Strides forward in biobanking ethics

The Comment by Jonathan Ashcroft and Cheryl Macpherson[1] highlight some important aspects in the ethical application and practice in the field of biobanking. They present the general view (and perhaps implication) that the ethical landscape in biobanking is complex and appears irreducible, and thus hinders the conduct of effective research to the benefit of public health.

The inexorable demand for high-quality, research-ready, and clinically annotated biological samples to support post-genomic and personalised medical research is important to consider. Biobanks offer such an infrastructure to support major medical research milestones. However, the evolution of biobanks has been decentralised, with different national directives on ethical frameworks and data governance and protection rules,[2] and different methods for collection, storage, and use of samples and data. These factors have generated a high level of operational heterogeneity within biobanking, also inevitably reflected in its ethical aspects.[3] The biobanking community has sought solutions that are transparent, are effective, and offer efficient governance structures and procedures for access to available samples and compensation, as well as a framework for priority setting. These solutions involve international agencies (eg, International Agency for Research on Cancer [IARC] and International Organization for Standardization [ISO]) and infrastructures (eg, Biobanking and BioMolecular resources Research Infrastructure [BBMRI] and International Society for Biological and Environmental Repositories [ISBER]) in recognition of the need to adopt best practices and provide scientific, ethical, and legal guidelines for the industry and public health. These agencies strive to take into account the ethical complexities within specific geographical areas or further technical advances, such as clinical imaging banks. This effort has resulted in the ISO standard (20387:2018-Biotechnology; Biobanking), the IARC Common Minimum Technical Standards and Protocols for Biobanks Dedicated to Cancer Research;[4] the BBMRI-European Research Infrastructure Consortium helpdesk for ethical, legal, and social issues, which is the de facto service advising on ethical aspects on biobanking in the EU; and the updated ISBER Best Practices for Biorepositories.[5] Thus, while acknowledging the complexity inherent to the ethics in biobanking activities, there have been some great strides forward achieved collectively in the past 5 years. The implementation of such standards and guidelines is now expected to inform how best to move forward in addressing the ethical challenges in the field.

I declare no competing interests. I alone am responsible for the views expressed here; these views do not necessarily represent the decisions, policy, or views of the International Agency for Research on Cancer or WHO.

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1 Ashcroft JW, Macpherson CC. The complex ethical landscape of biobanking. *Lancet Public Health* 2019; **4:** e274–75.
2 Vaught J. Biobanking comes of age: the transition to biospecimen science. *Ann Rev Pharmacol Toxicol* 2016; **56:** 211–28.
3 Langhof H, Kahrass H, Sievers S, Strech D. Access policies in biobank research: what criteria do they include and how publicly available are they? A cross-sectional study. *Eur J Hum Genet* 2017; **25:** 293–300.
4 Maimuna M, Lawlor RT, Wright J, Wild CP. Common minimum technical standards and protocols for biobanks dedicated to cancer research. 2017. https://publications.iarc.fr/Book-And-Report-Series/Iarc-Technical-Publications/Common-Minimum-Technical-Standards-And-Protocols-For-Biobanks-Dedicated-To-Cancer-Research-2017 (accessed July 29, 2019).
5 Simeon-Dubach D and Kozlakidis Z. New standards and updated best practices will give modern biobanking a boost in professionalism. *Biopreserv Biobank* 2018; **16:** 1–2.

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