Sini Pasanen Positiiviset, HivFinland

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?

- Priviledged to get treatment and care from some of the best health systems in the world.
 - Many plhiv 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 adherance, 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 patientdoctor 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.

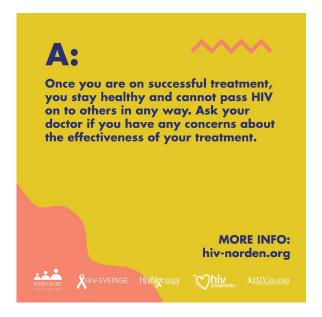












NORDIC MEETUP

- 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















Thank you!

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

