

# Traceability as a means in data protection of research Biobanks

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## Abstract

IT is a critical tool for data storage, acquisition and analysis; however the approach in different biobanks varies. Pseudoanonymization on the other hand is a means for exchanging a range of personal identifier for an indirect identifier, which is usually a code key. However even a code key is not sufficient to dissociate the data and the sample, consequently the donor, due to the fact that other indirect information, such as place, collection time or DNA, could make the sample identical. Thus a coding system is required and different levels of security related to code keys should be in place. In the proposed system the type of donor's consent is taken into account in order to define the different access levels to the data base. A special provision should also be taken in case the donor wishes not to be informed of incidental health findings. The more specific is the given consent the less autonomy is provided regarding the possible sample uses. The architecture of the system is based on a traceability system, where permissions to operators wishing to follow back the sample origin, is given according to their role in the sample treatment and the donor's given consent.

**Key words:** Biobanks, Genetic, Data, Security, IT, Donor, anonymisation, Filemaker, WebDirect