

# Researchers guardians of trust in biobank research

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Do we trust biobank researchers? In a doctoral thesis from Uppsala University, medical doctor and bioethicist Linus Johnsson claims that we do: At least in Sweden. And since we do, researchers in turn have a moral responsibility towards us.

On March 9, Linus Johnsson, medical doctor and [bioethicist](#) at the Centre for Research Ethics & Bioethics (CRB), will defend his thesis on trust in biobank research. Trust is a sensitive issue in all research, but perhaps particularly so when it comes to biobanks. There has been debate on whether the police should be able to access samples, and whether this would lead to distrust and to people withdrawing their samples. In [Sweden](#), the PKU biobank became famous in 2003 after foreign minister Anna Lindh's murderer was identified through blood stored there.

Public trust in the research community is often measured in surveys. In one study, Linus Johnsson shows that people may be more willing to donate samples than most of these surveys indicate. Especially if health care personnel approach them face-to-face. He believes that this is because relationships of trust are important in our decision making.

In another study, Linus Johnsson found that trust is very much present, at least in the Swedish biobank settings he has studied. According to him, researchers have to consider the expectations that people have of them. The fact that they are trusted in turn means that they have a responsibility towards the public.

Despite ethics review, guidelines and informed consent procedures, ethical issues will always arise during the course of a research project, says Linus Johnsson. He warns against putting too much trust in regulatory systems.

"Relying on formal rules and regulations to guarantee research participants' trust is not enough. They can never cover all ethical considerations that researchers should make", he says.

In his thesis, Linus Johnsson sees a danger that the review system fosters researchers to a kind of moral complacency. If we trust the system to take care of everything we risk researchers becoming blind to the ethical issues that are not covered by rules.

"Putting too much trust in the system could potentially alienate researchers to ethics. Following rules is not enough. Researchers and institutions have to reflect on what their duties are", Linus Johnsson says.

Provided by Uppsala University

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