



# An exploratory survey of professionals on the use of stored tissue samples from minors for genetic research

K. Hens<sup>1</sup>, J. Snoeck<sup>2</sup>, H. Nys<sup>2</sup>, J.-J. Cassiman<sup>3</sup> and K. Dierickx<sup>1</sup>

<sup>1</sup>Centre for Biomedical Ethics and Law, Katholieke Universiteit Leuven, Leuven, Belgium

<sup>2</sup>Rega Institute for Medical Research, Katholieke Universiteit Leuven, Leuven, Belgium

<sup>3</sup>Departement Menselijke Erfelijkheid, Katholieke Universiteit Leuven, Leuven, Belgium

Corresponding author: K. Hens

E-mail: [Kristien.Hens@med.kuleuven.be](mailto:Kristien.Hens@med.kuleuven.be)

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**ABSTRACT.** The ethical aspects of the use of stored tissue samples collected from minors are of topical interest. However, the views of professionals working in the field of genetics have not been investigated in depth anywhere. We conducted a survey among 194 such professionals in Belgium. This list was composed of the members of the High Council for Anthropogenetics, supplemented with all professionals working in the field of genetics that we found on the websites of the eight Belgian centers of human genetics and of the associated university registries. We achieved a response rate of 35.5%. The vast majority (92%) think that research on stored tissue samples is useful. Most respondents stated that parental consent is valid (82.5%), and 76.5% thought that children should also be given the right to assent when they are able to comprehend the implications of the storage of biological samples and of genetic research. Slightly more than half put the age at which young people can understand storage or

research rather high: 16-18 years (51 and 53.1%, respectively). Although there is some consensus in the literature that donors should be allowed to give broad consent for future research on their biological samples, only 47.6% in our survey thought that parents should be allowed to consent to any future research on their children's samples. The aim of our study was to give some basis for future ethical reflections and policies on the subject of stored tissue samples from minors for genetic research. We concluded that a large majority of Belgian researchers and clinicians in the field of genetic research think research on stored tissue samples from minors is useful. They also think that parental consent for such research is valid, but that children should be allowed to assent as they grow older.

**Key words:** Survey; Ethics; Biobank; Genetic research; Consent