

The BIO-PIN paradigm: 'access to' or 'return of' results?

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With the increasing importance of biobank infrastructures for research, new ways to deal with personal data are being developed. The 'Bio-PIN' as proposed in the recent article by J. J. Nietfeld, Jeremy Sugarman and Jan-Eric Litton (The Bio-PIN: a concept to improve biobanking. *Nature Rev. Cancer* **11**, 303–308 (2011))¹ uses genotype identification of biological samples from participants to establish a coding system that guarantees the privacy of the donors of specimens to biobanks. The Bio-PIN exemplifies an important shift in thinking about biobanking: biobanks should no longer return results to donors (which is practically unsustainable for biobanks and might also be undesirable for donors in the long term) but should instead allow donors access to results by providing donors with a means to check the kind of research that has been or will be done with their sample and also the ability to check the (individual) results of this research.

The Bio-PIN contributes to the debate about the governance of biobank infrastructure, but it is also a technique with a central flaw that is connected to the paradigm shift from return of results to access to results. The Bio-PIN is firmly based in the protection of the privacy of donors, but as a consequence the biobank cannot contact the donors: "A biobank using the Bio-PIN system is dependent on the willingness of the depositors to contact the biobank" (REF. 1). We think that this is undesirable as it is important for biobanks to be able to contact donors — for research purposes, for example — for updates of disease history or for confirmation of information, and for donors themselves — for example, in the case of severely life-threatening but curable incidental findings. In the case of a one-time contact and truly anonymous data this would be impossible; however, in principle, this is all the Bio-PIN allows. Moreover, unless donors have a relationship with the biobank (such as the relationship of patients with their treating physician and the hospital) we find it difficult to believe that donors could be easily evoked to submit additional information to the biobank on their own account.

The guiding document for research with human tissues in the Netherlands is a self-regulatory Code that was drafted by the scientific community in cooperation with patient organizations². The Code distinguishes between biobanks that store residual biospecimens — for example, the tissues or blood of patients that are preserved for potential future care — and 'de novo' biobanks that store the biospecimens of donors that were collected especially for research. According to this Code, biobanks that store residual biospecimens have patient care as their first and foremost goal, implying that these biobanks should always be able to seek contact with patients.

Another problem with the Bio-PIN, which the authors do not touch on, concentrating on the technique itself, is that it is still to be determined how donors want or can have access to their data and results. Considering the ongoing debate about which genetic research results should be returned and the possible benefits or harm of such disclosure³, we believe the access of donors to computerized scientific data (about themselves) without including some form of personal contact (for example, for the interpretation of data or counselling) is disputable.

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doi:10.1038/nrc3022-c1

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Competing interests statement

The authors declare no competing financial interests.