

Publication

Consent and use of samples

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Objectives To estimate how many people object to storage of biological samples collected in health care in Sweden and to their use in research and how many withdraw previous consent. **Design** Cross sectional study of register data. **Setting** Biobanks used in Swedish health care, 2005-6. **Population** Data on refusal to consent were obtained for 1.4 million biobank samples per year from 20 of 21 counties. **Main outcome measures** Rates of preliminary refusal to consent, confirmed refusal, and withdrawal of consent. **Results** Patients refused consent to either storage or use of their samples in about 1 in 690 cases; about 1 in 1600 confirmed their decision by completing a dissent form. Rather than having the samples destroyed, about 1 in 6200 patients wanted to restrict their use. Of those who had previously consented, about 1 in 19 000 withdrew their consent. **Conclusions** Refusal to consent to biobank research in Sweden is rare, and the interests of individuals and research interests need not be at odds. The Swedish healthcare organisation is currently obliged to obtain either consent or refusal to each potential use of each sample taken, and lack of consent to research is used as the default position. A system of presumed consent with straightforward opt out; would correspond with people's attitudes, as expressed in their actions, towards biobank research.

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