

LIVING WITH HIV IN SWEDEN

Over a period of four months, more than 1,000 HIV-positive Swedes throughout the country will be asked about participating in a study that looks at what it is like to live with the condition these days. Up-to-date information about the circumstances and quality of life among various population groups is required in order to improve healthcare and other social institutions as needed. In other words, your participation will be highly valuable.

How does it work?

During your appointment at the infection clinic, you will fill out a questionnaire about how you are doing and the things that may or may not be difficult for you to deal with at work, when travelling, when communicating with the healthcare system or in your personal relationships. The questionnaire takes 20-40 minutes to complete.

The questions were put together in collaboration with a number of organisations (including HIV Sweden, Noah's Ark and the Swedish Drug Users Union in Stockholm) that support HIV-positive people. You might feel that some of the questions are repetitive or invasive, but they are important so that we can compare the responses to those of people in other countries. The results of the study will be compiled and made available for anybody who is interested in late spring 2014.

The questionnaire is completely anonymous and voluntary. Nobody will be able to make any connection between you and your responses. None of your caregivers will have access to your responses.

You can drop out of the study at any time. The health care you receive will not be affected if you decide not to participate in the study.

Who is in charge of the study?

The study is a collaborative project of the Swedish Institute for Communicable Disease Control, Karolinska Institutet, Karolinska University Hospital, Vehälsan and Astrid Lindgren Children's Hospital in Stockholm, as well as infection clinics in Helsingborg, Malmö, Karlskrona, Kalmar, Visby, Skövde, Gothenburg, Örebro, Falun, Gävle, Umeå and Luleå. Anna Mia Ekström, a professor at Karolinska Institutet and a specialist in infectious conditions, is in charge of the study. The Regional Ethical Review Board in Stockholm has approved both the study and the questionnaire.

Is there anything you are wondering about?

If there is anything you would like to ask about the questionnaire, feel free to talk to the person who contacted you about participating in the study.

If there is anything you would like to ask about the study, feel free to call the research coordinators at 0735 - 605 942, www.attlevamedhiv.se or write to Dr Ekström at anna.mia.ekstrom@ki.se

If there is anything you want to ask about HIV in general, or if you are looking for advice from somebody who knows what it is like to live with the condition, contact:

- Swedish Association for HIV-Positive People at 08-714 54 10 or www.hiv-sverige.se
- Positiva Gruppen at 0736-24 24 22 or **Fel! Ogiltig hyperlänkreferens.**
- National Federation of Noah's Ark Associations at www.noaksark.org or your local association at 020-78 44 40

Consent to participate in the study "Living with HIV in Sweden 2013"

Responding to the questions indicates that you have consented to participate in the study and that you realise that your participation is voluntary and that your responses are completely anonymous.