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OUTLINE

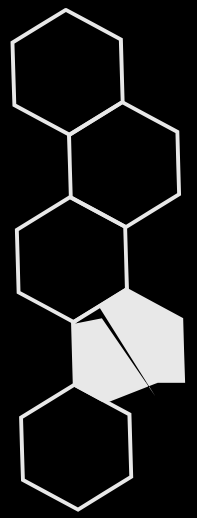
- Overview of NB-IRDT

- Legislative pathway to establishing NB-IRDT
  - the process of amending legislation & developing new legislation

- Establishing reassurance
  - practicing privacy

- Relationship with GNB
  - Governance and research agreements

- Enablers of success (so far)



WHAT NB-IRDT DOES

- Operates as a provincial research data centre and data custodian as defined in NB legislation
- Hosts and provides access to person-level de-identified but linkable program data in a highly secure research network (Fredericton, Moncton, Saint John sites)
- Conducts objective, rigorous and evidence-based research and program evaluation to support GNB planning and policy development
- Receives, links, hosts and analyzes user-provided personal information from clinical trials, observational studies, devices etc.
- Anchors the NB Maritime SPOR SUPPORT Unit

WHAT NB-IRDT DOESN'T DO

- Does not get 'real-time' data; is not integrated into Health information systems
- Does not provide guidance on treatment or practice for specific individuals
- Does not replace regular reporting by health authorities or agencies

- 2 Research associates
- Õ 6 Database analysts
- 2 Research assistants
- 1 A A•

LEGISLATIVE PATHWAY FOR NB-IRDT

- 2012 – changes to the NB Personal Health Information Privacy and Access Act (PHIPAA) to define a research data centre and designate as a data custodian
- 2015 – PHIPAA allows Medicare health insurance number to be used for data matching to conduct research
- 2015 – NB-IRDT officially launched as UNB institute by UNB and the Premier of NB
- 2015 – first dataset is delivered (Discharge Abstracts Database)
- 2016 – review/approval of originating agreement, operating agreement, foundational PIA and TRA, and data sharing agreement templates by multiple agencies

- Personal Health Information Protection and Access Act (PHIPAA) was modified to define NB-IRDT as a data custodian, but lack of clear legislative authority in other legislation meant that all further data transfers were halted
  - Medicare Act – physician billing
  - Right to Information and Protection of Privacy Act (RTIPPA) – all personal information, including Medicare provider information, education, income support, justice, training, immigration, housing
  - Family Services Act and Nursing Home Act – long term care
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AN ACT RESPECTING RESEARCH

- Modifies a list of other legislation to provide legal authority for NB -IRDT to receive and use research-relevant data from the provincial government and public bodies in a de-identified but linkable form

- Provides authority for Departments and public bodies to share identifying information with NB Department of Health for data matching purposes with NB-IRDT

- Bill 57 proclaimed into law May 2017
  - 10+ pieces of legislation including RTIPPA and Medicare Act

- Bill 29 proclaimed into law June 2019
  - MPHEC Act, Education Act, Medical Services Act, Labour Market Research Act, Family Income Security Act, Family Services Act, Early Childhood Services Act, Clean Water Act

THE IMPLICATION

- Obstacles to the transfer of administrative data were narrowed to operational issues
  - Drafting agreements
  - Identifying and mobilizing available resources

- Master

- Cancer and Breast Cancer screening registries
- Chronic disease indicators for diabetes, MS, COD6.5589 3C EMC

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Department of Health EHR and Regional Health Authority data

- Clinical ALS patient data
- NB Trauma registry
- HB-A1C
- Pulmonary function test lab data
- Diagnostic imaging database (LBP)
- IV administered chemotherapy (Vitalite HN)
- COVID-19 test results

PENDING

- Drug Information System data
- ER encounters
- IV administered chemotherapy (Horizon HN)
- CTAR radiation therapy
- Memory clinic data

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Other government data

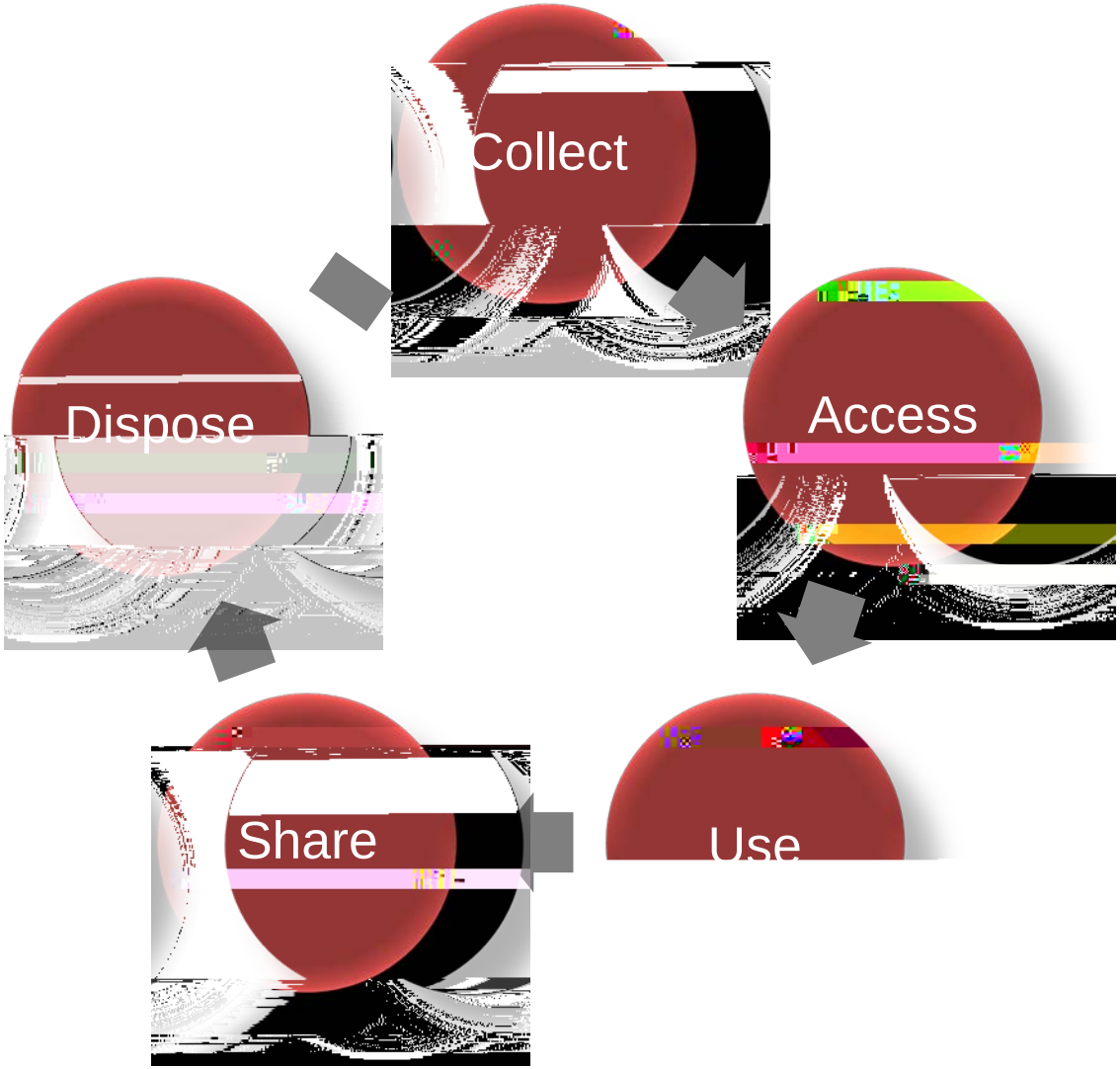
- NB Powerschool K-12 student grades and attendance
- Provincial assessment scores
- Early Years Evaluation
- Adult education and training program participation
- Immigration landing records
- Long term care
- Suicide Registry
- University and community college enrollment
- Worksafe NB claims

PENDING

- Apprenticeship data
- Social support program participation
- RAI-LTCF Nursing home data
- Motor vehicle accidents
- Court appearances
- Quarry and industrial site data

Establishing Reassurance
- Practicing Privacy

DATA LIFE CYCLE



WORKING WITHIN THE LAW

Policy

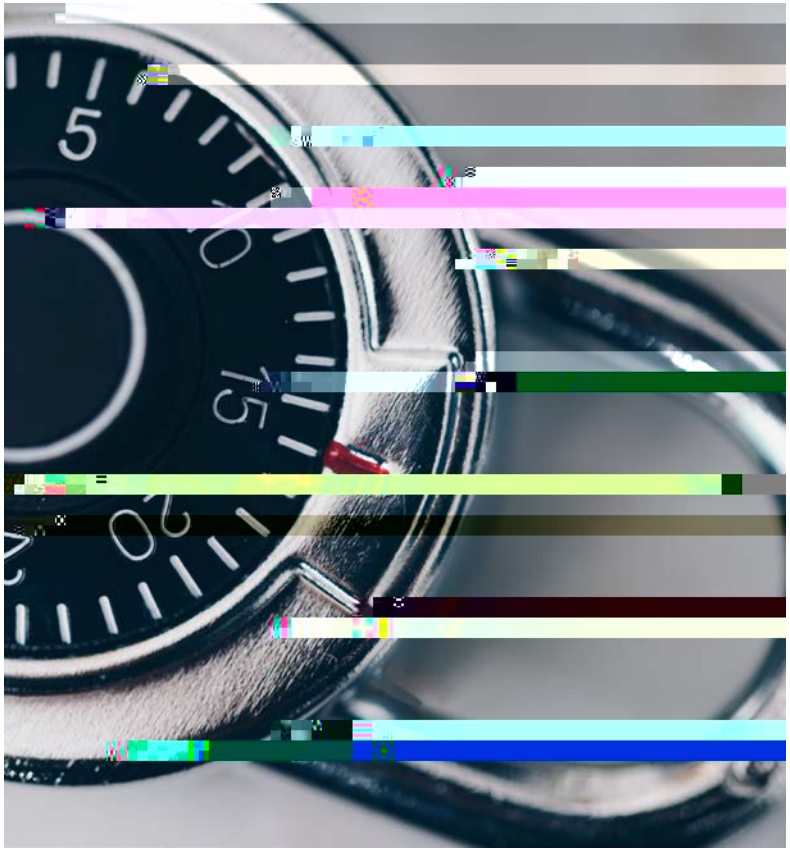
- Legislative guidance
- Research specific requirements
- Safeguards
  - Administrative
  - Physical
  - Technical

- Accountability
- Identifying Purpose
- Limiting Collection
- Limiting Use, Disclosure and Retention
- Safeguards

PRIVACY PRINCIPLES

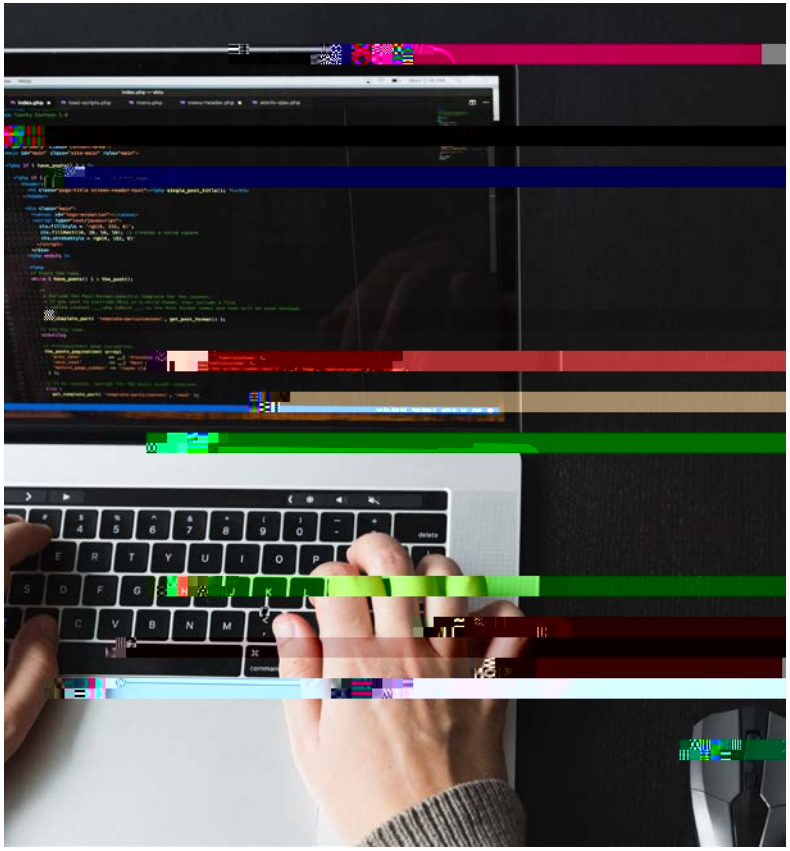
Principles

- Consent
- Accuracy
- Openness
- Individual access to ones own data
- Challenge compliance



PRIVACY BY DESIGN

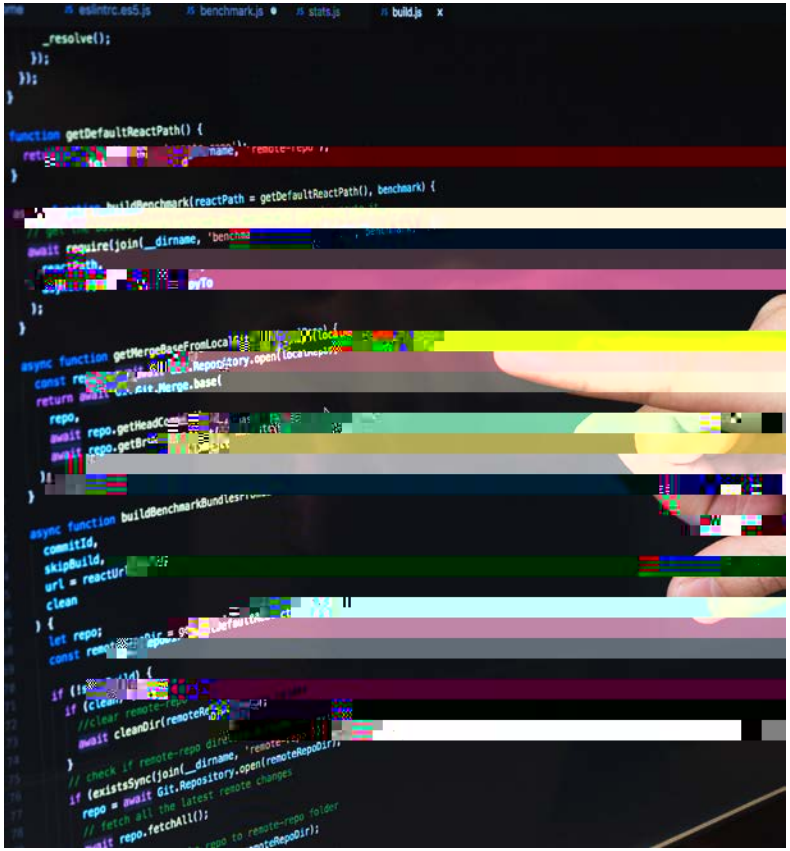
Planning



- Proactive not reactive; Preventive not remedial
- Privacy as the default setting
- Privacy embedded into design
- Full functionality – Positive sum not zero sum
- End-to-End security – Full life cycle protection
- Visibility and Transparency
- Respect for User Privacy

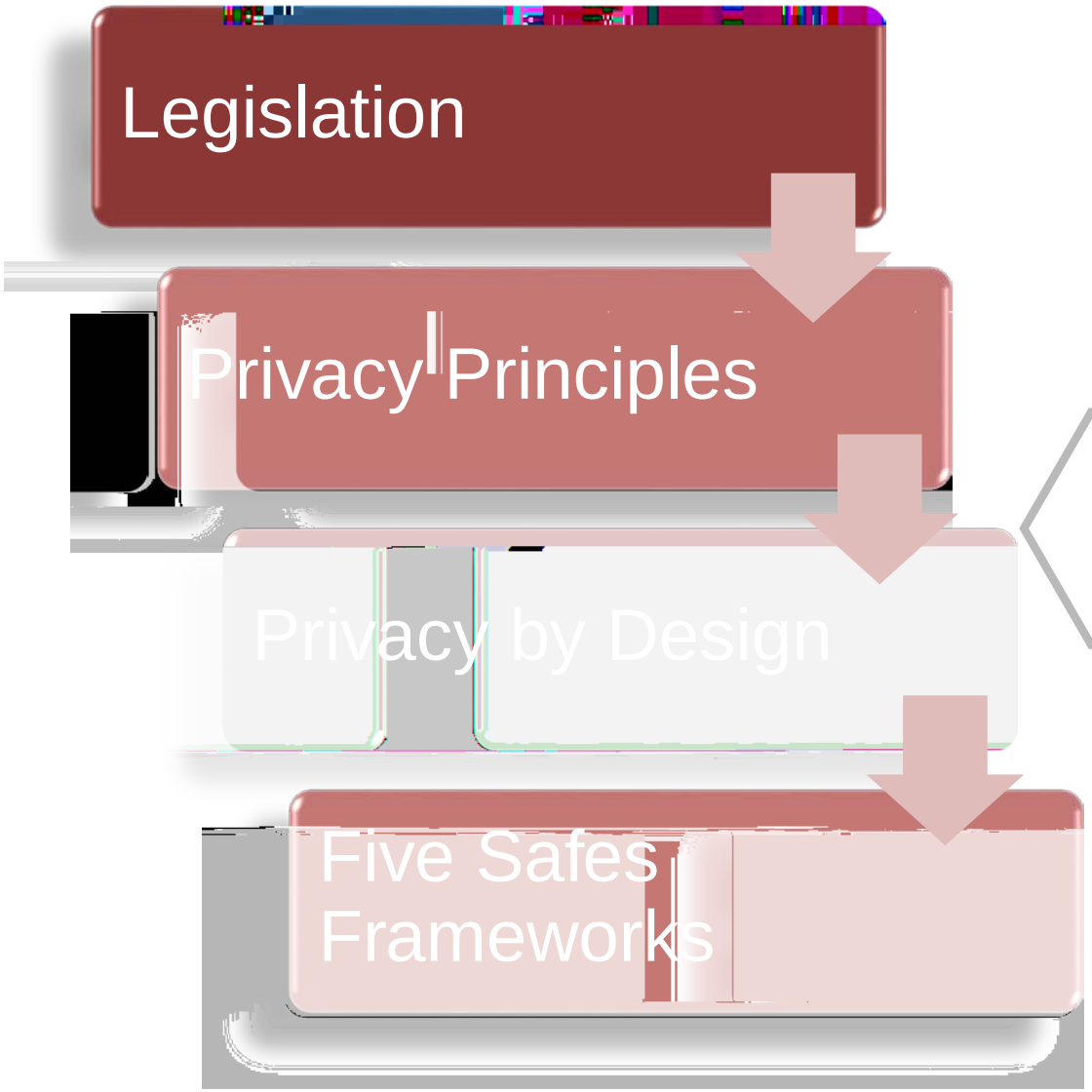
FIVE SAFES FRAMEWORK

Procedures



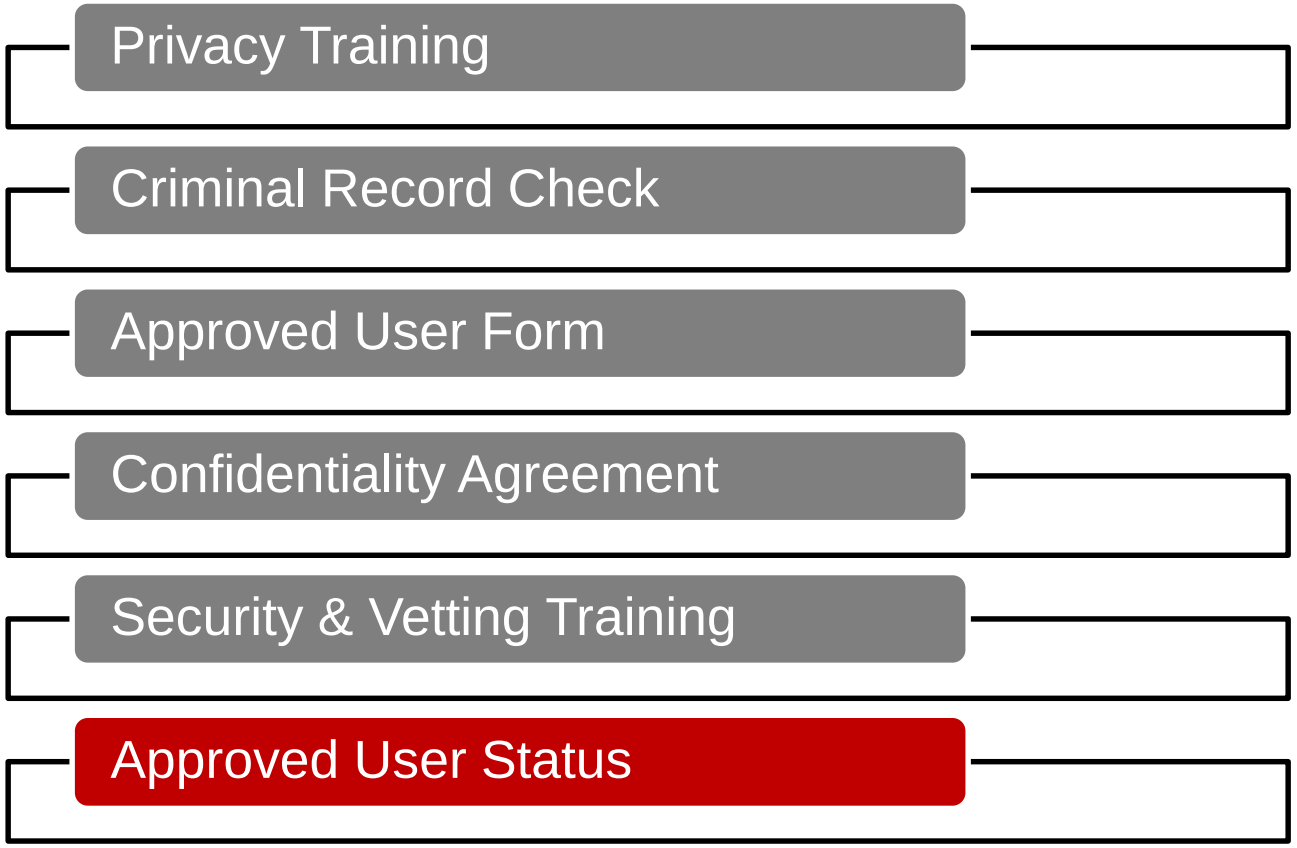
- Safe People
- Safe Projects
- Safe Settings
- Safe Data
- Safe Outputs

POLICY + PRINCIPLES + PLANNING + PROCEDURES



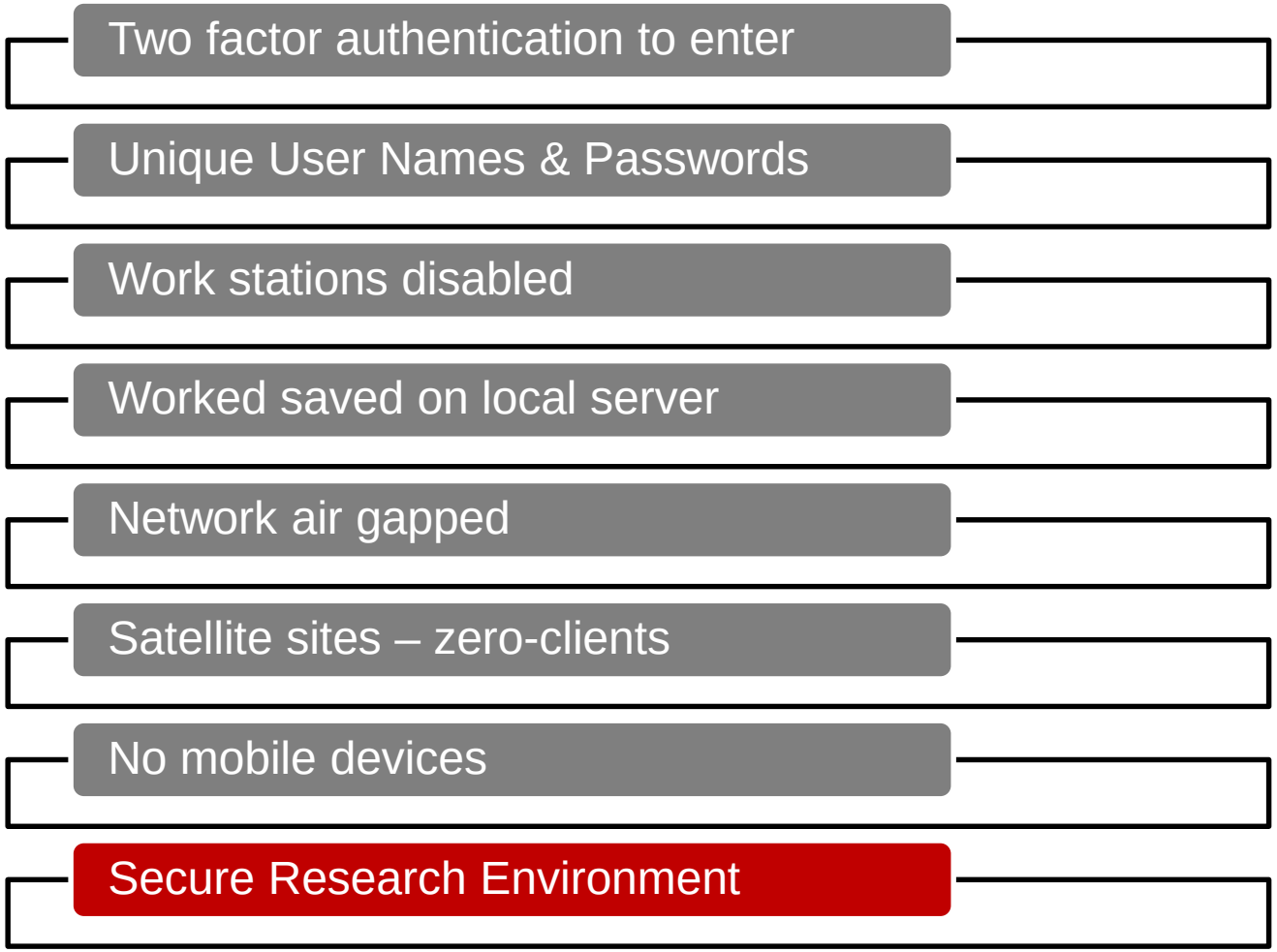
SAFE PEOPLE

Evaluating researchers who see data



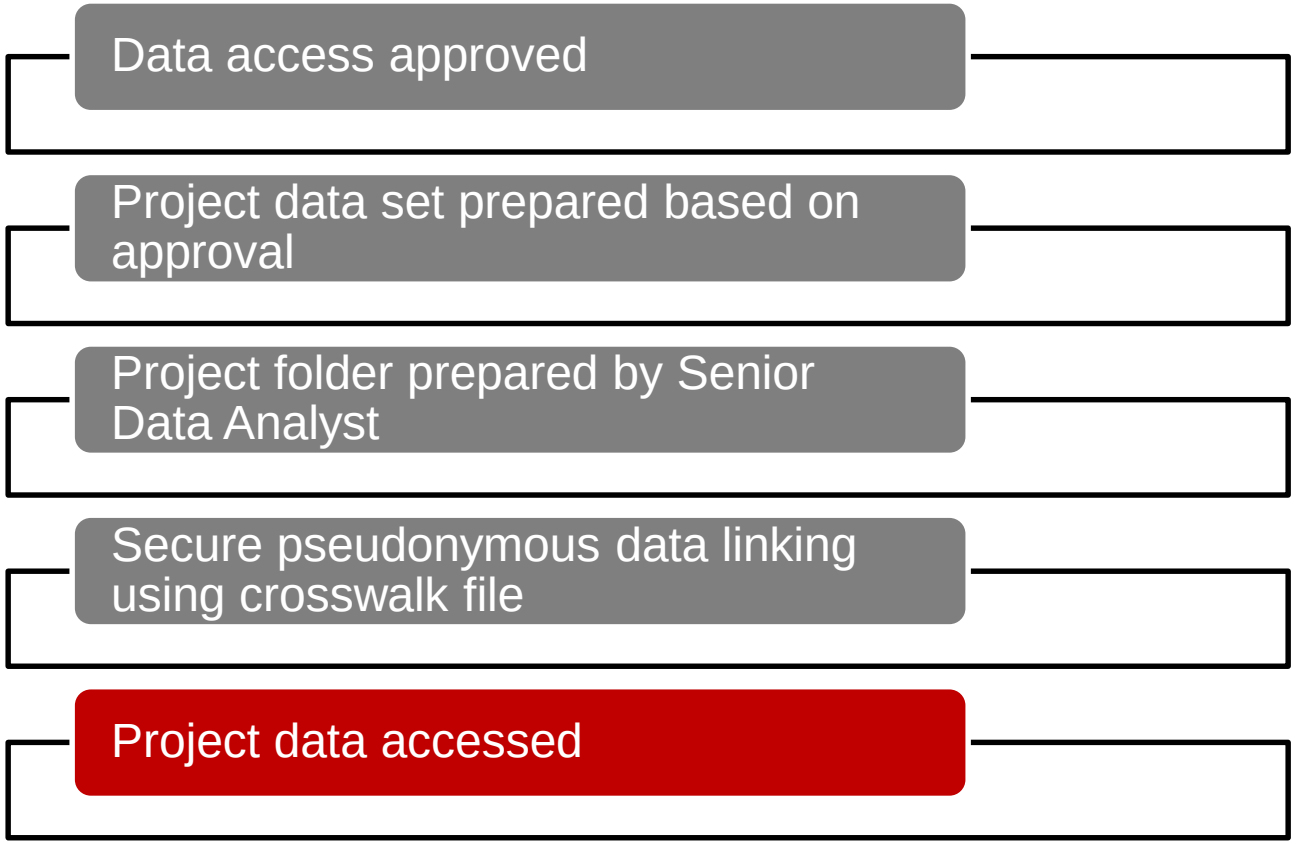
SAFE SETTINGS

Data access



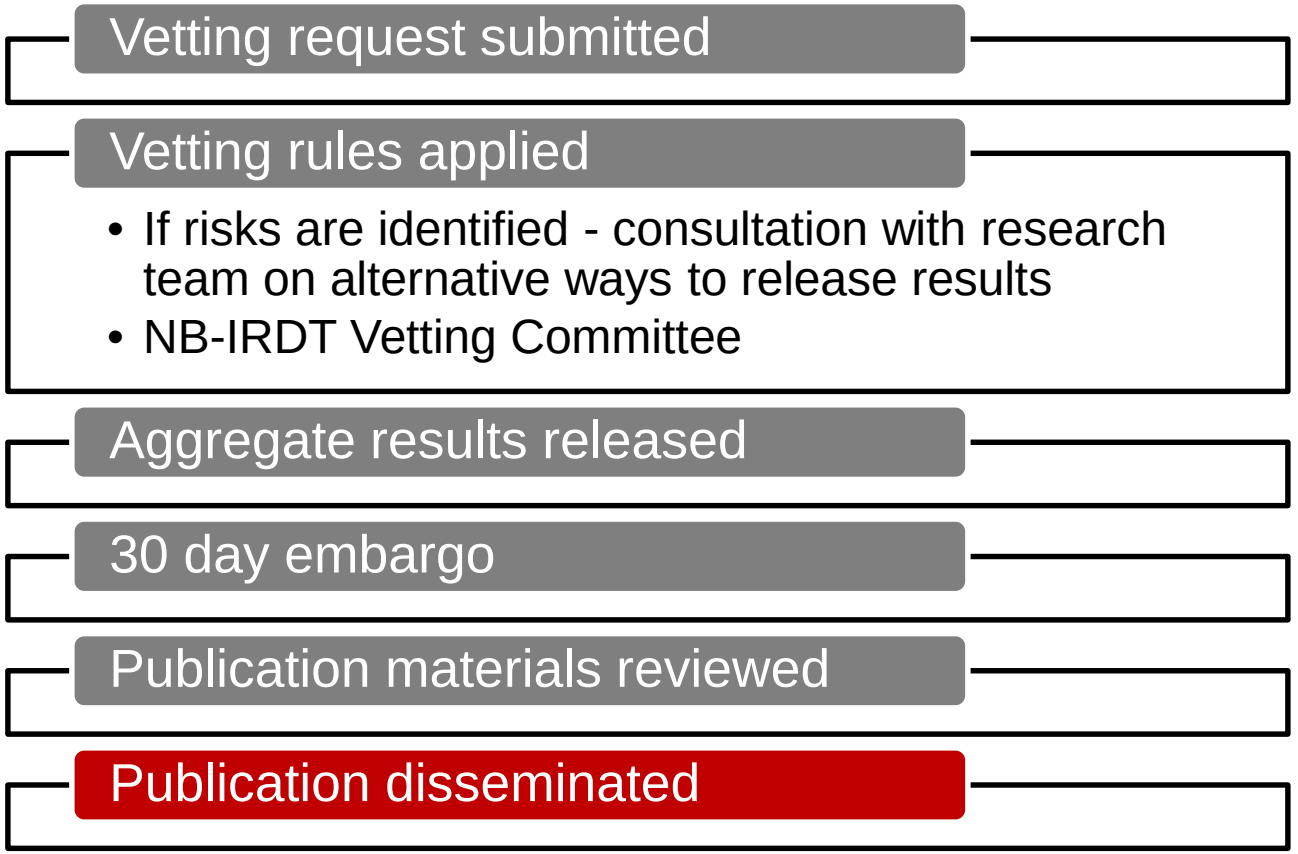
SAFE DATA

Verifying and Mitigating Disclosure Risk in the Data



SAFE OUTPUTS

Verifying and Mitigating Disclosure Risk in Statistical Analysis Results and Tabulations



GOVERNANCE

Partnership Coordination Committee

- Provides high-level guidance and direction on sustainability

- Membership: UNB VP-Research (Chair), Clerk of Executive Council Office, three Deputy Ministers, VP Research of both Regional Health Authorities

Data and Research Committee

- Reviews all applications submitted to access NB-IRDT data; reviews all publication/presentation material prior to public release

- Membership: Deputy Secretary to Cabinet, Director of Health Analytics, GNB Chief Privacy Officer, representatives from each agency from which data is sought, NB-IRDT's Director and Privacy Officer

RESEARCH AGREEMENTS WITH GNB

5-year Research Agreement with Postsecondary Education, Training and Labour (PETL)

- Research related to labour market program evaluation, immigrant retention and outcomes, postsecondary graduate retention and outcomes, and labour market information projects

- Governance board sets priority areas each year and monitors progress quarterly

- Includes PETL Deputy Minister and assistant Deputy Ministers as well as assistant Deputy Minister from Executive Council Office

RESEARCH AGREEMENTS WITH GNB

2 Research Agreements with Education and Early Childhood Development

- Evaluation of Early Childhood Centres (daycare subsidy program) - health, education and social impacts on children and parents in the short, medium and longer terms

- Evaluation of research initiative on hours of instruction increase for kindergarten through grade 2 – effects on children, parents, teachers, school support staff in the short, medium and longer terms

PETL PRIORITY PROJECT – STUDENT RETENTION

- How well does NB do in retaining post-secondary graduates of NB institutions after graduation?

- Using:
  - K-12 school data
  - Post-secondary enrollment and graduation data for all 4 public universities and 3 community college systems
  - Medicare registration data

- How do retention rates vary by:
  - Home province or country
  - Field of study, location of study
  - Personal characteristics

- How do our results compare to MPHEC survey results?

OTHER RESEARCH WITH GNB UNDERWAY / IN DEVELOPMENT

-

WHY HAS IT WORKED

- Shared vision and commitment to supporting evidence-based policy and program development
- Clearly defining the mandate to meet demand while avoiding duplication – complementary capacity
- Champions within ECO, line departments and public bodies
- Sustained infrastructure funding through MSSU-NB but leveraging MSSU funds wherever possible
- Long term relationships built on mutual trust and communication

CONTACT INFORMATION

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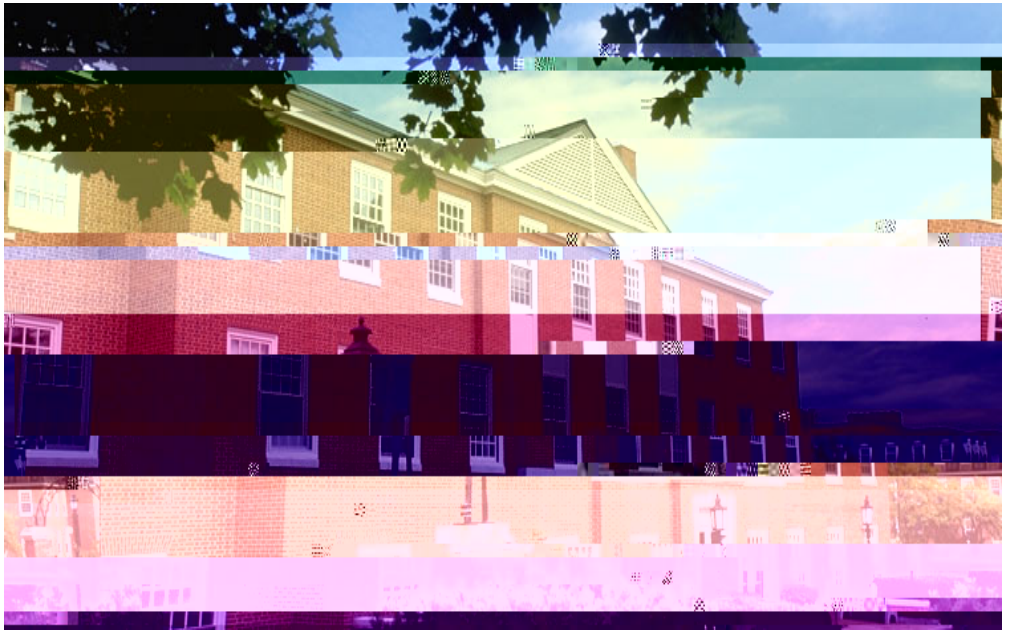
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