

Conference Abstract

31st EUROPEAN CONFERENCE ON PHILOSOPHY OF MEDICINE AND HEALTH CARE

The European Society for Philosophy of Medicine and Health Care (ESMPH)
Belgrade, Serbia, 16-19 August 2017

Author: Joanna Rozynska, Ph.D.

Affiliation: Center for Bioethics & Biolaw, Institute of Philosophy, University of Warsaw
3 Krakowskie Przedmiescie Street, 00-097 Warsaw, Poland

E-mail: j.rozynska@uw.edu.pl; jrozynska@gmail.com

Title: Risk-benefit assessment in biobank research

Abstract text: A biobank is a collection of human biological material coupled with personal, medical, genetic or other information about individuals who have donated samples to the biobank. Since the late 1990s specimens and data collected in biobanks have become an important resource in biomedical research. To be admissible, all projects of such research must be approved by relevant research ethics committees (RECs; or similar bodies). In this presentation I will focus on ethical and practical problems RECs may face when making risk-benefit assessment in biobank-dependent research.

First, drawing from literature and history of famous real-life cases – such as *Beleno et al. v. Texas Department of State Health Services* and *Havasupai Tribe v. Arizona State University Board of Regents* (Mello & Wolf 2010; Carnahan 2011; Nurmsoo & Hayes 2015), I will analyze various types of risks that may be posed by biobank-dependent research. I will argue that risks of biobank research (i) *always* extend beyond interests and rights of the individual donor to population groups represented by the donor as well as the general public at large, and that (ii) they *always* exist, but are usually low (or even minimal) and mainly of social, legal and dignitary character (Rothstein 2005; Dhali et al. 2013).

Secondly, I will discuss the difficulties of weighing potential benefits to be gained from biobank-dependent research against potential harms for donor, represented populations, and society at large. I will argue that it is difficult for RECs to determine risk-benefit profile of such research, because: (1) the risks and benefits are often heterogeneous and incommensurable; (2) it is still unsettled whether and how risks to groups or communities from which samples donors are recruited (e.g. risks of group discrimination or risks for indigenous communities cultural identity) should be considered (Weijer 1999; Emanuel & Weijer 2005; Santos 2008; McWhirter et al. 2012); (3) it is unclear how should social value of knowledge expected to be gained from the research be understood and evaluated against the risks involved (Freedman 1987; Karlawish 1999; Grady 2002; Casarett et al. 2002; Habets et al. 2014; Wenner 2015, 2017; Wendler & Rid 2017). I will make several suggestions how these problems might be mitigated or resolved in RECs' practice.

Financial support:

This project was funded by the National Science Centre, Poland, DEC-2014/15/B/HS1/03829.