

Caring for the trust

National and regional quality registers play an important role in the development of Swedish healthcare, and they are also an invaluable source for scientific research in the medical field.

Any County Council, or a public Swedish healthcare-provider, may take on the responsibility for a National/regional quality register that will gather and process personal information regarding patients health from other healthcare providers – public and private – provided that certain statutory rules are met. These rules are found primarily in the Patient Data Act.

The overriding purpose of these registers is to systematically and continuously develop and secure the quality of healthcare. The collected data may also be used for statistical purposes and medical research.

The patient is the main contributor to a quality registry and must be invited to contribute relevant data. All patients being considered for participation must be informed about the purpose of register and that participation is voluntary. A patient may at any time choose to have his or her data excluded from the register.

Since national and regional quality registers contain sensitive information about patients and their health, security and confidentiality of data are critical success factors.

The Stockholm County Council has produced a brief manual outlining the principal legal requirements for involved parties, e.g. local care-givers that provide data to the national quality register, the care-giver in charge of the national register, steering boards and other functions normally associated with a quality register. In addition, the manual defines the measures and obligations under which scientific research can be conducted with data from a quality register.