

A Proposal for Biobank Data Protection

A H M Saifuddin

MSc student, Biomedical science (oncology), Università degli Studi dell'Insubria, Italy

***Corresponding Author:** A H M Saifuddin, MSc student, Biomedical science (oncology), Università degli Studi dell'Insubria, Italy. Email: ahm.saifuddin11@gmail.com, ahmsaifuddin@studenti.uninsubria.it

The intended uses of biobank data are research, diagnostic, therapeutic and forensic. To extent biobanks collect, store and/or process human biological material, in combination with other form of personal data, including sensitive data such as genetic and health data [1]. Although nonhuman materials collections such as plant, animal, microbe and other may also be described as biobanks but in some discussions the term is reserved for human specimens [2]. Legislation, ethical and social issues for biological specimens are remarkably different. Among other challenges one important issue in biobank is confidentiality of participant's data.

Our knowledge is facilitated by technology as well as limited by technology also. In this scientific age, today we have the technology for generating lots of data in lab experiment. Problem arises sometimes when we want co-ordination of data and/or data management for future research. That's why scientific research requires developing new concept in order to overcome the challenge and proper research outcome. On 22nd November 2018, when one of my professor was delivering her lecture on biobank data privacy and talking it can be established within academic, medical, research institute, pharmaceuticals/biotechnological companies or stand alone organization. However, for biobank establishment, large amount of donated human sample (e.g. tissue, cell, body fluid, DNA/RNA) requires to identify the genetic basis of common complex disease. That moment I was thinking something different about data protection, as lot of volunteer need for such

research and privacy is one of the important concerns regarding such research. What about the card system for data protection regarding this type of research?

My proposal is simple and maybe we can launch such system without so many complexities. "If I compare the health insurance card with bank card, which has the password for withdrawing money from ATM booth. For doing biobank research we can provide individual card to the participants, where all information will input, but data will be protected by PIN code or finger print of participants".

I thought in such way, this is because loss of privacy of personal information and/or research data can cause psychosocial problem to participants and/or may challenge the morality of biobank research. When participants feel transparency of his/her data is secured by them, this will motivate more people to enroll in biobank. Secondly, a participant to enroll in biobank, participation is voluntary and participants have the right to withdraw consent. However, if we can launch such system may help to reduce legislation problem, as card will be return to the volunteer after data interpretation.

REFERENCES

- [1] The EU general data protection regulation. Answers to frequently asked questions 1.0. Prepared by the BBMRI Common Service ELSI. May 1, 2016. Page: 4.
- [2] <https://en.wikipedia.org/wiki/Biobank> (Accessed on 30th December 2018)

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