

Parent Perspectives on Privacy and Governance for a Pediatric Repository of Non-Biological, Research Data

Journal of Empirical Research on
Human Research Ethics
1–12
© The Author(s) 2014
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/1556264614564970
jre.sagepub.com


Kiran P. Manhas^{1,2}, Stacey Page², Shawn X. Dodd², Nicole Letourneau²,
Aleta Ambrose³, Xinjie Cui¹, and Suzanne C. Tough^{1,2}

Abstract

Research data repositories (RDRs) are data storage entities where data can be submitted, stored, and subsequently accessed for purposes beyond the original intent. There is little information relating to non-biological RDRs, nor considerations regarding pediatric data storage and re-use. We examined parent perspectives on pediatric, non-biological RDRs. Qualitative, descriptive methods including both interviews and focus groups were used. Purposive sampling of adult participants in two provincial birth cohorts yielded 19 interviewees and 18 focus group participants (4 groups). Transcripts were analyzed by thematic content analysis. Parent research participants strongly supported the sharing of their own, and their child's, non-biological research data. Four themes emerged: that altruism has limits, that participants have ongoing privacy concerns, that some participants need the assurance of congruent values between themselves and researchers/research questions, and that opinions diverge for some governance issues. The establishment of RDRs is important and maximizes participants', researchers', and funders' investments. Participants as data donors have concerns relating to privacy, relationships, and governance that must be considered in RDR development.

Keywords

governance, privacy, data sharing, parents, non-biological data, repository, pediatric, stakeholder, ethics

An ever-increasing amount of health research is being undertaken. In the medical humanities and social sciences, electronic data capture and storage mediums have facilitated the collection of vast amounts of information. In the biological sciences, research including genomics and pharmacogenetics is made possible by the availability of bio-banks and tissue repositories. Research data repositories (RDRs) are data storage centers where both non-biological and biological research data can be submitted, stored, and subsequently accessed for purposes beyond the original intent (i.e., secondary uses).

Worldwide, funders and custodians of public research encourage, if not mandate, the sharing of research data (Committee on Transborder Flow of Scientific Data, National Research Council, 1997; Medical Research Council, 2011; National Institutes of Health, 2003; Social Sciences and Humanities Research Council, 2012). The recognized benefits of secondary data use, defined as the use of data previously collected to address a new research question, are numerous. Such benefits include (a) increased diversity, novelty, and complexity of research opportunities thereby exhausting analysis potential; (b) cost savings through economies of scale to benefit the public, funders, researchers, and trainees; (c) lessened risk of not discovering key findings in

the data; (d) promotion of intra- and inter-disciplinary research allowing multifaceted analysis; (e) maximization of research participants' contributions by fully utilizing the data; (f) lessened future research and respondent burdens; and (g) validation of previous work (Canadian Institutes of Health Research, 2011; Medical Research Council, 2011; National Institutes of Health, 2003; Office of the Information and Privacy Commissioner for British Columbia, 2012; Organization for Economic Co-Operation and Development, 2007; Social Sciences and Humanities Research Council, 2012). Collectively, these benefits reflect savings in time and money across stakeholder groups (i.e., participants, investigators, and funders). Once desired data are collected, they need not be collected again.

¹Alberta Centre for Child, Family & Community Research, Calgary, Canada

²University of Calgary, Alberta, Canada

³Alberta Health Services, Calgary, Canada

Corresponding Author:

Kiran P. Manhas, Alberta Centre for Child, Family & Community Research, Child Development Centre, c/o 2888 Shaganappi Trail NW, Calgary, Alberta, Canada T3B 6A8.
Email: kmanhas@ucalgary.ca