Applying for Data Access: General Principles

Jennifer Payne, PhD
Co-Chair, Data & Privacy Advisory Committee
&
Associate Professor,
Department of Diagnostic Radiology,
Dalhousie University

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Outline

- Purpose of Data Access Process
- Link Data Access to Research Proposal
- Principles
- Next Steps:

  - province-specific sessions

NOT:

- Jurisdiction-specific issues

  e.g., data sources, committees, legislation

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‘Secondary Data’ Projects

Projects that may involve:

- use of data that are not collected primarily for research purposes
- use of data held by ‘data custodian’

  (e.g., public, private)
- use of dataset consisting of hundreds or thousands of observations
- historical data on subjects
- data for subjects who may have since died or moved
- a rationale for a consent waiver

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Purpose of Data Access

- Custodian has duty to safeguard data
- Identify required data source(s)
- Ensure feasibility of proposed work
  - Data (available/appropriate)
  - Resource planning (extraction/linkage)
- Review of data collection processes
- Review nature of results (release)

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Project rationale

- Review rationale
- Links between:
  - Study objectives
  - Study methods
  - Available data
  * Do these all tie together? Is this feasible?

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Data Collection - I

- Data source(s):
  - Identify data source
  - Describe context for data source
- Records - eligibility criteria (in/ex-clusion)

  e.g., date range, age range
- Variables (may include values)
  - Analytic variables (extracted or derived)
  - Linkage variables (personal identifiers)

NOTE: access does not imply 'for analytical

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Principle #1 (Step #1) – Meet with Custodian about Data Needs

- Research question vs data source
  - Is the research feasible?
  - Is the data source appropriate for the work?
  - Talk to data custodian
    - Rationale for research (question)
    - Explain approach to data collection
  - Letter from custodian (indicates feasibility)

    e.g., REB, grant

NOTE: REB approval does not guarantee access!

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Principle #2 - Minimum

- Minimum data required to carry out work
  * Ask for only what you need

e.g., date of birth vs age group at admission

ICD codes vs ‘flag’ for diagnostic group

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Data Collection - II

- 'Data Flow' (prose and/or diagram):
  - Who will extract
  - Who will receive
  - How will data be moved
  - Where will data be held for analysis
  * Who sees (has access to) what

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Data Collection - Linkage

- Linkage: combine data from 2+ sources
- Methods:
  - Deterministic (perfect match) or Probabilistic (probability thresholds)
  - Linkage variables (unique identifier):
    - Health card number
    - Date of birth
    - Sex
    - Name (last, first)

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Principle #3 – No Sharing

- Data custodians should not see each other's data (data linkage – analytic data)
  * When extracting/linking data from multiple sources, design data collection to ensure minimal access by all parties
  * personal identifiers and analytic variables do not 'travel' together

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Data analysis

- Are data appropriate for required analysis?
- Who will perform analysis?
- Who will have access to 'row-level' data?

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Principle #4 – Separation

- Person carrying out linkage does not perform analysis
  * person who has access to personal identifiers does not analyse data

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Principles – 'ethical considerations'

- Privacy
  - Consent waiver (REB & custodian agreement)
  - Minimal data used
  - Limit use of personal identifiers
- Confidentiality
  - Limit access to personal identifiers
  - Limit access to analytic data files
  - Release of aggregate results
- Security
  - Secure transmission of files
  - Files on secure server (analysis & storage)

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Other bits

- Data extraction costs:
  - Discussion with custodian
  - Letter from custodian – budget estimate
- Timelines:
  - Time upfront pays off in long run when applying for data access (faster!!)
  - Project timelines:
    - Data access
    - Data extraction

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REB & Data Access
(Chicken & Egg)

- Jurisdictions differ in their process
  - Nature of data access process (committee)
  - Timing of REB relative to data access

- Conceptually, parallel processes:
  - Content required for both quite similar
  - Order of submissions determined locally

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Data Flow Diagram

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Case #1 – Simple Extraction

NSBSP Extracts File:
study id
age at diagnosis
age at death
flag – breast cancer death

Securely to statistician

Analysis

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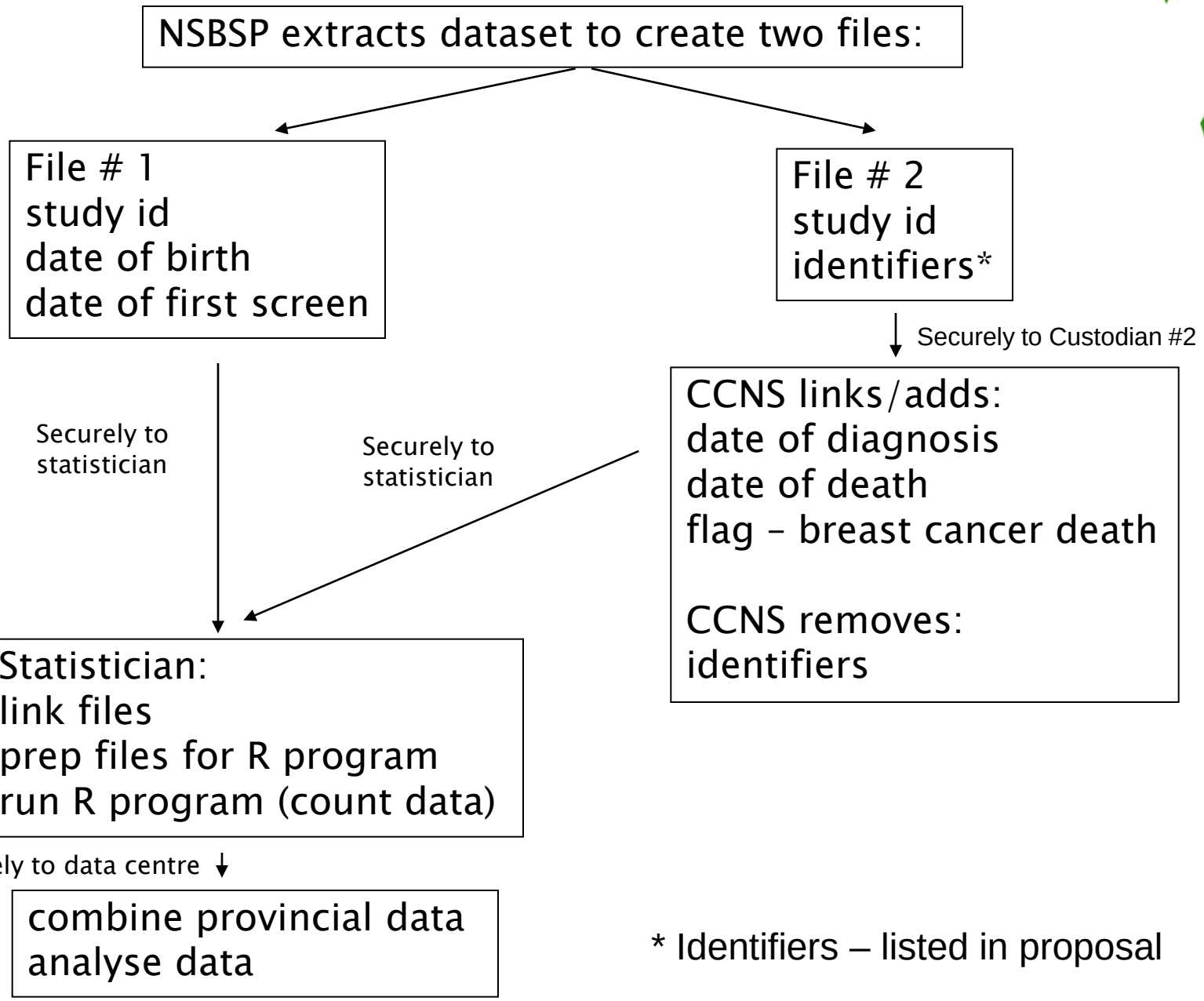
Case #2 – Extraction/Linkage



* Identifiers – listed in proposal

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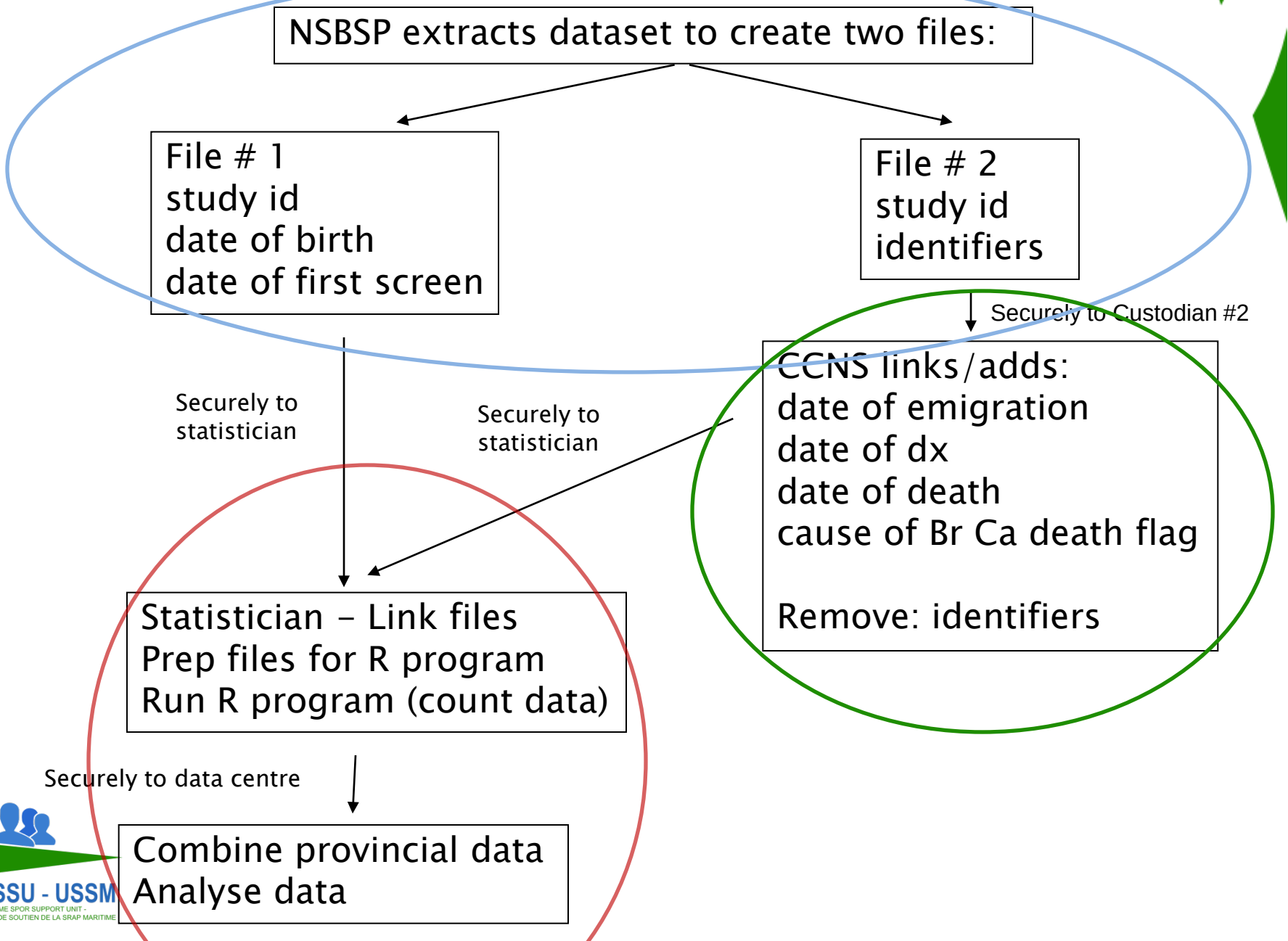
Case #2 – Extraction/Linkage



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Next Steps

- province-specific seminars (Fall 2016):
  - Local processes
  - Data sources
  - Data access committees (multiple)
  - Data access & REB process (order?)
  * Input welcome!

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REB Best Practice Document

www.spor-maritime-srap.ca

- research support (tab at top)
- resources
- privacy & ethics
  (under MSSU subheading)

* Data flow diagrams
* Consent waiver criteria

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Questions?

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