

The Ethics of Ownership: Developing Guidelines on Data Ownership in Participatory Research



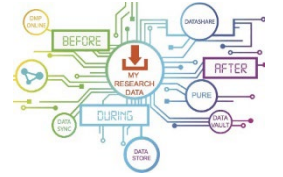
THE UNIVERSITY
of EDINBURGH

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Library & University Collections

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A Long Time Ago in a Galaxy Far, Far Away...



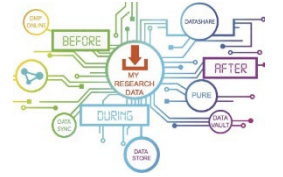
We Got an Email:

- Who owns the data?

Mad Studies?

[A] field of scholarship that brings together theory, activism and creativity, drawing on the lived experiences, thinking, history and politics of people who variously identify as mad, psychiatric survivors, mental health consumers/service users/patients, voice hearers, plural/multiple, neurodiverse, and/or disabled (this list is always expanding).

International Mad Studies Journal.



It's... Complicated

Ethical and Legal Issues in a Co-Creative Environment

- Power differentials
- Meaning of terms, e.g., integrity, transparency

Effect Understanding of

- Ownership of co-created outputs, e.g., data

This is where the story really starts!



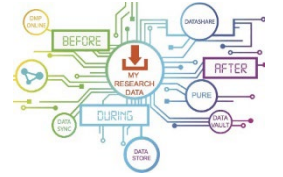
What Are We Talking About, Exactly?

What Does 'Ownership' Mean?

- Access
- Control
- Compensation

Potentially Competing Interests:

- Researcher: publications, citations, contribution
- Co-creators: subject interest, contribution, career goals, personal development



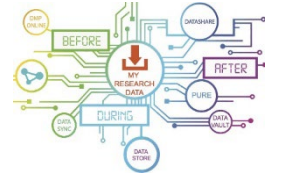
A Solution?

Academic Collaboration

- Contract / Data Sharing Agreement

Legal Instruments Disadvantage Actively Involved Participants

- Reinforce power differentials
- Discourage Involvement



So What's The Answer?

Full Participation Requires Discussion

- **All** Co-Creator interests/expectations
- Data access and control

Intervention Point: Open Science Training & Awareness

- Requirements
- Tools and techniques
- Infrastructure

And this is where the story really starts!



The CARE Principles

The Global Indigenous Data Alliance

- Indigenous Peoples: data rights/interests

C – A – R – E

- **C**ollective Benefit: Supporting Community Use & Re-use of Data
- **A**uthority to Control: Recognising Rights & Interests
- **R**esponsibility: Trust & Mutual Understanding; Enhancing Data Literacy
- **E**thics: Representation, Justice, Acknowledgement



A New(ish) Foundation

Researcher/Participant Relationship

- Philosophical Anthropology
- What does it mean to be human?

Western Rationalist Epistemic Model

- Observer Paradigm
- Subject/Object Dichotomy

Now, this is where the story really starts!

Ceci N'est Pas Un Horse





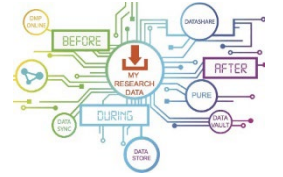
What Do We Know?

Step 2: Epistemology Becomes Ontology

- What something does tells me what it is
- Action is bi-directional

Step 3: Ontology

- Knowledge is a communally constituted act and so am I
- We are not self-made, we are co-created
- We learn to think, speak and write



A Definition & An Ontology

Human Being:

- Creative participation in development of another human being

Ontologies of Reciprocity

- Rebuts subject/object dichotomy
- Researcher is NOT objectively real subject
- Research Subject is NOT object of study

Researcher + Participant = Mutually Dependent Inter-Agents



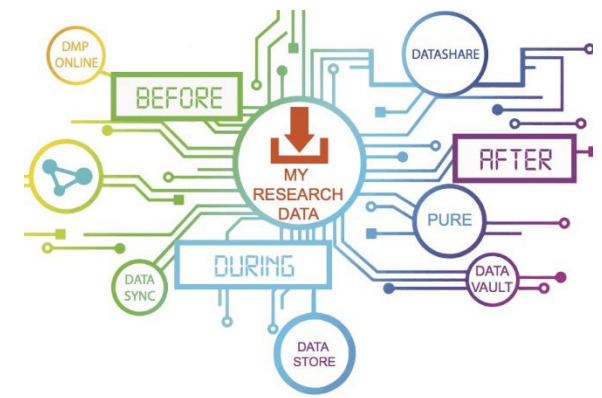
But What Does It All Mean?

‘Being CARE Full is a prerequisite for equitable data and data practices.’

Carroll, S et al. ‘The CARE principles for Indigenous data governance’

Ontologies of Reciprocity underpin CARE Principles

- Collective Benefit: individual AND mutual benefit
- Agency: active involvement in EVERY project stage
- Responsibility: respect, trust, mutual understanding
- Ethics: acknowledge and respond to human situation



This is where the story really starts!

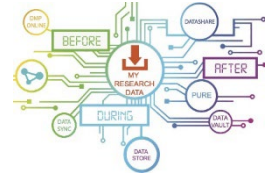
Thank You

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