

Donors should have access to their own raw data provided to biobanks

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Scientists have called for data held in biobanks to be made accessible to the people donating material and data to them. In a paper published today in *Science*, Jeantine Lunshof and George Church from Harvard Medical School and Barbara Prainsack from King's College London write that donors should have unrestricted access to data derived from their own material and that advanced technology means allowing such access is today a question of will rather than feasibility.

Databanks containing information and [biological materials](#) from individuals are a crucial resource for medical and other research. Currently, [data](#) held in such biobanks are accessible only to researchers and not to the individuals who contributed the samples and data. Lunshof, Church and Prainsack argue that people donating material and data to biobanks should also have access to their own [raw data](#).

Prainsack, reader (associate professor) in the Department of Social Science, Health & Medicine at King's, said, "We believe there are compelling ethical reasons for enabling donors to access the raw data derived from their material deposited in any kind of repository. Providing access to the data that are derived directly from the sample, before analysis and interpretation, recognizes the donor's agency in at least three ways: freedom to decide (if they wish to access data), option of independent analysis and informed decision about participation.

"Although we use biobanks as an example in our paper, our argument is applicable in principle to all contexts of database-based research. There

is a crucial difference between providing access to data and returning findings. The possibility for research participants to access their raw data is a basic requirement for a just and reciprocal relationship, establishing at least a basic symmetry between those who donate and those who use data for their research."

Lunshof, Marie Curie Fellow in the HMS Department of Genetics and assistant professor in the VU University Amsterdam Department of Molecular Cell Physiology, said, "There is currently a rich debate about what results from data and sample analysis should be returned to participants. In addition to that, individuals should be able to access their raw data right from the start.

"These data—which should be available for people to download themselves, if they choose to do so—could be used by biobank participants to have independent analyses done, to analyse these data themselves or to store them in case they may become useful for personal decision-making in the future. Given that web-based technologies are regularly available to enable such access without incurring high additional cost, providing access to people's own raw data is a matter of will more than of feasibility."

In their paper, the authors neither expect nor suggest that all participants in a biobank will make use of an opportunity to access their raw data, but they assert that the principle of having such an opportunity will be an important step toward greater reciprocity in the relationship between biobanks and their participants.

Prainsack said, "It is clear that giving donors access to their raw data is essential to taking individuals seriously as partners in research, not merely as sources of sample and data."

More information: "Raw Personal Data: Providing Access," by J.E.

Lunshof et al. *Science*, 2014.

Provided by Harvard Medical School

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