

## Research Project

### Ethical, Legal, Social and Practical Barriers to Sharing between Biobanks in Europe

#### Third-party funded project

**Project title** Ethical, Legal, Social and Practical Barriers to Sharing between Biobanks in Europe

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**Co-Investigator(s)** [Howard, Heidi](#) ;

**Organisation / Research unit**

Ethik / Bio- und Medizinethik (Elger)

**Department**

**Project start** 01.09.2011

**Probable end** 31.08.2013

**Status** Completed

In the last two decades, important efforts have been made to organize such biological samples such as tissues, blood, DNA, and cells and to organize data into biobanks in order to make these samples and data available for sharing between researchers. That being said, there remains many barriers and challenges to sharing between researchers and biobanks (whether regionally, nationally or internationally). The overall objective of this research project is to obtain a better definition and understanding of the ethical, legal, social and practical problems preventing the sharing of data and/or samples between biobanks, as well as between researchers, and to suggest ethically sound (i.e. just) solutions that are feasible in practice.

**Financed by**

Commission of the European Union

#### Add publication

##### Published results

1006811, Zawati, Ma'n H; Borry, Pascal; Howard, Heidi Carmen, Closure of population biobanks and direct-to-consumer genetic testing companies, 0340-6717, Human genetics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

1533582, Borry, Pascal; van Hellemond, Rachel E; Sprumont, Dominique; Jales, Camilla Fittipaldi Duarte; Rial-Sebbag, Emmanuelle; Spranger, Tade Matthias; Curren, Liam; Kaye, Jane; Nys, Herman; Howard, Heidi, Legislation on direct-to-consumer genetic testing in seven European countries, 1018-4813, European journal of human genetics, Publication: JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

1533611, Su, Y.; Otte, I. C.; Borry, P.; Howard, H. C., 'It's our DNA, we deserve the right to test!? A qualitative analysis of a petition for the right to access direct-to-consumer genetic testing without the intermediate of a health care professional'. Publication: ConferencePaper (Artikel, die in Tagungsbänden erschienen sind)

**Add documents****Specify cooperation partners**

<b>ID</b>	<b>Kreditinhaber</b>	<b>Kooperationspartner</b>	<b>Institution</b>	<b>Laufzeit - von</b>	<b>Laufzeit - bis</b>
1017825	Elger, Bernice Simone	Manai-Wehrli, Dominique, Prof. Dr.	Law Faculty University of Geneva	01.09.2011	31.08.2013
1017826	Elger, Bernice Simone	Burton-Jeangros, Claudine, Prof. Dr.	Department of Sociology, University of Geneva	01.09.2011	31.08.2013
1017828	Elger, Bernice Simone	Mauron, Alexandre, Dr.	Bioethics Unit, Faculty of Medicine, University of Geneva	01.09.2011	31.08.2013
1017831	Elger, Bernice Simone	Antonarakis, Stylianos E., Prof.	Faculty of Medicine, Univer- sity of Geneva	01.09.2011	30.11.2011
1023168	Howard, Heidi	Borry, Pascal, Prof. Dr.	Centre for Biomedical Ethics and Law, KULeuven	01.09.2011	31.08.2013
1023170	Howard, Heidi	Pinxten, Wim, Research Fellow	ErasmusMC, Department of Medical Ethics and Philosophy of Medicine	01.09.2011	31.08.2013