Researcher argues moral duty of participation in biobank research

September 20 2012, by Linda Koffmar

We all need medical advances. Biobank research can benefit both current and future patients, but it requires participants. So what can we do to promote research? On October 6, Joanna Stjernschantz Forsberg from the Centre for Research Ethics & Bioethics at Uppsala University, will defend her PhD thesis "Biobank Research: Individual Rights and Public Benefit." In the thesis she suggests that research using stored tissue samples and data should be thought of as a natural component of healthcare, rather than something dangerous and exceptional that people must be protected from.

"The starting point is often that regulations are needed to protect individuals from the risks involved in medical research, but it is important to remember that hindering research is also risky," Joanna Stjernschantz Forsberg says.

According to Ms. Forsberg, the risks you are subjected to as a participant in biobank research differ significantly from the risks you take when you participate in many other kinds of medical research.

"We all have an interest in good and effective healthcare. We do not know in advance what kind of medical care we, or those we care about, will need. This is why research that involves minimal risks should be endorsed and facilitated."

In her thesis, she concludes that the moral duty to contribute to biobank research means accepting that stored samples and data are used in

research. This duty can be thought of as a social contract based in self-interest:

"We cannot reject it by appealing to the primacy of individual rights over the public good, simply because there is no need for arguments based on societal benefit."

More information: Stjernschantz Forsberg, J, Biobank Research: Individual Rights and Public Benefit, doctoral thesis, *Acta Universitatis Upsaliensis*, 2012.

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