Collaborative international research on biomaterial in the age of Web 2.0

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Abstract

We propose a research infrastructure allowing participating biobanks and partners to manage, annotate and exchange sample stock among each other. Descriptive attributes are maintained utilizing a set of categorized annotations dynamically expandable by the users using Web 2.0-inspired techniques, thus covering any of the otherwise isolated individual and specialized annotation sets. A free, modular open-source client will allow to manage sample stock as well as to contribute to the infrastructure. The client can be used on multiple machines by several users simultaneously. Rights management allows delegating tasks, and automatic import of existing data is supported as well as secure online backup. The presented system will connect researchers from different fields of research by uniting their isolated and fragmented data and sample stock in a comprehensive, user-centric database to the benefit of international research and the patients.

Keywords:

Biobanks, Web 2.0, Medical informatics computing, Information storage and retrieval, Online systems

Describing and mediating samples

Biobanks are operated in order to store organic raw material such as tissue or blood for further research. Existing biobank networks allowing the exchange of samples are usually tailored to specific institutions, mostly pathologies, making them unsuitable for users from other fields of research or departments. We address biobanks unable to participate in a network so far: small and middle-size biobanks as well as those focusing on research fields too specialized to be adequately covered by existing networks. Such institutions often have not participated in biobank networking before although they would benefit from sample exchange and hold valuable specimens themselves.

Instead of defining a fixed catalogue of annotations to describe samples, we hand that responsibility over to the biobanks, empowering them to solve the problem themselves: We propose a set of categorized attributes pre-filled with those required by the initial participants and then gradually extended by the research community. Similar to Web 2.0 portals driven by user collaboration, participants work together not only in creating but also in rating attributes by either using or rejecting them, thus reducing the effect of redundantly created attributes. A generic form creator allows for an easy transition from paper-based documentation.

A participant may choose freely which biobank networks to take part in. For instance, a network may require its participants to sign contracts or pay fees for services such as sample browsing and mediation. To help evaluating whether a service is worth its cost, methods for the exchange of experiences are evaluated as well as an automatic recommendation system.

Data security and data protection

A generic data protection concept for biobanks developed by the "Telematikplattform für Medizinische Forschungsnetze" (TMF) proposes that annotations be categorized into several data classes (e.g. data covering a sample's analysis, a sample's organizational data, a donor's medical context data or a donor's identifying data). These data classes must be stored and maintained strictly separated both physically (i.e. different servers in different datacenters) and organizationally (i.e. separated responsibilities). In order to comply with the participants' individual data protection policies, the proposed system distributes and collects its data stock automatically based on user-defined categorizations.

The biobank permanently stays in full control of its samples and annotations: It chooses which partners to collaborate with, which annotations to enter and to whom to reveal its identity. The client will be developed open-source not only to establish trust, but also to allow for easy community-driven modifications via a central module repository.

Progress

Planning and development is intensely brought forward in collaboration with one of the largest university pathologies in Germany (University Hospital of Münster) as well as with all 16 competence networks focusing on rare diseases which are funded by the German Federal Ministry of Education and Research.