Welcome to InfCareHIV

What is InfCareHIV?

InfCareHIV contains data on more than 99% of everyone living with diagnosed HIV in Sweden. InfCareHIV is built by doctors and nurses at various HIV clinics across the country entering data when patients register at their clinic and when they come for 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.

Data

We collect data that is important for your **follow-up care** and for the **quality of that care**. 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). We also use the Health Questionnaire to record what you think about your health and the care you receive at your HIV clinic.

Our responsibility

We ensure that your data in InfCareHIV is protected. Your data in the quality register may only be used to develop and ensure the quality of care for people living with HIV and for research purposes. Any data disclosed is pseudonymised (all identifying information replaced with codes). If data is to be disclosed, a confidentiality assessment is required (to ensure that you cannot be harmed by the disclosure). All research must first be approved by the Swedish Ethical Review Authority (Etikprövningsmyndigheten).

Your rights

You always have the right to refuse to participate, to withdraw from the quality register and to have previous data deleted. You also have the right to know the information that has been recorded about you and to ensure that incorrect or incomplete information is corrected. To exercise these rights, please contact your healthcare provider. Read more about your rights in the patient information section at infcarehiv.se.

You are helping to improve care

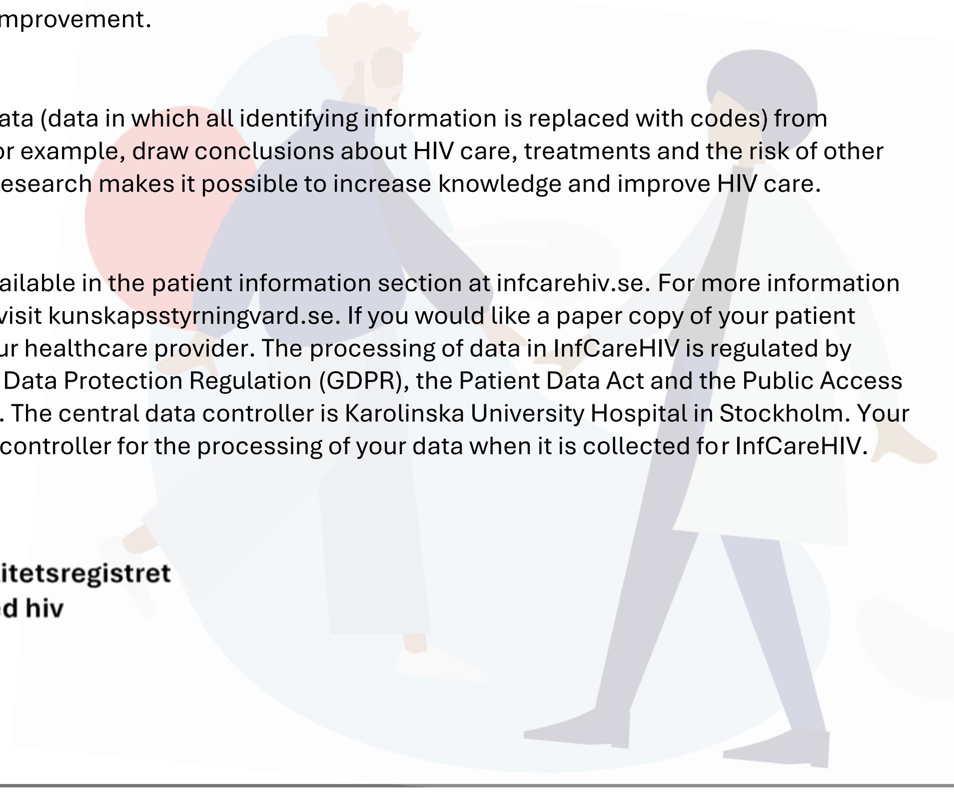
By taking part in InfCareHIV, you are helping to improve care for people with HIV. Participation in InfCareHIV is voluntary and has no impact on the care you receive. The data is used to compare the provision of care between different hospitals and healthcare providers across the country. The results are then used to identify areas for improvement.

Research

By analysing pseudonymised data (data in which all identifying information is replaced with codes) from InfCareHIV, researchers can, for example, draw conclusions about HIV care, treatments and the risk of other conditions (comorbidity). This research makes it possible to increase knowledge and improve HIV care.

Laws and regulations

More detailed information is available in the patient information section at infcarehiv.se. For more information about quality registers, please visit kunskapsstyrningvard.se. If you would like a paper copy of your patient information, please contact your healthcare provider. The processing of data in InfCareHIV is regulated by legislation such as the General Data Protection Regulation (GDPR), the Patient Data Act and the Public Access to Information and Secrecy Act. The central data controller is Karolinska University Hospital in Stockholm. Your healthcare provider is the data controller for the processing of your data when it is collected for InfCareHIV.



InfCareHIV Kvalitetsregistret
för personer med hiv