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Ethical considerations for child welfare administrative data in population health assessment and research

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Presentation overview

- Project overview & products
- Introduction
- Objectives
- Literature review
- Next steps – Interviews & key audience
- Discussion about next steps



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Project overview

- Public Health Agency of Canada (PHAC) Family Violence Epidemiology Section is collaborating with the International Society for the Prevention of Child Abuse and Neglect (ISPCAN)
- The purpose of this collaboration is to:
 - Increase knowledge about the ethical considerations of using administrative data from the child welfare sector
 - Support PHAC's ongoing efforts to: improve the ethical use of administrative data; increase trust in national child welfare data; and become a more effective data steward
 - Highlight relevance of this work globally



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Products

- Oral presentations, e.g.
 - International Society for Prevention of Child Abuse and Neglect (ISPCAN) Congress
 - International Congress on Circumpolar Health
- Peer-reviewed publications
 - Literature review
 - Manuscript with interview findings



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Child welfare administrative data

- Child welfare administrative data are derived from demographic, clinical and legal information that is routinely collected and recorded in electronic case management systems by frontline staff as a part of delivering child welfare services.
- They are primarily developed for monitoring or delivering services (not to answer analytical questions) and, they tend to:
 - Be longitudinal, de-identified, and available in electronic format
 - Include demographics and service utilization by person, place and time
- They can also be leveraged for population health assessment and research to:
 - Monitor population-level service characteristics and indicators related to child welfare or child maltreatment
 - Better understand drivers of health and social inequities among children and youth
 - Support policy and program decisions related to child and family well-being
 - Observe changes associated with the implementation of prevention policies



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Ethics of child welfare data: What are the challenges?

- Ethical challenges about the collection and use of survey data have been studied extensively:
 - Personal and community consent
 - Age related ethical issues (e.g., ability to consent, cognition)
 - Inuit self-determination in research (e.g., Inuit Strategy on Research)
 - Stakeholder engagement and co-development
- What do we know about the ethical considerations of using child welfare administrative data?
 - Existing policies have been largely driven by data privacy legislation/regulations at the local or national level, resulting in a one size fit all approach
 - A lack of comprehensive knowledge about ethical dimensions of child welfare administrative data can create challenges for data holders and consolidators

Objectives

- 1) Summarize existing evidence on the ethical considerations of using administrative child maltreatment and child welfare data in public health surveillance and research, through a narrative literature review (***Focus of this presentation**)
- 2) Identify solutions to ethical challenges or dilemmas that occurred when developing public health information systems based on child welfare administrative data, through interviews with data holders and consolidators (***awaiting Research Ethics Board approval to begin**)



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Phase 1 - Literature review

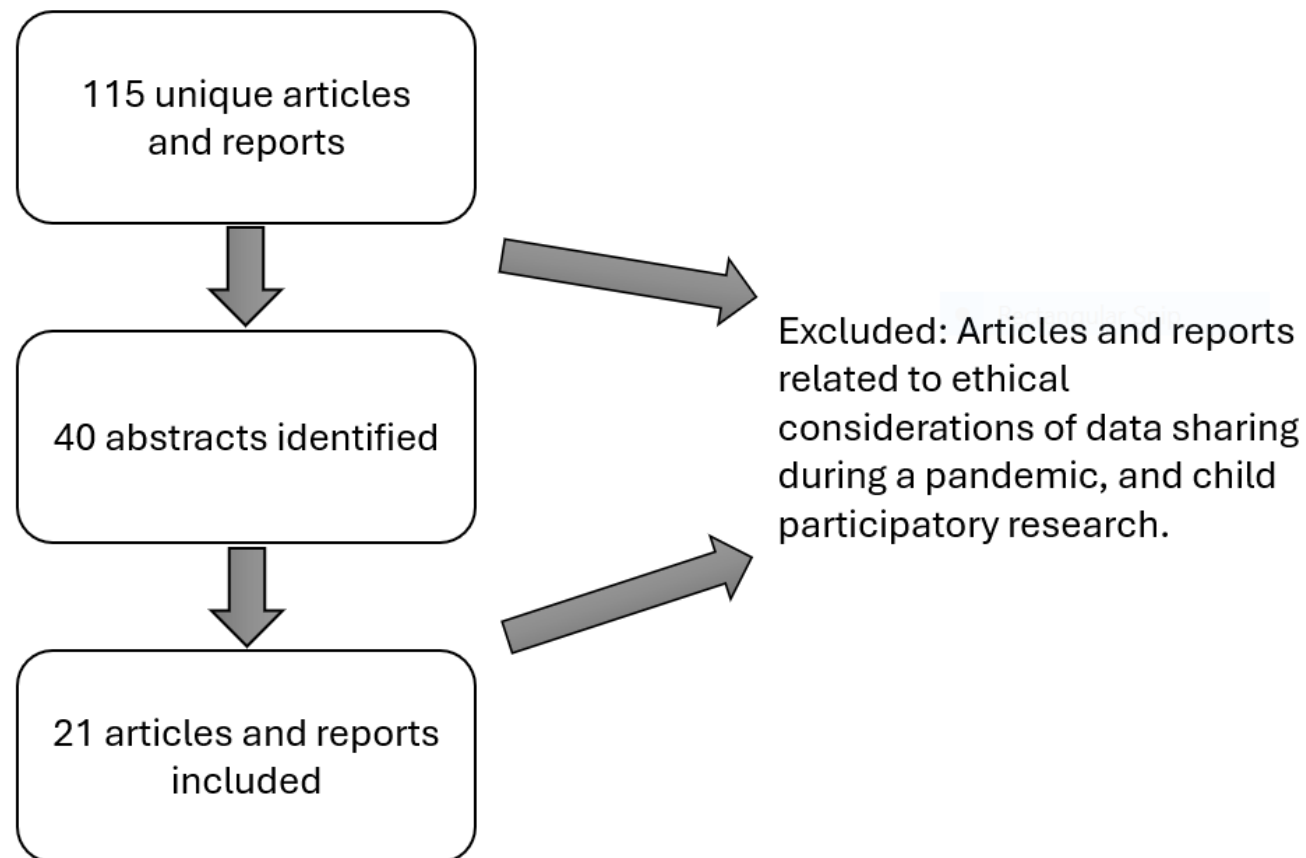


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Literature review methods



Search strategy developed in consultation with a PHAC Librarian



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Themes drawn from the literature review

Services Recipient Consent for Data Access

- Limited ability to obtain consent as data is already collected

Privacy and Confidentiality

- Data protection rules can create barriers to access and beneficial use of data

Stakeholder Engagement

- Limited ability to engage with diverse stakeholders

Data Bias and Accuracy

- Data quality issues (e.g., measurement/data entry errors, limited completeness) can bias results and increase risks of perpetuating inequities

Indigenous and Underserved Populations - Data Governance and Sovereignty

- Growing advocacy for implementing models but limited applications and examples available

Phase 2 - Interviews



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Next steps – Interviews

- **Who**

- Additional key stakeholder categories
- International representation
- Exemplar systems
- Experience with administrative data

- **What**

- Nine to seventeen interviews
- Interview protocol
 - Consent/confidentiality
 - Structured questions
- Thematic analysis

- **Why**

- Better understand ethical considerations and drivers
- Identify recommendations to balance ethical and surveillance/ research needs
- Inform existing data infrastructure to support public health surveillance and research
- Become more effective stewards of child welfare administrative data

Key focus audiences for interviews

Data holders/custodians

Organizations with defined responsibilities usually under the legal and regulatory mandates of a governmental agency



Data consolidators/archivers

Organizations that serve to make data available to users for secondary analysis (e.g. statistical agencies, universities, research institutions)

Data users

Government, university or organizational researchers/analysts.

Discussion about next steps

- Who else should we consider?
 - Data users
 - Others?
- Which jurisdictions should we include?
- Other concerns or suggestions about the entire project?



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