

## Public attitudes regarding the use of electronic health information and residual clinical tissues for research

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Dear Editor,

We appreciate the comments by Drs. Nurmsoo and Hayes regarding our work on public attitudes on the use of electronic health information and biospecimens for research. They take issue with our contention that “biobank-dependent research has been safe, with no published reports, to our knowledge, of harm to individuals from breaches of privacy or confidentiality.” They reference the controversies over research use of residual newborn screening samples and the Havasupai case as counter-examples.

Our research group has done extensive work on the issue of research use of residual newborn screening specimens (Botkin et al. 2014 Nov; Botkin et al. 2013; Botkin et al. 2012) and the Havasupai case has been extensively discussed in the literature. (Mellow and Wolf 2010) The question raised by Nurmsoo and Hayes is whether these cases represent harms to individuals involving breaches of privacy or confidentiality. We contend that they do not. To our knowledge, none of the plaintiffs in the Texas or Minnesota lawsuits demonstrated individual harm from research uses of residual NBS specimens. Similarly, we

are not aware of any individuals in the Havasupai tribe who alleged individual harm from the secondary use of samples.

Of course, this assessment hinges on what we consider to be “harm” in these contexts. Our contention is that the notion of individual harm does not capture what might be ethically inappropriate in these two cases. We would contend that the individuals in these cases may have been wronged but they were not harmed in a tangible sense.

Nevertheless, should our participants have been told of such cases to illustrate other kinds of risks related to biobanking? The purpose of our research, and a central element in the focus group discussions, was that medical records and biospecimens are commonly used in research without the knowledge or consent by the source individuals. So while the newborn screening and Havasupai cases were not raised as illustrative of risks, the concerns these cases raise were the primary focus of the conversation. For the most part, our participants felt that the “opt-out” approach was adequate to alert patients that their data and tissues might be used for secondary purposes and it permits individuals to decline permission for such uses.

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