Patients’ and public’ perception of genomic research

A review of socio-empirical research and ethical analysis

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Background
New technologies such as genome wide association studies and related biobank research challenge concepts and practices of informed consent for research participants. In this paper we present data of socio-empirical studies on the perceptions and views of research participants regarding consent in the context of biobank research and provide an account on how such data can inform the debate about normative aspects of appropriate consent.

Method
A literature search was performed in PubMed to identify socio-empirical studies on research participants’ perceptions and views regarding consent in biobanking published before 23rd October 2012. The data of empirical research are analysed against the background of key issues discussed in the ethico-legal debate on consent in biobank research.

Results
The search in PubMed generated 244 abstracts. 64 articles fulfilled the inclusion criteria. Main results of the review of socio-empirical literature comprise the limited understanding of research participants with regards to biobank research, preferences of participants regarding characteristics of the informed consent procedures and concerns for privacy and data sharing. Moreover the review indicates that factors such as country specific and institutional aspects (e.g. owner of biobank) or the model of consent used in research practice, as well as socio-demographic characteristics on side of the research participants, may influence perceptions, views and choices regarding biobank research.

Discussion
The review of the socio-empirical literature provides a starting point for critical reflections on information in biobank research. While much of the normative analysis focuses on the problems associated with lack of information in biobank research, the data of empirical literature indicate that even in cases of available information research participants have limited understanding of the matter to which they consent. Furthermore the reviewed empirical research indicates that there are a number of context factors (e.g. owner of biobank, culture and country specific issues) which seem relevant for a morally appropriate practice of consent but which are little discussed in the normative debate. Taking the aforementioned and other supplementary examples we will show how further interdisciplinary empirical-ethical research can inform and contribute to the development of consent models for biobank research.