

# ETHICS FIRST

## PRIVACY, CONSENT AND DIGITAL DATA

Ethical questions and concerns have emerged with the evolution of the digitisation and sharing of data and the growing use and archiving of biomarkers. Privacy and consent are at the heart of these issues. Research practitioners can accommodate these issues by addressing them in early design stages:

**1. PRIVACY AND SECURITY:** Are controls on accessing online data sufficient, particularly given the push to adopt the open-source approach to data, releasing it to no-holds-barred access? Are data ‘anonymised’ adequately so that, if they are released into the public domain or otherwise shared, participants cannot be identified? If access is to be widened but controlled, have study leaders put in place an adequate permission system? This could range from limiting access to those with online passwords, to requiring permission from a security or ethics committee.

**2. CONSENT:** With older studies stretching back as far as the 1940s, the issue of consent regarding long-term use of participants’ survey responses raises difficult privacy concerns. “We need to think about how to deal with fair sharing of data from older studies, which have been supported by different donors, where we can’t reach all the participants,” said Susan Luczak of University of Southern

California, a researcher working with the Mauritian Joint Health Project.

And what about people who unwittingly joined a survey in infancy, with their parents giving researchers permission to study their child? What happens when, as adults, such participants withdraw permission and all their data from the study?

Finally, how can biomarkers be preserved indefinitely, for future study, particularly in low-income settings with few resources available for archiving? Can individuals really provide consent today for unknown uses of their samples in the distant future?

The Global Longitudinal Research Initiative (GLORI) aims to support the adoption of standards for dealing with these sensitive issues while promoting the fullest possible use and sharing of innovation in all aspects of conducting longitudinal studies.



The Global Longitudinal Research Initiative (GLORI) aims to improve the practice and use of longitudinal methods and evidence. Read the full report of the October 2014 Symposium that inspired GLORI's formation at [www.unicef-irc.org/knowledge-pages/Symposium-on-Cohorts-and-Longitudinal-Studies-2014/1088](http://www.unicef-irc.org/knowledge-pages/Symposium-on-Cohorts-and-Longitudinal-Studies-2014/1088). To learn more about GLORI, read *Strength in Numbers: How longitudinal research can support child development* at [www.UNICEF-irc.org](http://www.UNICEF-irc.org)