Awareness of risks of biobank research may affect public attitudes toward consent

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In their recent paper, Botkin et al. (2014) contribute much-needed data on public attitudes toward genetic research and the use of residual tissues for scientific research. Informed consent is a critical factor affecting public acceptance of biobanks for genetic research. The authors claim, “biobank-dependent research has been safe, with no published reports, to our knowledge, of harm to individuals from breaches of privacy or confidentiality.” This premise is used to justify the researchers’ decision to present the opt-out consent model to participants as the “preferred” consent model, with which focus group participants can disagree if they so choose.

Yet, there exist at least two cases in the literature in which research participants perceived themselves harmed through breach of privacy in biobank-dependent research. One is Beleno et al. v. Texas Department of State Health Services, in which bloodspots from newborns were placed in a biobank for future genetic research without parental consent (Carnahan 2011). In this case, the plaintiffs objected to the non-consensual seizure and storage of genetic material. They argued it should be a parent’s decision whether their infant contributes to a biobank, and that the banking of samples without consent constituted unreasonable search and seizure (Carnahan 2011). The

case was settled out of court when the State agreed to destroy over four million banked blood samples and disclose all financial transactions involving the samples (Carnahan 2011).

Another case of perceived harm resulting from biobank research is Havasupai Tribe v. Arizona State University Board of Regents, in which genetic material taken from Havasupai tribe members, with consent for the purpose of studying diabetes, was used to study schizophrenia, alcoholism, and inbreeding. This was done contrary to participants’ wishes and without consent (Mello and Wolf 2010). This case, too, was settled out of court when Arizona State University Board of Regents agreed to compensate the Havasupai \$700,000, return all blood samples in the university’s possession, return all documents containing research derived from those samples, terminate IRB approvals for all existing and new research using the samples, and provide a list of entities to which samples had been transferred (Drabiak-Syed 2010). Sources of perceived harm in this case include the use of genetic materials for research without consent, and encroachment on the tribe’s privacy, dignity, and culture (Drabiak-Syed 2010).

At this time, no consensus exists on the appropriate consent model for biobanking (Master et al. 2012). Yet, Botkin et al. (2014) chose to inform study participants of their own “clear preference for the opt-out approach”, and openly acknowledged that in doing so they “almost certainly influenced the results” in favor of opt-out consent. This omission of pertinent information regarding perceived harm from biobank-dependent research may have introduced a significant bias to the study. Evidently, a “lack of published cases of harm due to breach of privacy or confidentiality” was a tenuous justification for the authors’ decision, in light of published instances in which participants perceived violation of these rights to such an extent that they filed suit against researchers.

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Compliance with ethics guidelines Sean Nurmsoo and Molly Hayes declare that they have no conflict of interest. This article does not contain any studies with human or animal subjects performed by the any of the authors.

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