Response to Patryn and Zagaja

To the Editor: We appreciate the opportunity to respond to the letter by Patryn and Zagaja[1] regarding our publication on participants' perspectives on broad consent and data sharing for biobanks.[2] Patryn and Zagaja raise an important issue regarding informed consent in biobanking. They propose that participants be told about time restrictions on how long biospecimens will be retained for research as a key part of obtaining an appropriate understanding regarding consent for their samples to be banked for research.

Our article described an empirical review of participants' views and opinions on broad consent for data sharing. Most of the articles we reviewed—all of which were published after 2000—did not address time restrictions for donated biospecimens. Therefore, we did not explicitly look at time as an important element, although we agree that time limits should be explicitly communicated to participants who are considering participating in a biobank so that they have the understanding to make an informed decision. For many biobanks, it is increasingly common to seek broad consent for use for an unlimited period of time. However, many participants in our review indicated an interest in being kept informed of the type of research being conducted by the institution, even if they did not see a need to be reconsented for new research.

Patryn and Zagaja propose the concept of perpetual usufruct, which would include a terminal clause with time restrictions on storage and usage of genetic material. We note that the current proposal to amend the research regulations in the United States would require the consent to use biospecimens to be renewed no less frequently than every 10 years.[3] Including a time restriction would achieve Patryn and Zagaja's fuller understanding of informed consent. While an obvious disadvantage of time limitations is not being able to use the sample at the end of a specified time period (i.e., 10 years), such limits may lead to greater public trust in research, a possibility that would need to be assessed empirically.

DISCLOSURE

The authors declare no conflict of interest.

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