

Publication

Sample and data sharing barriers in biobanking : consent, committees and compromises

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The ability to exchange samples and data is crucial for the rapidly growth of biobanking. However, sharing is based on the assumption that the donor has given consent to a given use of her or his sample. Biobanking stakeholders, therefore, must choose 1 of 3 options: obtain general consent enabling multiple future uses before taking a sample from the donor, try to obtain consent again before sharing a previously obtained sample, or look for a legally endorsed way to share a sample without the donor's consent. In this study, we present the results of 36 semistructured qualitative interviews with Swiss biobanking stakeholders regarding these options and the role of ethics committees in the process of authorizing sharing. Our results show that despite a lack of legal or guideline-based barriers to general consent, some stakeholders and ethics committees have reservations about this method of consent. In most cases, however, a general consent form is already in use. Many interviewees describe processes involving the ethics committees as time-consuming and cumbersome and their requirements as too demanding for donors/patients. Greater awareness of donors' opinions and preferences and the content of guidelines and recommendations could therefore be helpful for a better justified perspective of biobanking stakeholders and ethical committee members, equally. Finally, it may be necessary to differentiate between procedures governing future samples, where general consent is clearly desirable, and the use of old yet still relevant samples, where the option of using them without consent can be highly beneficial for research.

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