

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *The linking and use of biological and health data* between 17 October 2013 and 10 January 2014. The views expressed are solely those of the respondent(s) and not those of the Council.

Consultation question 1:

Do biomedical data have special significance?

First of all, it is important to give a clear definition and aim of collecting biological data, which can be understood by lay people, non-specialists. There should be some reliable guarantee to ensure people, that their data will not be used in improper way.

Human biomedical data have special significance because they concerns human beings and that is why should be distinguished from animal bio-data or other organic data.

Human biomedical data reveals the history of a certain person, history his or her lifestyle, cause of disease and sometimes cause of death. This fact makes human biodata intrinsically very special and that is why they should be protected in a special way.

Genomic data are even more special because they reveal possible future inclinations, diseases and features of offspring. And because of this reason, usage of genetic data should be consulted with family members.

Consultation question 2:

What are the new privacy issues?

Donors of biomedical data are not sure, how their information will be used. Some people do not want to disclose any information about their personal diseases and details from their lifestyle, as they are afraid that in some occasion that data can be used against them. After giving consent do they have some control over the usage of their data? It might be profitable to treat data as a property, as it will strengthen researchers' responsibility for bio-data usage.

Consultation question 3:

What is the impact of developments in data science and information technology?

“Big data” term needs a better definition and description of ways of their protection.

Consultation question 4:

What are the opportunities for, and the impacts of, use of linked biomedical data in research?

Donors of bio-data do not know who will have the direct and indirect access to their information. They may give consent to one researcher and do not agree for using their data by another. Data donors have right to know the results of research, in which they participated.

Consultation question 5:

What are the opportunities for, and the impacts of, data linking in medical practice?

Bio-data are expected to have impact on improvement of future medical treatment, diagnosis making and innovation of medicines. Patients in high-risk should be informed and offered appropriate treatment and support. Researchers have moral obligation to inform participants about such risk.

Information and benefits gained from collected bio-data should be used for common good (for entire society, not only for bio-data donors).

Consultation question 6:

What are the opportunities for, and the impacts of, using biomedical data outside biomedical research and health care?

Bio-data cannot be used to harm their donors (for example in work recruitment or any other competitive ways). Donors should have the knowledge about the ways and purposes of using their bio-data. However, bio-data should not be object of buying or selling by anyone.

Consultation question 7:

What legal and governance mechanisms might support the ethical linking and use of biomedical data?

The aim of collecting bio-data is to apply results for the common good, public benefit. That is why the principle of solidarity is crucial here. At the same time, the principle of donors' property right should be respected (the right to control, how bio-data are used and the right to withdraw the consent). Legal and governance mechanisms should protect donors from misuse of their data.