Information about InfCareHepatit

How we improve the quality of hepatitis care for you and other patients

In order to improve and ensure the quality of hepatitis care given in Swedish hospitals, we collect selected information annually and compile it in order to analyse how well your care, and that of other hepatitis B and C infected persons, is working. This is done under the direction of Dr. Magdalena Ydreborg at the Department of Infectious Diseases, Sahlgrenska University Hospital. In the compiled information, all patients who have participated are de-identified (i.e. anonymised). The aim of this work is to make hepatitis care even better and even safer. The compiled information is called the InfCareHepatit registry. You can read more about this, and about the laws that regulate Swedish National Quality Registries, on our website https://qrcstockholm.se/register/anslutna-register/infcarehiv-och-infcarehepatit. Through the Swedish Association of Local Authorities and Regions (SKR), InfCareHepatit has received quality assessment and financial support, and has been awarded the status of a National Quality Register.

You can contribute to the improvement of Hepatitis care!

By participating in our collection and compilation of information about hepatitis care in Sweden, you will be contributing in many ways to the improvement of hepatitis care. The more people who participate, the better and more representative the results will be. The results are used to improve and develop our everyday work in hepatitis care for you and for others with viral hepatitis.

What information do we compile?

The information that is included in our compilation concerns your care and the treatment of your hepatitis and its complications. The following information is collected: the amount of HCV-RNA, HBV DNA, your liver function tests, sex, age, personal identity number, route of infection, known date of infection, date of diagnosis, type of virus, which treatments you are receiving and have received, and any complications (other infections, tumours).

Our compiled information contributes to better quality of care

The annual collection and compilation of information in Sweden contributes new knowledge about how care at our hepatitis clinics can be improved with regard to your treatment, your other care, and events that are important for how you experience your care. In our compilation, information is collected from hepatitis-infected people attending clinics all over Sweden. This can, therefore, be used to compare the hepatitis care given by different clinics in Sweden so that they can learn from each other and improve.

Your confidentiality is protected

In accordance with the Public Access to Information and Secrecy Act, all information kept about individuals' health conditions and other personal circumstances within healthcare is confidential, if it is not clearly stated that the information can be disclosed without the individual or any close relative of the individual suffering damage. This means that the information may not be disclosed to unauthorised persons.

Your information in our compilation is therefore confidential and is treated in the same way as the information in your healthcare records. All patients who have participated in the compilation are de-identified (i.e. made anonymous) and the data received from all patients are merged. In other words, it is impossible to recognise any individual person in our compiled information.

Your rights as a patient

Registration is optional. None of your personal information is taken from any source other than your patient healthcare record or information you provide yourself. You can refuse to participate. You can also, at any time, request that your data is deleted from InfCareHepatit. In this case, it is not permitted for any additional information about you to be registered. As a patient, you have the right to know who is likely to receive the de-identified compilations; for example, if it would be relevant for information to be disclosed for research purposes (which must always first be approved by the ethics committee). You are protected by the European General Data Protection Regulation (GDPR 2016/679) and the supplementary Swedish Data Protection Act (2018:218), and the Swedish Patient Data Act, chapter 7.

In addition, you have the right to:

- request an extract from the register, free of charge, in accordance with the European General Data Protection Regulation (GDPR 2016/679) and Swedish Data Protection Act (2018:218)
- receive information about any access to your data that has been made
- have any incorrect information in the register corrected and third parties notified about the incorrect information
- receive damages if your data is processed in violation of the Swedish Patient Data Act

Personal data controller

The Central Personal Data Controller (CPUA) is the Board of Directors of Karolinska University Hospital. Every hospital/healthcare region has a local Data Protection Officer. The Central Data Protection Officer is based at Karolinska University Hospital.

Contact information

If you would like more information or an extract of what information is compiled, please contact the person responsible for InfCareHepatit at your clinic or
the registry holder **Dr. Magdalena Ydreborg (e-mail: magdalena.ydreborg@vgregion.se)**
or the **Data Protection Officer, Karolinska University Hospital, 17176 Stockholm, tel. 08-51770000 (switchboard), (e-mail: dataskyddsombud.karolinska@regionstockholm.se.)**