

 UNIVERSITY OF ALBERTA
FACULTY OF MEDICINE & DENTISTRY

Clinical Research Seminar Series
November 22, 2017


SAGE: Collaborations through Data Sharing

Hannah Lloyd-Jones

 UNIVERSITY OF ALBERTA
FACULTY OF MEDICINE & DENTISTRY


 NACTRC
Network of Alberta
Translational Research Centres


 women & children's
health research institute


 **Policy Wise**
for Children & Families


SAGE:
Collaborations Through Data Sharing

Hannah Lloyd-Jones
November 22, 2017

 Alberta
Government

 ALBERTA
INNOVATES

 women & children's
health research institute

 Children's
HOSPITAL

POLICYWISE FOR CHILDREN & FAMILIES

Outline

- PolicyWise for Children & Families
- Data Sharing
- SAGE
- Lessons Learnt and Future Plans
- Questions and Discussion

POLICYWISE FOR CHILDREN & FAMILIES

PolicyWise for Children & Families

About Us


PolicyWise for Children & Families exists to improve child, family and community well-being by leading, creating, enabling and mobilizing research and evaluation for evidence-informed policy and practice.



POLICYWISE FOR CHILDREN & FAMILIES

Our Five Core Functions

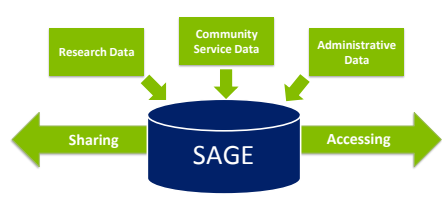
- Undertake research, evaluation, communication, and knowledge mobilization
- Conduct, fund, and build policy-relevant research capacity
- **Link, analyze, and manage data**
- Manage resources and strategic relationships
- Measure and communicate our impact and value



POLICYWISE FOR CHILDREN & FAMILIES

SAGE

(Secondary Analysis to Generate Evidence)



Enable and support use to Inform Policy and Practice

POLICYWISE FOR CHILDREN & FAMILIES

Data Definitions

- **Research data:** "The recorded factual material commonly accepted in the scientific community as necessary to validate research findings." (OMB Circular 110 - US).
- **Administrative data:** Collected for administrative purposes such as registration, transaction and record keeping (Adapted from ADLS - UK). Example: data collected by government ministries.
- **Community service data:** Data collected for the purpose of delivering services. Example: data collected by food banks, emergency shelters.

POLICYWISE FOR CHILDREN & FAMILIES

Question 1

Do you currently use secondary data in your research?

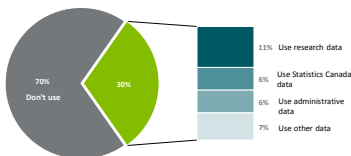
Answers:

1. Yes, research data
2. Yes, administrative data
3. Yes, Statistics Canada data
4. Yes, other data (or a combination of the above types of data)
5. No

POLICYWISE FOR CHILDREN & FAMILIES

Researcher Survey 2016

Do you currently use secondary data in your research?



POLICYWISE FOR CHILDREN & FAMILIES

Question 2

If you collect data for research purposes, do you currently make it available for secondary use?

Answers:

- 1. Yes
- 2. No

POLICYWISE FOR CHILDREN & FAMILIES

Question 3

1. If you do share data, please tell us why.

2. If you don't share data, please tell us why.

POLICYWISE FOR CHILDREN & FAMILIES

What are the benefits of sharing data?

Shout out!

POLICYWISE FOR CHILDREN & FAMILIES

Benefits of Secondary Data Use 1

- Expedites scientific discovery and knowledge mobilization
- Encourages interdisciplinary research and collaboration between different sectors
- Greater return on investment
- Avoids duplication of primary collection
- Reduces burden on clients/participants/individuals (especially vulnerable communities)



POLICYWISE FOR CHILDREN & FAMILIES



Benefits of Secondary Data Use 2

- Ethical (especially for publicly funded data collection)
- Expands the use and value of existing data
- Gain systemic intelligence on performance, outcomes, and impact.
- Potential for linkage and cross-disciplinary analysis with other existing datasets

POLICYWISE FOR CHILDREN & FAMILIES

Funders and publishers want data sharing



NSERC
CRSNG



CIHR IRSC

SSHRC CRSR



SPRINGER
NATURE

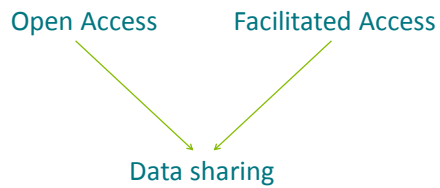
POLICYWISE FOR CHILDREN & FAMILIES

Current Environment



POLICYWISE FOR CHILDREN & FAMILIES

Methods of Data Sharing



POLICYWISE FOR CHILDREN & FAMILIES

What are the barriers to sharing data?

Shout out!

POLICYWISE FOR CHILDREN & FAMILIES

Secondary Data Use Issues

- Ethical and legal issues
- Costs: of cleaning, creating metadata, making data understandable and reusable
- Often larger dataset than for-purpose data collection, but not always the exact data point needed



POLICYWISE FOR CHILDREN & FAMILIES



Ethical Considerations

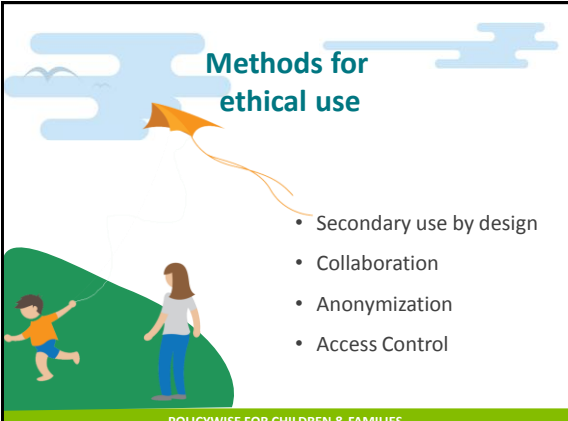
- Need to consent/re-consent
 - Covered in FOIP, HIA, PIPA
 - TCPS 2: Chapter 5, Section D
- Potential harm to individual
 - Misinterpretation/Misuse of data
 - Re-identification
 - Disclosure of sensitive information




POLICYWISE FOR CHILDREN & FAMILIES

Methods for ethical use

- Secondary use by design
- Collaboration
- Anonymization
- Access Control



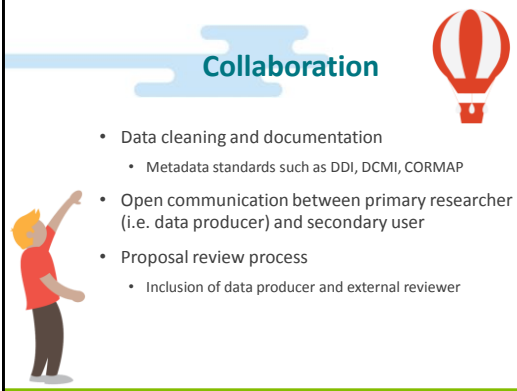
POLICYWISE FOR CHILDREN & FAMILIES



Secondary Use by Design

- Client/participant consents
 - Informed about collection, use and disclosure
 - Provisions for sharing and future use of data
- Secondary use incorporated in proposal and grants


POLICYWISE FOR CHILDREN & FAMILIES



Collaboration

- Data cleaning and documentation
 - Metadata standards such as DDI, DCMI, CORMAP
- Open communication between primary researcher (i.e. data producer) and secondary user
- Proposal review process
 - Inclusion of data producer and external reviewer

POLICYWISE FOR CHILDREN & FAMILIES



Anonymization

- Limit upper and lower ranges
 - Hide outliers
- Aggregation/Categorization
 - Reducing the precision of variables
- Suppression
- Extreme methods
 - Dummy data sets
 - Perturbative methods (adding noises, swapping records, etc.)

POLICYWISE FOR CHILDREN & FAMILIES

Access Control

- Data Access Agreement
 - Data use is limited to the proposed research
 - Clauses: No attempts to establish the identity of individuals
- SAGE Analytics Environment
 - Two-factor authentication of authorized used
 - No internet access
- Vetting Rules
 - Result output: aggregated results, suppression of cell sizes

POLICYWISE FOR CHILDREN & FAMILIES

How can we help you?

1. Wording for consent forms

- Template wording around consent:
 - Informed about collection, use and disclosure of personal information
 - Provisions for sharing and future use of data

POLICYWISE FOR CHILDREN & FAMILIES

How can we help you?

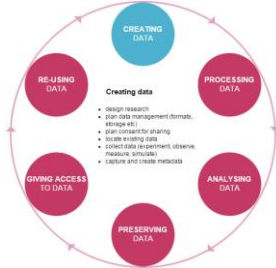
2. Wording for ethics applications

- Template wording for ethics applications:
 - Data storage
 - Data privacy and security
 - Data access

POLICYWISE FOR CHILDREN & FAMILIES

How can we help you? 3. Data management planning

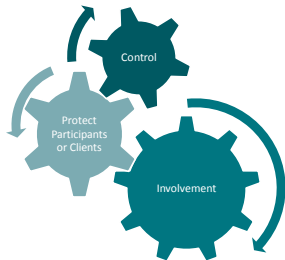
- Consider your research in the context of the research data lifecycle – you want it to be reproducible and reusable (by yourself and/or others)



UK Data Archive, University of Essex. (n.d.). Research data lifecycle. Retrieved from <http://www.data-archive.ac.uk/create-manage-life-cycle>

POLICYWISE FOR CHILDREN & FAMILIES

Building Trust



POLICYWISE FOR CHILDREN & FAMILIES

How can we help you?

4. Data Governance

- Template data deposit and data access agreement
- Governance: access process, de-identification, security etc.

POLICYWISE FOR CHILDREN & FAMILIES

How can we help you?

5. Advice on metadata

Metadata standards:

- Data Documentation Initiative (DDI), Dublin Core Metadata Initiative (DCMI), Government of Alberta Core Content Standard (CORMAP)
- Ensure that data is understandable and usable by other researchers - prevents misinterpretation of data

POLICYWISE FOR CHILDREN & FAMILIES

How can we help you?

6. Collaboration

- Our goal is to help build collaborations, and connect you to a broader network of researchers, evaluators and community organizations

POLICYWISE FOR CHILDREN & FAMILIES



Calgary Thrives Project: January – December 2017

- Calgary Food Bank
- Families Matter
- Calgary Counselling Centre
- South West Community Resource Centre
- Sunrise Link
- CUPS

POLICYWISE FOR CHILDREN & FAMILIES

Lessons Learnt: Sharing Research and NFP Data

- Cultural change is slow
- Need to budget and plan for resource to make data useful for secondary use
- Need to plan for and prioritize data management and sharing at an early stage



POLICYWISE FOR CHILDREN & FAMILIES

Lessons Learnt: Sharing NFP data 1

- Need for capacity building
- Need to value data
- Very different levels of "data maturity" (including capacity, governance, resource and expertise)
- Specific and diverse needs



POLICYWISE FOR CHILDREN & FAMILIES

Lessons Learnt: Sharing NFP Data 2

- Unclear legal situation
- Often fall in gaps of privacy legislation and ethical oversight
- Risk averse
- Protection of vulnerable populations
 - Prioritization of meeting immediate needs over long-term benefits of sharing data
 - Special considerations for Indigenous communities

POLICYWISE FOR CHILDREN & FAMILIES

Future Plans 1: Capacity Building

- Clear advice, expertise and tools
- Partner with existing sources of expertise where possible

POLICYWISE FOR CHILDREN & FAMILIES

Future Plans 2: Knowledge Mobilization

- Currently track knowledge mobilization activities and outputs
- Investigating if we can offer a knowledge mobilization service for our users

POLICYWISE FOR CHILDREN & FAMILIES



Any questions?

data@policywise.com

POLICYWISE FOR CHILDREN & FAMILIES



Datasets at SAGE

Surveys

- Alberta Benchmark Survey 2008: What Adults Know about Childhood Development
- Second Provincial Benchmark Survey 2013: What Adults Know About Child Development
- Alberta Adverse Childhood Experiences Survey 2013
- What Albertans Know about Youth Mental Health 2010 Survey
- What Albertans Know about Fetal Alcohol Spectrum Disorders 2011 Survey
- What Albertans Know about Maternal Mental Health 2012 Survey

Longitudinal Pregnancy Cohort

- **APrON**: Alberta Pregnancy Outcomes and Nutrition (APrON) Study
- **AOB/F**: All Our Babies/Families (AOB/F) Study

POLICYWISE FOR CHILDREN & FAMILIES

Data Deposit

DATA DEPOSIT

New study

Secondary use by design

Existing study

Assess reuse value

Data Deposit Agreement

Documentation and Metadata



Evaluation of research impact

POLICYWISE FOR CHILDREN & FAMILIES

Data Access

DATA ACCESS

Data Access Inquiry and Request

Access Review and Ethics

Data Access Agreement



Evaluation of research impact

POLICYWISE FOR CHILDREN & FAMILIES
