren't sure if they have side effects from their current HIV medication.
- About changing medication: 12% of the respondents felt that they didn't have a choice but to change the medication.

MY LIFE, MY HIV TREATMENT



Q:



How effective
is my HIV
treatment?



Swipe right to find out ▶

MY LIFE, MY HIV TREATMENT



Q:

HIV is more than
viral load and CD4s.
What other topics
should I discuss
with my doctor?



Swipe right to find out ▶

MY LIFE, MY HIV TREATMENT



Q:



How do I know if
my HIV treatment
is working?



Swipe right to find out ▶

A:

You will undergo regular blood tests as a part of your HIV treatment, to check that your medication is working. Tell your doctor if you have any concerns and they will help you find the best treatment for you.



MORE INFO:
hiv-norden.org



A:

Be involved in your own care. Ask questions and talk to your doctor about your concerns, or if you experience side effects or other health and treatment challenges. Contact your local HIV organization and join peer support activities.



MORE INFO:
hiv-norden.org



A:

Once you are on successful treatment, you stay healthy and cannot pass HIV on to others in any way. Ask your doctor if you have any concerns about the effectiveness of your treatment.



MORE INFO:
hiv-norden.org



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



HivNorway



Thank you!

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www.hiv-norden.org/wp-content/uploads/2021/06/FINAL-REPORT-.pdf

