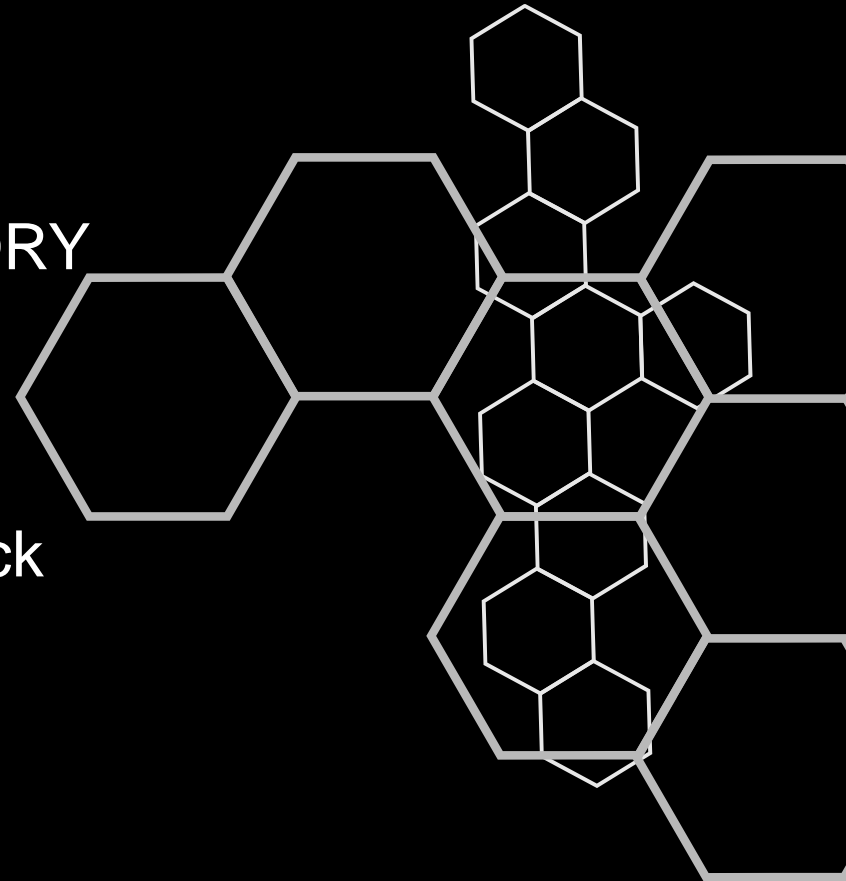


DEVELOPING A DATA REPOSITORY WHILE PROTECTING PRIVACY:

The experience and impact of
legislative change in New Brunswick

October 15, 2020

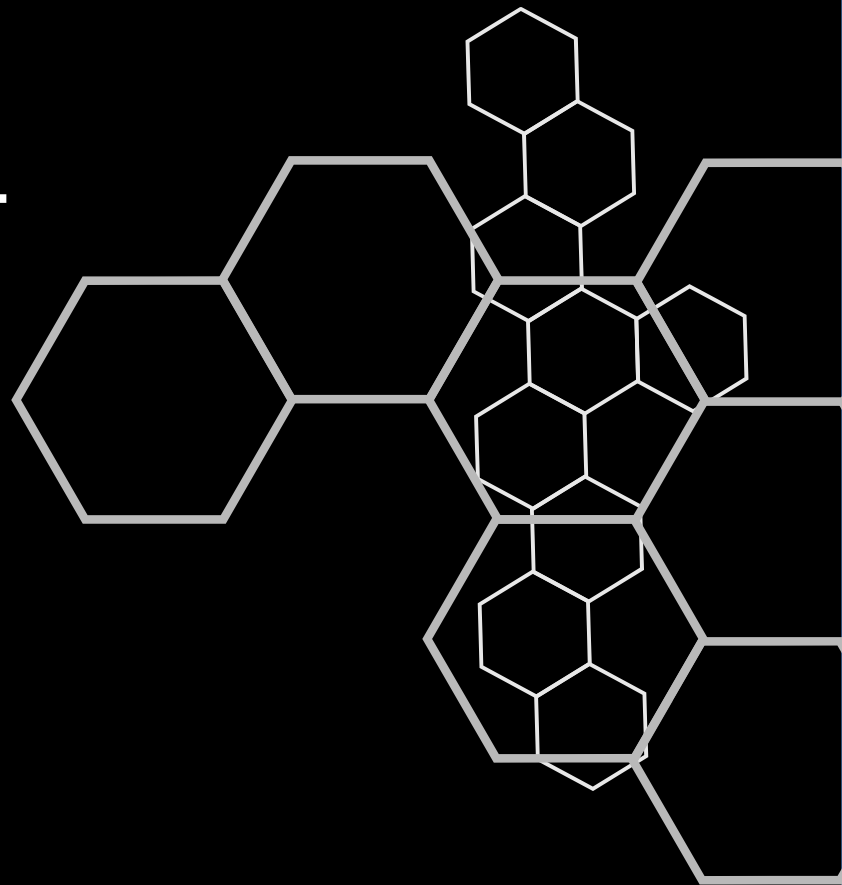


OUTLINE

- 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)



Overview of NB-IRDT



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

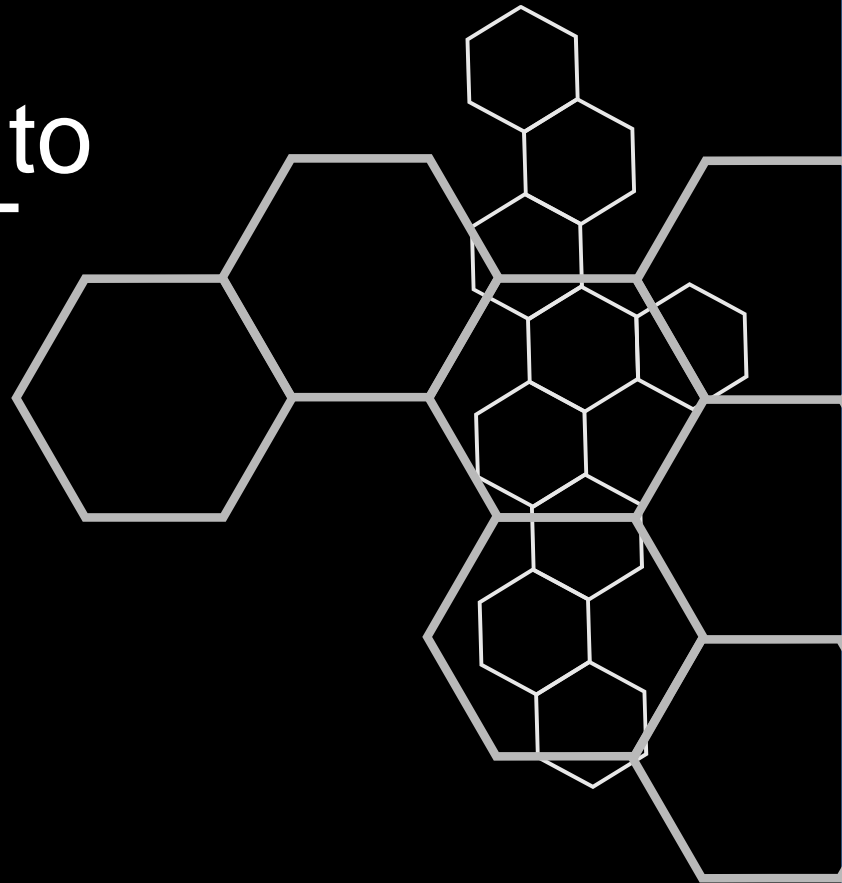


STAFF AND BUDGET

- 2 Research associates
- 6 Database analysts
- 2 Research assistants
- 1 Affiliated postdoctoral fellow
- 8 Operations staff
- 2 Seconded GNB employees
- 4 Program evaluators (Healthy Seniors Pilot Project)
- \$2.7m in grant and contract revenue in 2019



Legislative Pathways to Establishing NB-IRDT



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

THE KEY CHALLENGE

- 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
- Departments also could not share data with each other except for specifically prescribed reasons – so data couldn't be linked

THE SOLUTION

- **An Act Respecting Research**



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

HOW DID WE (NB) MAKE THIS HAPPEN?

- Executive Council Office, Deputy Clerk led the process – late 2016
- ‘Green lighted’ by the Premier of NB as a priority
- Coordination by a senior policy advisor assigned to the role
- Engagement with Deputy Ministers
- Early engagement with the Office of the Attorney General
- Follow-up by each Department with OAG
 - “please help draft text that will achieve the objectives”
- Consultations: The Official Opposition, The Privacy Commissioner, **many** stakeholder groups



THE IMPLICATION



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

DATA SHARING AGREEMENTS

- Master data sharing agreements (MDSA) define NB-IRDT as the data custodian for any data transferred and enable their access for research purposes
- MDSAs in place with:
 - NB Department of Health
 - Horizon and Vitalité Health Authorities
 - NB Department Education and Early Childhood Development
 - NB Department of Post-Secondary Education, Training and Labour
 - NB Department of Social Development
 - WorksafeNB
- MDSAs in development with MPHEC, Departments of Justice and Public Safety
- Data sharing agreement signed with Immigration, Refugee and Citizenship Canada

LINKABLE LONGITUDINAL DATASETS AT NB-IRDT

Department of Health Administrative Data

- Citizen Database (Medicare)
- Hospital Discharge Abstracts
- Provincial drug plans
- Physician billing
- Provider registry
- Vital Statistics death data
- NB Insulin pump program
- Cancer and Breast Cancer screening registries
- Chronic disease indicators for diabetes, MS, COPD, hypertension, etc.
- National Rehabilitation Database
- Healthy Toddler Assessment
- Management Information System

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

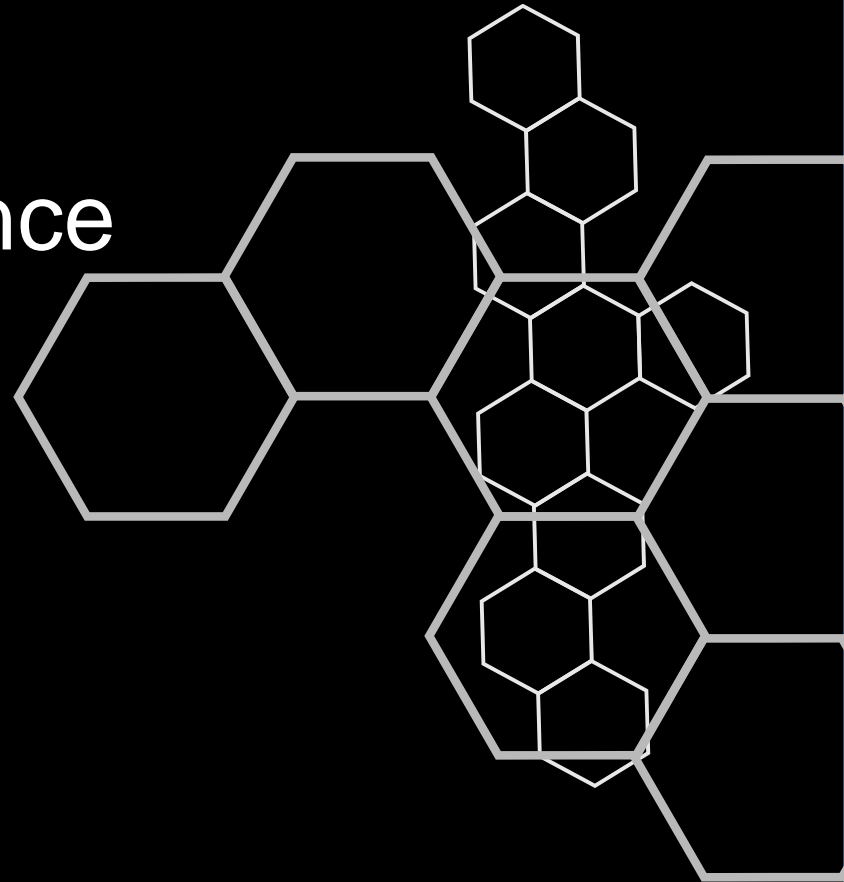
Other government data

- 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

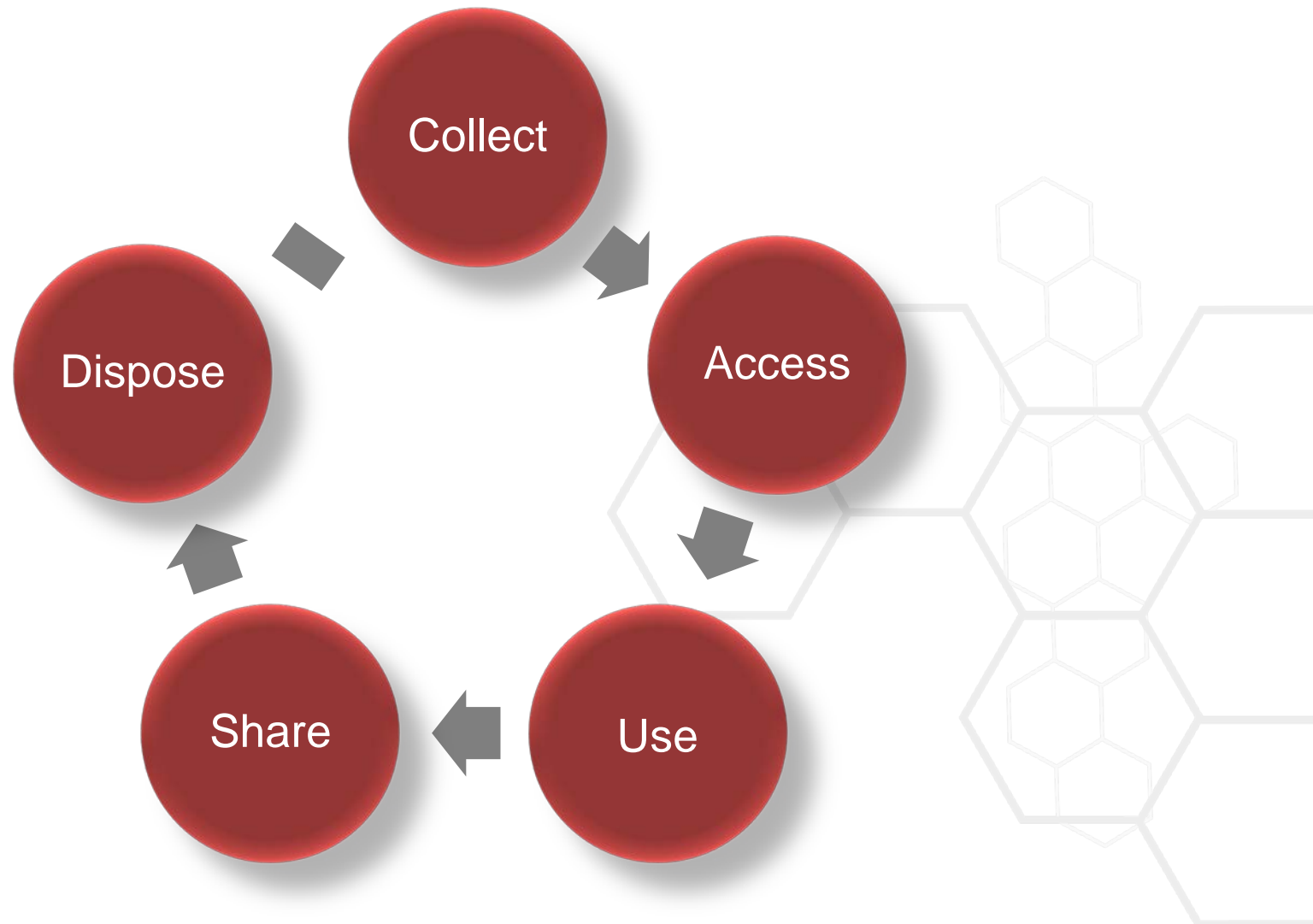
PENDING

- 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

PRIVACY PRINCIPLES

Principles

- 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

A hand is pointing at a computer screen displaying JavaScript code. The code is written in a dark-themed editor and includes functions for handling Git repositories and benchmarks. The code is as follows:

```
    _resolve();
  });
});
}

function getDefaultReactPath() {
  return join(__dirname, 'remote-repo');
}

async function buildBenchmark(reactPath = getDefaultReactPath(), benchmark) {
  // get the build.js from the benchmark directory and execute it
  await require(join(__dirname, 'benchmarks', benchmark, 'build.js'))(
    reactPath,
    asyncCopyTo
  );
}

async function getMergeBaseFromLocalGitRepo(localRepo) {
  const repo = await Git.Repository.open(localRepo);
  return await Git.Merge.base(
    repo,
    await repo.getHeadCommit(),
    await repo.getBranchCommit('master')
  );
}

async function buildBenchmarkBundlesFromGitRepo(
  commitId,
  skipBuild,
  url = reactUrl,
  clean
) {
  let repo;
  const remoteRepoDir = getDefaultReactPath();

  if (!skipBuild) {
    if (clean) {
      // clear remote-repo folder
      await cleanDir(remoteRepoDir);
    }
    // check if remote-repo directory already exists
    if (existsSync(join(__dirname, 'remote-repo'))) {
      repo = await Git.Repository.open(remoteRepoDir);
      // fetch all the latest remote changes
      await repo.fetchAll();
    }
  }
}
```

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

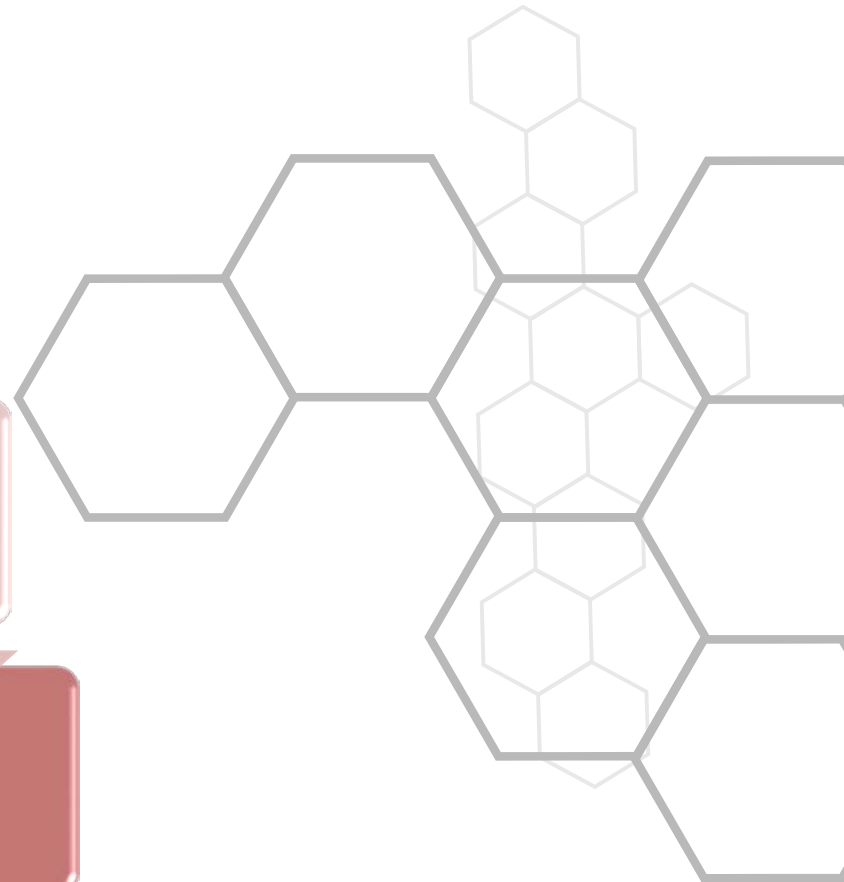
POLICY + PRINCIPLES + PLANNING + PROCEDURES

Legislation

Privacy Principles

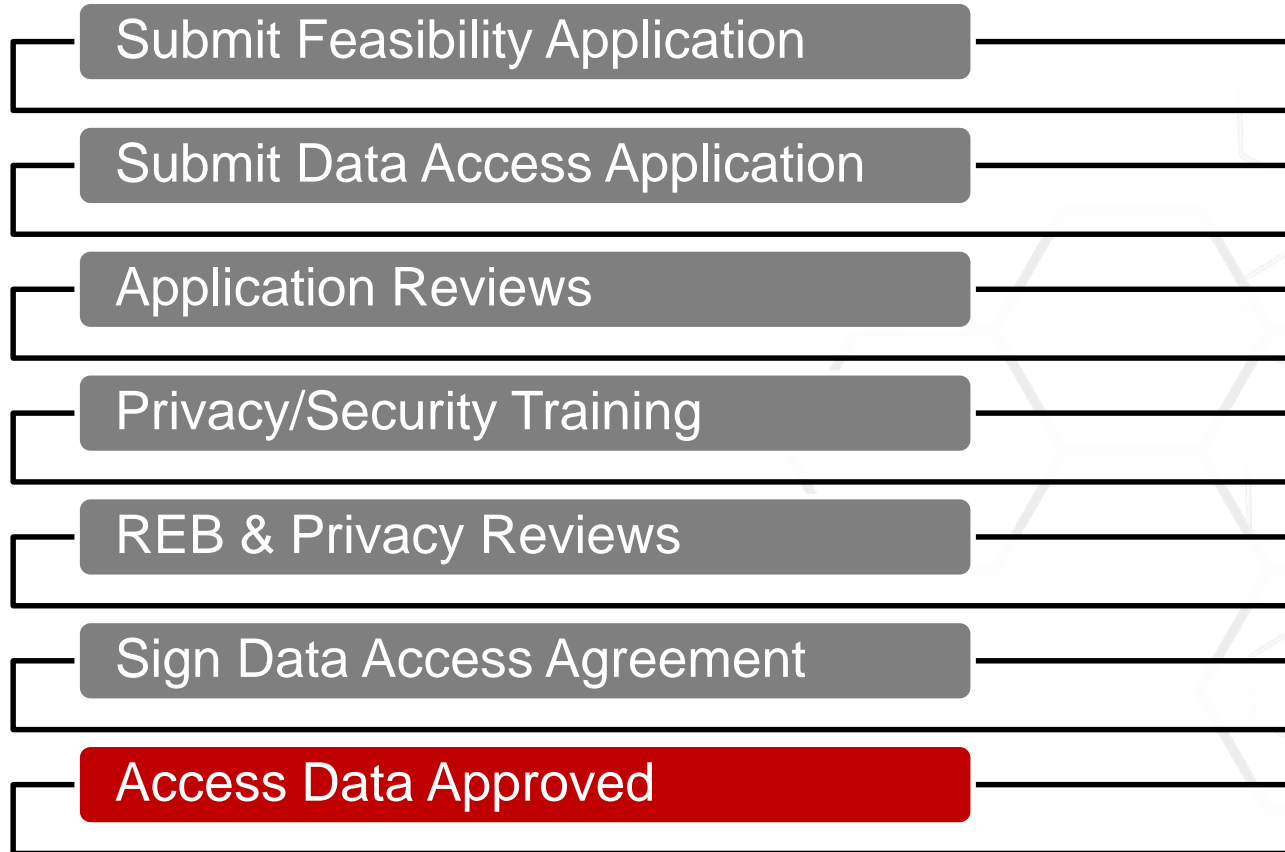
Privacy by Design

Five Safes
Frameworks



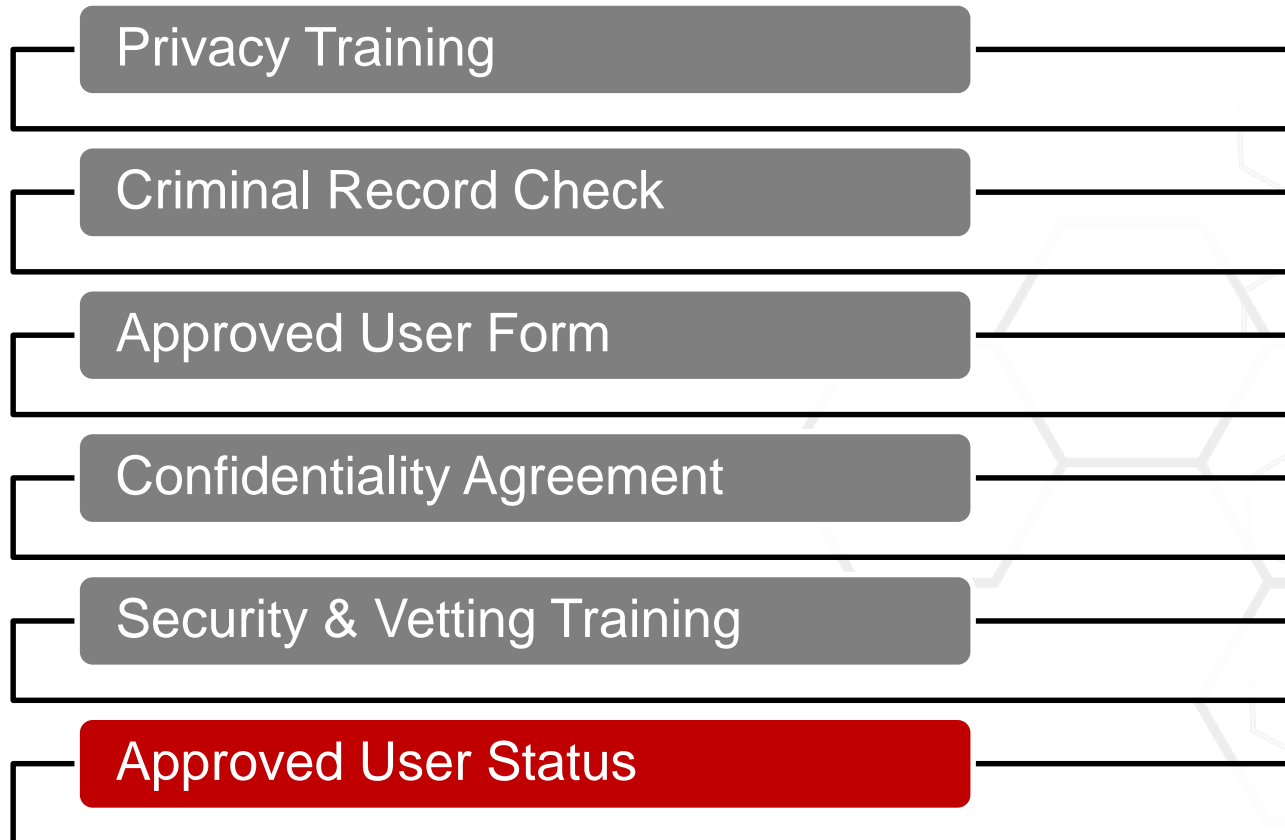
SAFE PROJECTS

Evaluating data analysis projects for appropriateness



SAFE PEOPLE

Evaluating researchers who see data



SAFE SETTINGS

Data access

Two factor authentication to enter

Unique User Names & Passwords

Work stations disabled

Worked saved on local server

Network air gapped

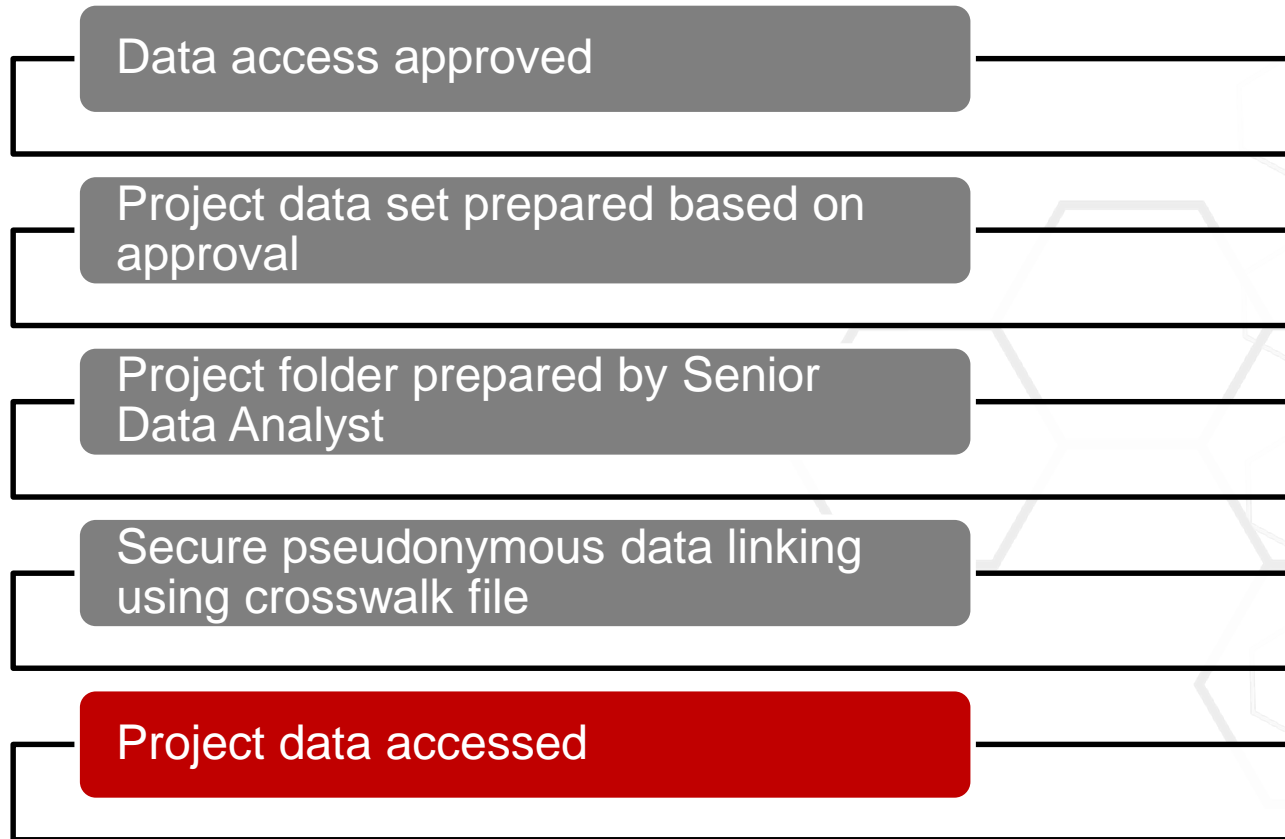
Satellite sites – zero-clients

No mobile devices

Secure Research Environment

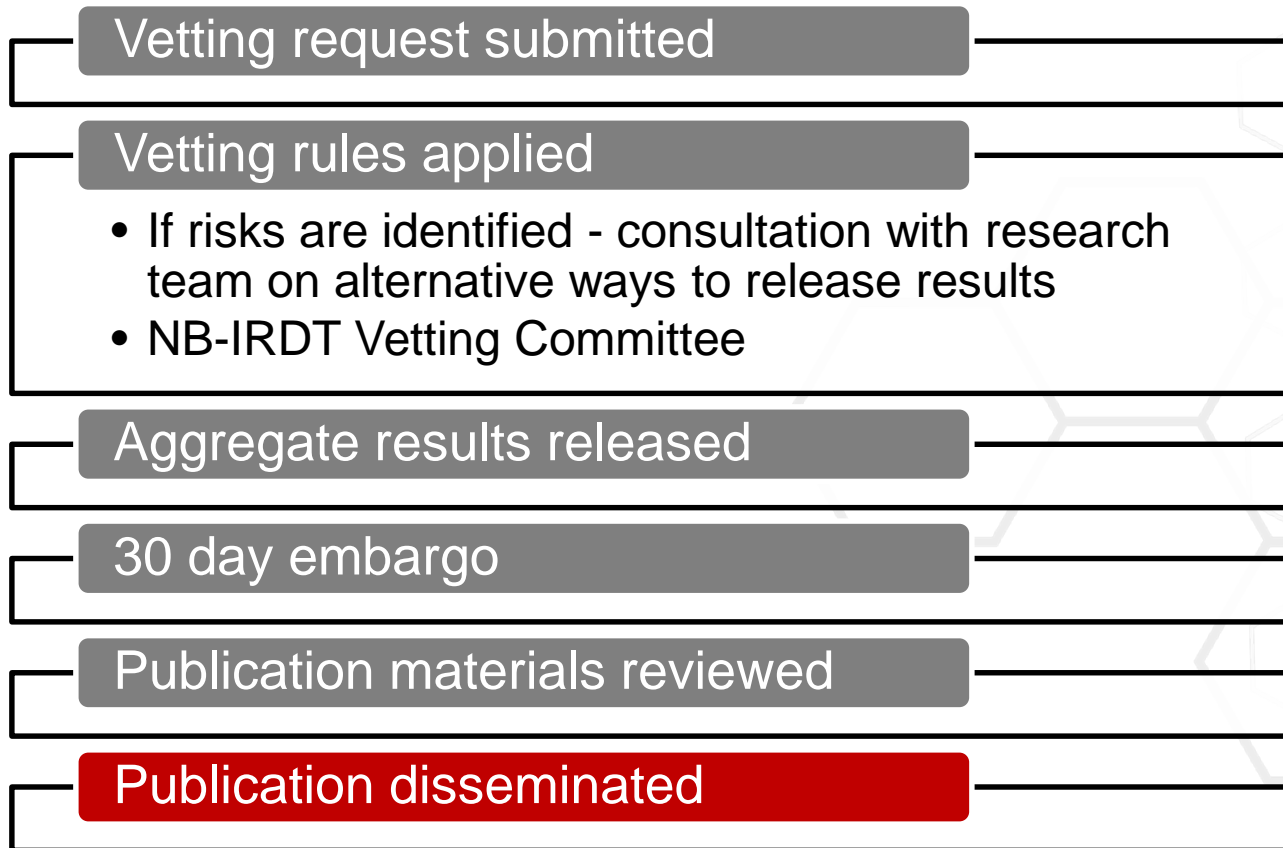
SAFE DATA

Verifying and Mitigating Disclosure Risk in the Data



SAFE OUTPUTS

Verifying and Mitigating Disclosure Risk in Statistical Analysis Results and Tabulations



TRANSFERRING DATA TO NB-IRDT

Confirm appropriate agreement

Identify data set

NB-IRDT data transfer documentation

- Data Sharing Agreement
- Individual Disclosure Schedule
- Privacy Impact Assessment

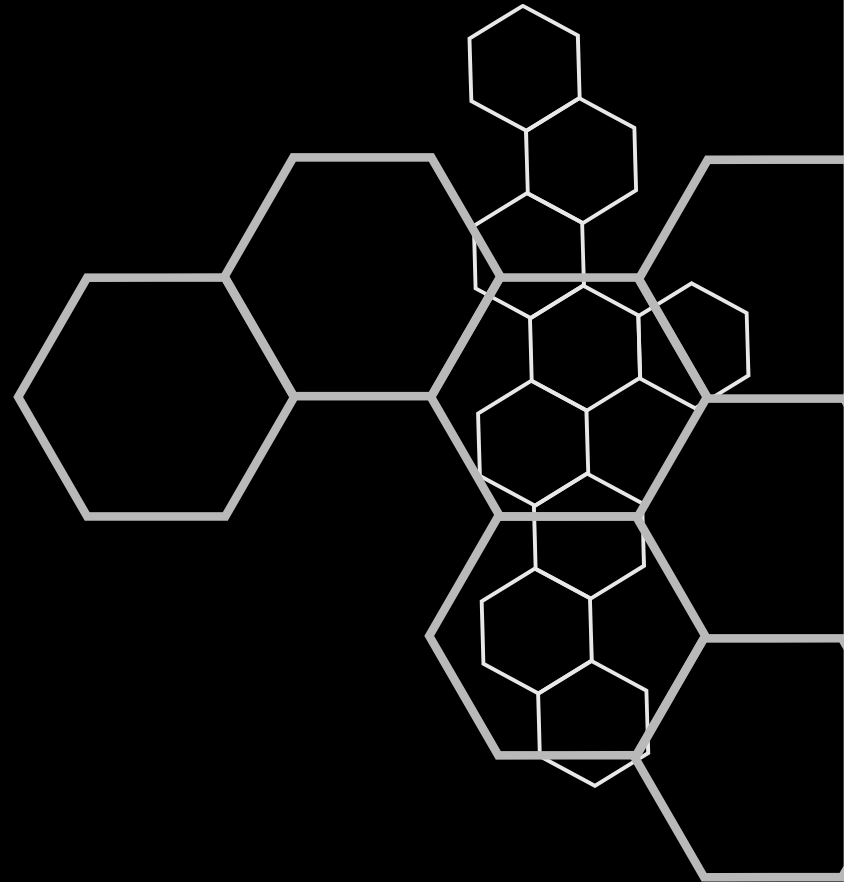
DH data transfer documentation

- Data Sharing Agreement
- Crosswalk File application

Data preparation

Data transfer

Relationship with the Government of New Brunswick



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

MEMORANDUM OF UNDERSTANDING

Signed by President of UNB and GNB Clerk Feb 2018

Commits both GNB and UNB to:

- Long term sustainability of NB-IRDT
- Annual Research Plan
- Annual Training Plan
- NB-IRDT as “researcher of choice” for GNB

Reaffirms participation in GNB / NB-IRDT governance committees



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

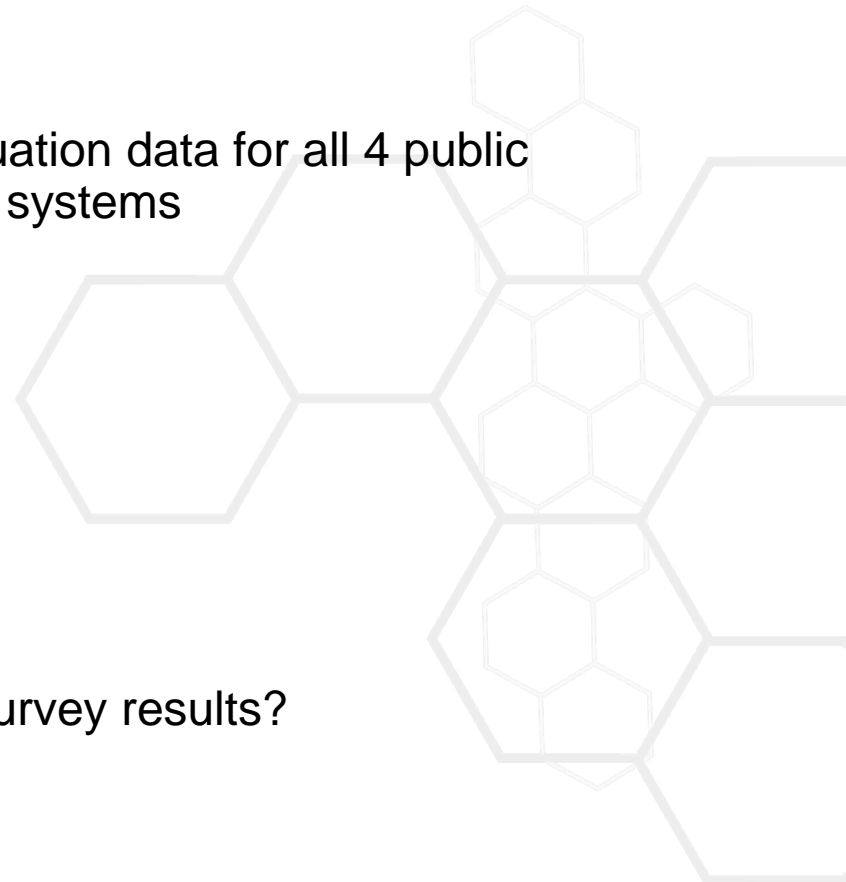
RESEARCH AGREEMENTS WITH GNB

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?



RESEARCH AGREEMENT WITH THE COUNCIL OF ATLANTIC MINISTERS OF EDUCATION AND TRAINING (CAMET)

- Analysis of postsecondary education outcomes for residents of Atlantic Canada using linked administrative data
- Using:
 - K-12 school data
 - Post-secondary enrollment and graduation data
 - Tax filer data (via the Statistics Canada Research Data Centre)
- To study:
 - The choice to enter postsecondary education
 - Geographic mobility following graduation
 - Labour market outcomes following graduation

OTHER RESEARCH WITH GNB UNDERWAY / IN DEVELOPMENT

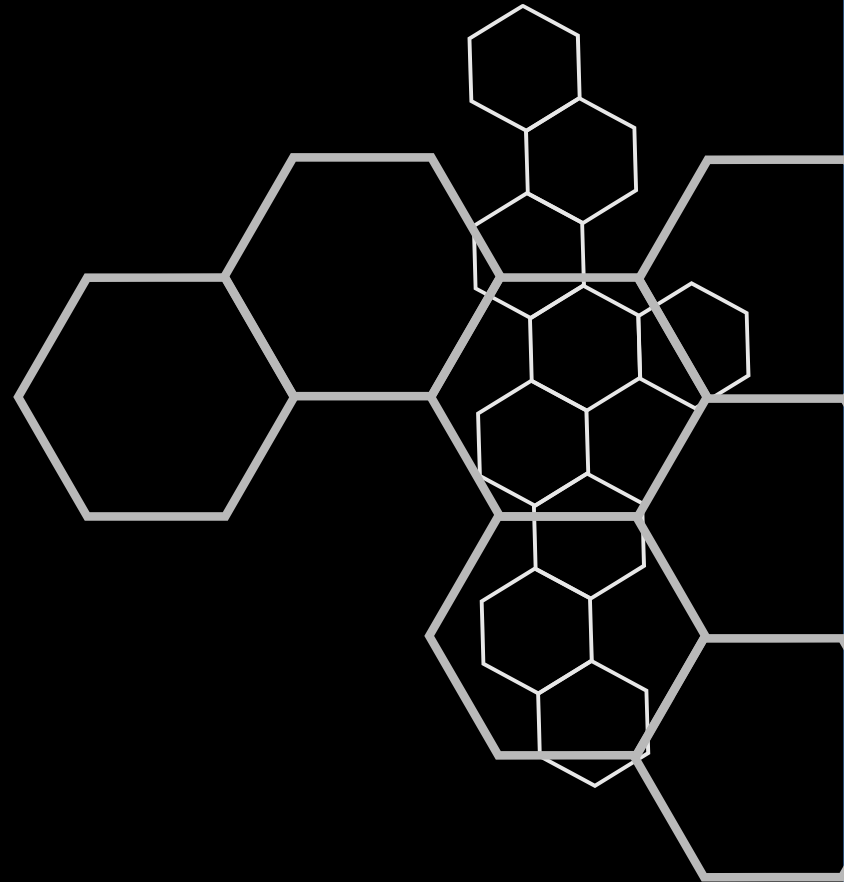
- **Public Safety and the Chief Coroner** – Suicide prevention and infrastructure
- **Environment and Local Government** – Health effects of industrial activity
- **Social Development** – Non-profit organization data development and program evaluation
- **Departments of Health and Social Development** – pathways from home care to hospital *alternative level of care* to nursing home care

COVID-RELATED RESEARCH

- Seven rapid reviews and forecast reports
- Measuring vulnerability and resiliency in NB communities
- Socioeconomic status and the take-up of COVID testing
- Analysis of COVID exposure using serology testing



Enablers of Success
(so far)



FEATURES OF THE NB APPROACH

- NB-IRDT is a data custodian with a clearly defined research mandate
- Central role played by the GNB Executive Council Office in integration, sustainability and oversight
- Corporate role played by GNB Department of Health for data matching
- No UNB affiliation is required to access data
- No restriction on who can request to access data but the purpose must be legitimate research
- Standard templates for data sharing agreements and privacy impact assessments for data transfer to both NB-IRDT and GNB DH
- Politically neutral

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

WHERE TO NOW?



- More structured relationship with GNB – priority setting, resource allocation, inter-departmental collaboration, evaluating longer term program effects
- More federal-provincial data linkages through Statistics Canada
 - Interprovincial comparisons
 - Longitudinal analysis
 - Income tax and Census linkages
- More joint problem-solving

CONTACT INFORMATION

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