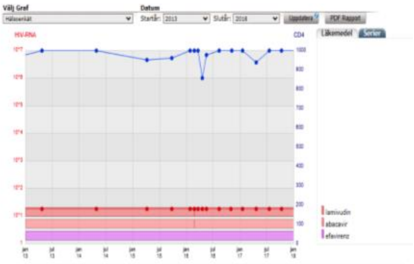
Information about InfCareHIV – Decision Support System and Quality Register

InfCareHIV contains data on more than 99% of everyone living with diagnosed HIV in Sweden. The data is collected when patients register at the HIV clinic and during follow-up visits. This data serves both as a decision support system for you and your doctor and as a quality register that can help improve HIV care in Sweden. Read more about this Decision Support System and the Quality Register in InfCareHIV in this document.

The Decision Support System in InfCareHIV

This Decision Support System is used during your clinic appointment so that you and your doctor/nurse can easily view and discuss your results. It shows clearly how your treatment is working and whether you are virus-free (undetectable viral load in your blood). If you change HIV clinics, they can very quickly get an overview of your previous treatments and how well they have worked. **Your rights:** The Decision Support System is considered a medical tool and is therefore part of your medical records so the same laws and regulations that apply to your medical records also apply to the Decision Support Tool. Only authorised staff at your HIV clinic have access to this.



Quality Register in InfCareHIV

Participation in the register is voluntary and has no impact on the care you receive. If you choose to participate, you will be helping to improve care for more people.

What information can we collect?

The InfCareHIV Quality Register contains data relating to the care and treatment of your HIV infection. Some data is gathered while talking to you as a patient (e.g. gender assigned at birth, gender identity, country of birth, probable route of transmission), while other data is taken from your medical records (test results, current and previous HIV treatment, any other diagnoses). When results are compared between different hospitals and clinics, all participating patients are anonymised (all identifying information removed) and data from all sources is combined. This makes it impossible to identify individual people in summaries from the InfCareHIV Quality Register.

How your data is used

Your data may only be used to develop and ensure the quality of care, compile statistics and conduct research within the healthcare sector. After undergoing a confidentiality assessment, the data may also be shared with external parties for the same purposes. When such data is disclosed, it is pseudonymised, meaning that you cannot be identified. Before it starts, all research must first be approved by the Swedish Ethical Review Authority (Etikprövningsmyndigheten).

Responsibility

The body with overall responsibility for InfCareHIV is known as the Central Data Controller Authority (Centralt Personuppgiftsansvarig-myndighet, CPUA). Karolinska University Hospital has overall legal responsibility for this personal data. Your healthcare unit (HIV clinic) has local legal responsibility for the collection of data. The InfCareHIV steering committee handles the practical work on behalf of the Central Data Controller Authority, and is presented on the InfCareHIV website infcarehiv.se

Legal basis

Anyone processing your personal data must have a legal basis for doing so. The processing of personal data in quality registers is governed by the General Data Protection Regulation (GDPR), and Chapter 7 of the Patient Data Act (PDL). The recording of data in quality registers is permitted as the information is of importance to society and within the healthcare sector. Staff who handle personal data in quality registers are bound by a statutory duty of confidentiality.

Confidentiality

Your data in quality registers is protected by healthcare confidentiality under the Public Access to Information and Secrecy Act. As a general rule, this means that pseudonymised data (data in which all identifying information replaced with codes) about you may only be disclosed from quality registers if it is clear that neither you nor anyone close to you will be harmed if the information is disclosed.

Security

Your data in quality registers is protected against unauthorised access. Only those who need the data to carry out their work are permitted access to it. Checks are carried out to ensure that no unauthorised individuals have accessed the data, known as log monitoring. Logging into the register to access data is carried out in a secure fashion.

Access

Authorised staff at the HIV clinic who have entered the data into the Quality Register have access to that specific data. No other healthcare provider can access the data. The administrative staff responsible for the Quality Register have access to all the data in the register and are bound by a statutory duty of confidentiality.

Your rights

- You have the right to refuse to have your personal data recorded in the quality register.
- You have the right to have your data deleted from the register at any time.
- You have the right to find out whether data about you is held in the Quality Register and, if so, to receive a copy of it free of charge, known as a register extract. You have the right to receive the data in electronic form. Contact the Quality Register directly to obtain such a register extract.
- You have the right to have incorrect data about you corrected. You have the right to have incomplete data supplemented.
- You have the right to require that the processing of your data be restricted if: 1) You believe that the personal data is incorrect and while the Central Data Controller Authority is verifying this. 2) You believe that the processing is unlawful and object to your personal data being erased, requesting instead a restriction on its use. 3) In a situation where the National Quality Register no longer needs the personal data for the purposes of processing, but you believe you need it to establish, exercise or defend legal claims.
- Restriction means that the Quality Register may not do anything with your data other than continue to store it.
- You have the right to receive information about which healthcare unit and at what time someone has accessed your data, known as a log extract.
- You have the right to compensation if your personal data is processed in breach of the General Data Protection Regulation or the Patient Data Act.
- You have the right to lodge a complaint with the Swedish Authority for Privacy Protection (Integritetsskyddsmyndigheten), which is the supervisory authority in this area.

Additional information is available at infcarehiv.se and at kunskapsstyrningvard.se.

Contact

If you wish to contact InfCareHIV for more information, please use the following contact details: Senior Consultant Christina Carlander, christina.carlander@regionstockholm.se. You may also contact a data protection officer with any questions regarding your data in InfCareHIV. Data protection officers monitor compliance with laws relating to the processing of personal data. Data Protection Officer, Karolinska University Hospital, 171 76 Solna, telephone number: 08-517 700 00 (switchboard), email address: dataskyddsombud.karolinska@regionstockholm.se
Each individual hospital/region also has a local data protection officer.