

Health commentators say there is a lingering consent problem in biobanking

July 25 2017



Biobanks are going to great lengths to gather human tissues, but there are still questions over whether the consent process is adequate. Credit: Sean Caulfield
Virus #2, silkscreen and digital on drafting film and paper, 24

Researchers throughout the world are going to great lengths to get hold of your genes, tissue and health information. Yet, remarkably, there is very little consensus on how they should be going about doing that. In an essay publishing 25 July in the open access journal *PLOS Biology*, University of Alberta health law researchers Timothy Caulfield and Blake Murdoch argue that there remains a deep lack of clarity around basic legal and ethical principles surrounding consent, and that these issues are only going to intensify.

Indeed, governments, [research institutions](#) and industry have invested billions in the creation of large, complex biorepositories, such as UK Biobank and the US Precision Medicine Initiative. These projects involve promising research and often include hundreds of thousand of research participants. However, despite this investment in biobanking, there are still fundamental and unresolved issues associated with consent and the ownership of samples.

As well, there are numerous social trends—including the rise of a belief in biorights, the increasing involvement of industry, growing concern about privacy and high profile research controversies—that are increasing the policy tensions around this issue.

What is required, the authors argue, is real policy action.

"The international research community has built a massive and diverse research infrastructure on a foundation that has the potential to collapse, in bits or altogether. This issue would benefit from more explicit

recognition of the vast disconnect between the current practices and the realities of the law, research ethics and public perceptions," said Caulfield.

More information: Caulfield T, Murdoch B (2017) Genes, cells, and biobanks: Yes, there's still a consent problem. *PLoS Biol* 15(7): e2002654. doi.org/10.1371/journal.pbio.2002654

Provided by Public Library of Science

Citation: Health commentators say there is a lingering consent problem in biobanking (2017, July 25) retrieved 26 April 2024 from <https://phys.org/news/2017-07-health-commentators-lingering-consent-problem.html>

This document is subject to copyright. Apart from any fair dealing for the purpose of private study or research, no part may be reproduced without the written permission. The content is provided for information purposes only.