Health research with data and biosamples in a time of privacy: what information do patients want?

Miriam Beusink\textsuperscript{1} Folkert Koetsveld\textsuperscript{2} Sonja van Scheijen\textsuperscript{2}
Tomas Janssen\textsuperscript{2} Maarten Buiter\textsuperscript{2} Susanne Rebers\textsuperscript{1} Marjanka Schmidt\textsuperscript{1}

\textsuperscript{1}Health-RI, The Netherlands, Netherlands Cancer Institute, The Netherlands, Netherlands Cancer Institute, The Netherlands,
\textsuperscript{2}Netherlands Cancer Institute, The Netherlands

The Global Health Network

URL: https://tghncollections.pubpub.org/pub/quchrhnt
License: Creative Commons Attribution 4.0 International License (CC-BY 4.0)
Background: Patients value transparency concerning the potential use of their clinical data and samples in research. However, it is usually impossible to indicate for which future studies they will be used. To ensure patients will receive the information that they need, and to safeguard the continuation of trust in research, it is essential to investigate what patients consider to be an adequate type and level of information and transparency.

Methods: We used a mixed method design (questionnaires and interviews), investigating the preferred information level of cancer patients in a cancer hospital between January-March 2020.

Results: Seventy-one radiotherapy patients filled out the questionnaire (response rate 62%), and 24 patients were interviewed. A part of the participants indicated that they would be sufficiently informed by either being notified that data could be used for research, or by receiving a general brochure before being asked for consent. However, a minority of patients also wanted to receive additional information later in time, outlining research that has been carried out. Others stated that more information (additional to general information) would be interesting, but not required in order to feel properly informed. When bringing up that increased specificity of information would also require increased resources, most patients lowered the bar of what they considered minimally required, voicing that it is more important that resources are spent on research. Patients considered data protection the most important topic to be informed about.

Conclusion: Patients indicated they need general information about use of their data in research. Additional, detailed information about the research that is completed (provided afterwards) was not deemed necessary to feel properly informed, though appreciated.