

Curating Risk, Mediating Access: mapping the legal, policy and organizational context of data sharing in the health sciences

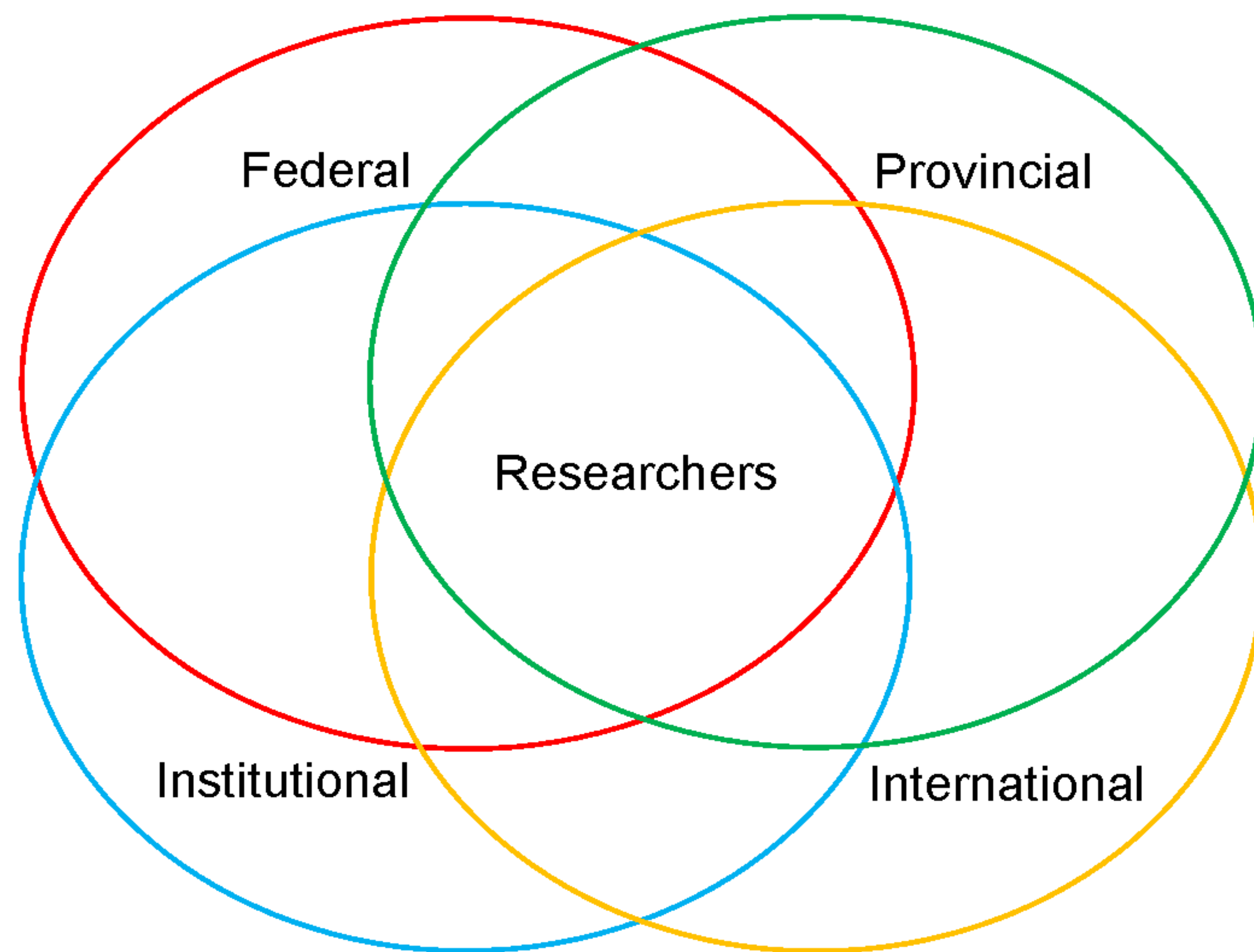


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Health Research Data Landscape

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Project Description

The purpose of the Curating Risk, Mediating Access (CRMA) project is to investigate practices, norms, policies, and infrastructure in clinical and health research that relate to sharing research data.

The objectives are two-fold:

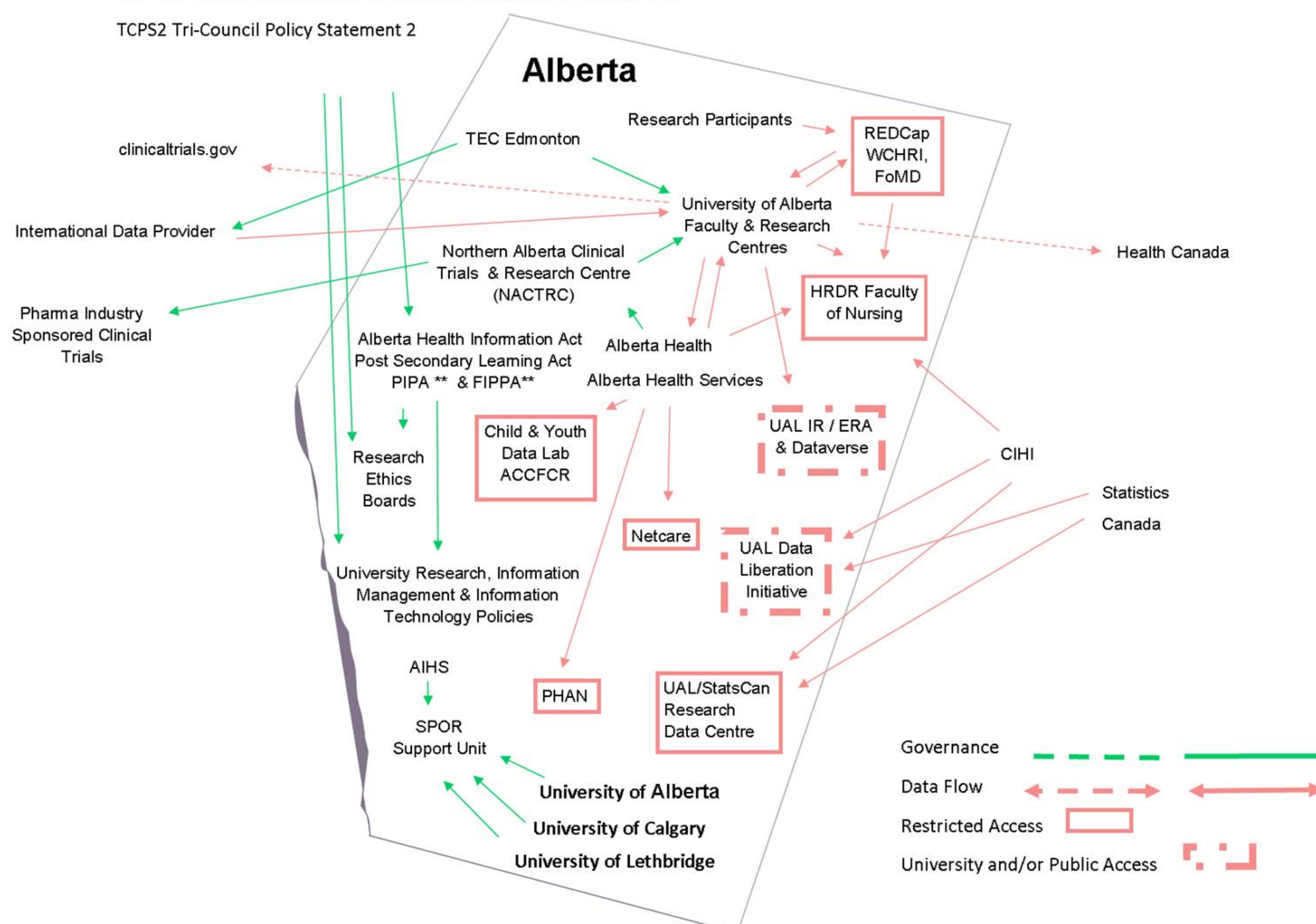
- 1) to map the current legal, ethical, and normative practices across the clinical and health research lifecycle that affect access to and the sharing of confidential health data; and
- 2) to examine the possible application of privacy-enhanced data sharing protocols for clinical and health research, given the results of the mapping exercise.

Context of Data Sharing

Canadian Human Rights Act
Canadian Charter of Rights & Freedoms
Privacy Act
National Standard of Canada Model Code for the Protection of Personal Information
PIPEDA Personal Information Protection & Electronic Documents Act
TCPS2 Tri-Council Policy Statement 2

Health Research Data Landscape

Preliminary mapping—University of Alberta



Methodology

A mixed-methods approach will be utilized to map out the current legal, policy and organizational environment for clinical and health research; collect model policy interventions, guidelines and services; evaluate these interventions and services in collaboration with a number of stakeholders including researchers, data managers and analysts, ethics and privacy officers, and patient advocates.

Methods:

- semi-structured open-ended interviews
- workflow mapping
- participant observation
- online survey instrument

Call for Participation

If you are researcher involved in health science related work, I would like to invite you to participate in a research study about the impact of data sharing practices, norms, policies, and infrastructure in your field. Interviews will take approximately one hour of your time. Researchers at all stages of their career are encouraged to participate (graduate, postdoc, faculty and other positions involved directly in the research process). The goal of this study is to document and contribute to interdisciplinary knowledge about the impact of emergent research practices and forms of data governance. If you would like to participate or find out more about this project, please contact the principal investigator Kendall Roark, roark@ualberta.ca This research project has been approved by the University of Alberta Research Ethics Board and is being conducted as part of a CLIR/DLF Postdoctoral Fellowship project in Data Curation with the University of Alberta Libraries.