

## ***Bioethics Digest***

*In this feature, our team provides you with an overview of the most recent publications in the field of bioethics, with a particular focus on contributions coming from (or having relevance for) Switzerland.*

*Buona lettura! Bonne lecture ! Viel Spass beim Lesen! Enjoy the reading!*

The editors: Andrea Martani, Maddalena Favaretto, and Felix Pageau

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#### **CLINICAL ETHICS**



#### **“In the name of the family? Against parents’ refusal to disclose prognostic information to children”**

In this publication, the authors tackle the question of whether it is desirable for parents to refuse disclosing prognostic information to their children when the latter are diagnosed with cancer. They argue that – by adopting a systemic conception of the family – the mediated and careful disclosure of information is preferable to non-disclosure. To do so, the author do not dispute the claims that a child with cancer is in need for stability, neither do they deny that paediatric oncologists should contribute to maintaining the inner stability of the family. They however contest the claim that non-disclosure of prognostic information is the best way to preserve a family’s inner stability in the long run. The authors thus recommend that paediatric oncologists and parents actively discuss together how to better disclose the prognostic information to the ill children in a careful and clear manner.

Rost M, Mihailov E. In the name of the family? Against parents’ refusal to disclose prognostic information to children. *Med Health Care and Philos.* 2021. doi: [10.1007/s11019-021-10017-4](https://doi.org/10.1007/s11019-021-10017-4)

#### **DIGITAL ETHICS**



#### **“Public willingness to participate in personalized health research and biobanking: A large-scale Swiss survey”**

This study reports the results of a questionnaire with more than 5000 Swiss residents on their willingness to share personal health data to facilitate research in personalised and precision medicine, given their increasing importance in science. Three very interesting results were presented by authors: young and more educated individuals have more positive attitudes towards sharing data for this type of research; the public appear to have particular aversion towards sharing data derived from phone apps; there seems to be a desire to receive results of the research after sharing data. The authors then discuss in their paper

the overall moderate willingness of the Swiss population to participate in personalised medicine research, linking it to the individualistic mentality of the Swiss population. In the end, the writers highlight the need to better motivate people towards participation by more pervasive informational campaigns and public involvement.

Brall C, Berlin C, Zwahlen M, Ormond KE, Egger M, Vayena E. Public willingness to participate in personalized health research and biobanking: A large-scale Swiss survey. *PLoS One*. 2021 Apr 1;16(4):e0249141. doi: [10.1371/journal.pone.0249141](https://doi.org/10.1371/journal.pone.0249141).

**“Digital Technologies for Schizophrenia Management: A Descriptive Review.”**

In this article, the authors discuss the ethical challenges raised by the use of digital technologies for schizophrenia management. Based on a descriptive review of the literature, the authors identify and reflect on several ethical issues, including confidentiality, the impact of technologies on self-perception and the effect on several aspects of patient-doctor relationship (e.g. fidelity, respect of autonomy, and more). Of particular interest, the authors discuss the problems related to the lack of validation that many digital technologies developed for schizophrenia management have. This seems particularly problematic especially because the access to such technologies is not always mediated by a doctor especially in the so-called Direct-To-Consumer technologies. Another important topic analysed by the authors is the shift that digital technologies create, whereby patients are increasingly conceived as self-responsible consumers/users, rather than vulnerable subjects in need of care. In conclusion, authors call for the upmost cautiousness with respect to extensive use of digital technologies in the treatment of psychiatric disorders.

Chivilgina O, Elger BS, Jotterand F. Digital Technologies for Schizophrenia Management: A Descriptive Review. *Sci Eng Ethics* 2021;27(25). doi: [10.1007/s11948-021-00302-z](https://doi.org/10.1007/s11948-021-00302-z)