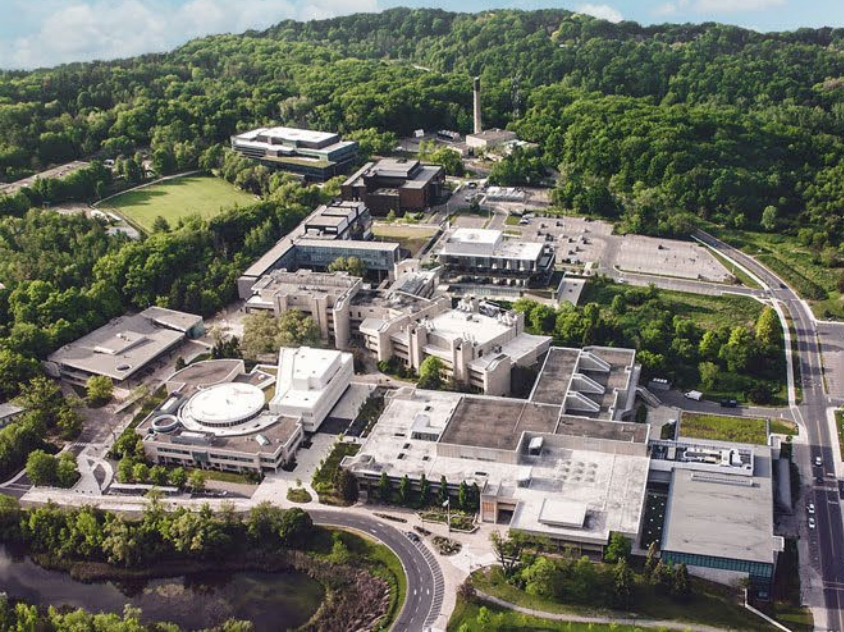


Common Review Process for Accessing Institutional Data for 'Non-Routine' Purposes

Institutional Research and Data
Governance Office



Goal

To create a common process for managing requests to collect new data or to access data for non-routine purposes that will:

- Provide a single point of contact for applicants.
- Assist applicants with the application process and subsequent data supports once access has been granted.
- Reduces administrative burden

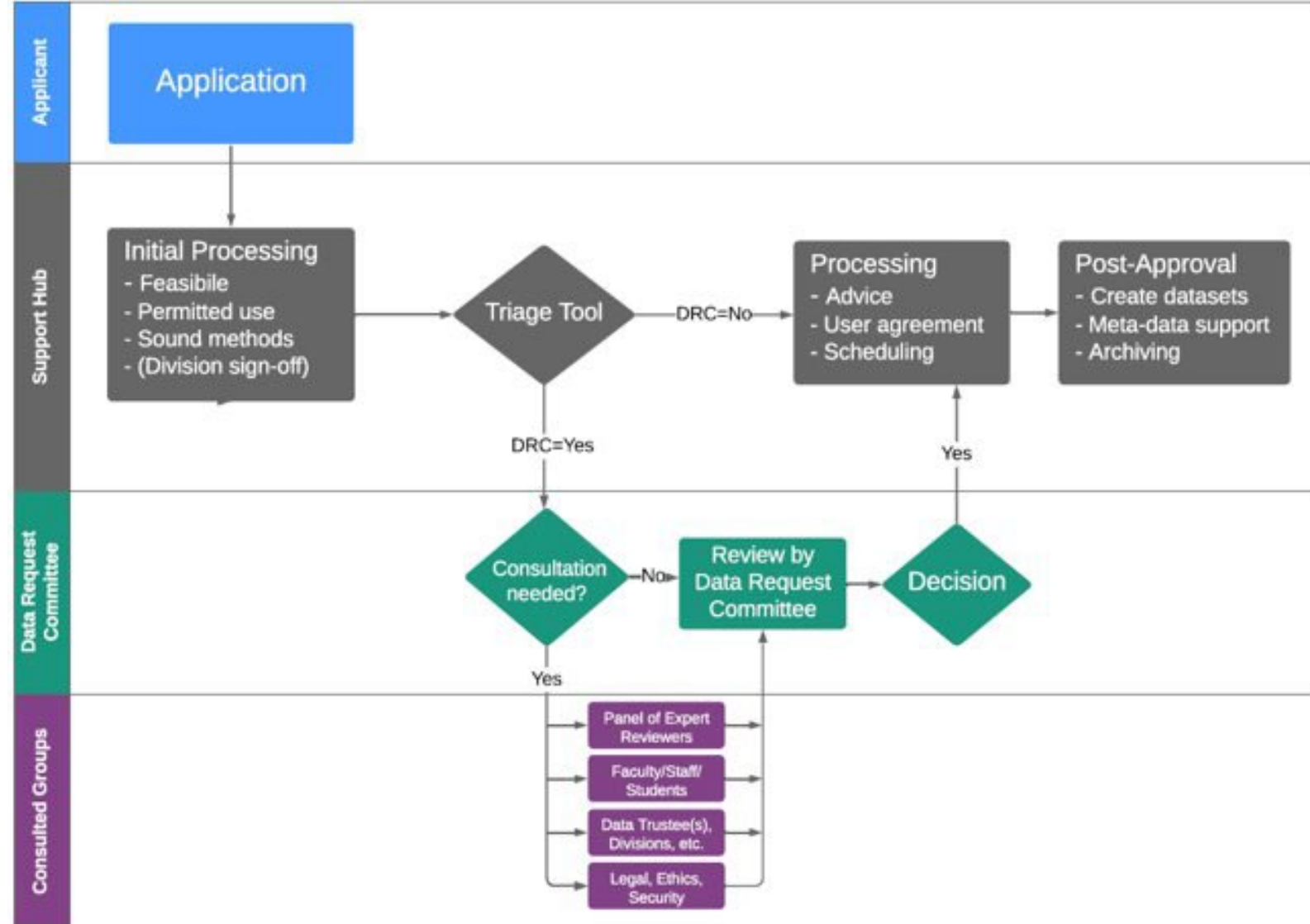
Examples of Non-Routine Uses of Institutional Data

- Scholarly research
- Highly sensitive data fields
- Highly sensitive analyses
- Results may become publicly available
- Data used to contact individuals
- Data used to influence directly/indirectly
- Unprecedented data linkages
- External partnerships

Key Elements

- Single point of contact for requests
 - Support hub
- Risk screening tool
 - Triage level of review
- Systematic approach to gaining additional input, as required
 - Data Request Committee
 - Consulted Groups
- User Agreements
- Registry of approved requests and audit capacity

Common Review Process



Data Request Committee

Membership:

- 3 Data Trustees (2 shared services, 1 divisional)
 - 4 – Broad Analytics Expertise (faculty, admin)
 - 1 – Privacy
 - 2 – Research Ethics
 - 1 – Data Security
-
- Other groups may be consulted including Data Trustees, affected parties



User Agreement

- Limit uses and access to those authorized in the protocol
- Advise if amendment or suspension of protocol
- Security measures (physical, technical, procedural)
- Whether or not investigator may contact data subjects
- Publication
 - Sufficiently de-identified data
 - Limitations on data to be released (e.g. to publisher) for verification
- Confidentiality obligations – beyond the expiry of the Agreement
- Signed by DRC Chair, on behalf of Data Trustee

Benefits of a common review process

Process feature

- Transparent and consistent process
- Consistent handling of (sensitive) data
- Input of affected parties
- Audit process
- Meta-data & analytics support
- Methodologic review of proposals/reports, as needed



Outcome

- More equitable access and greater efficiency for end-user
- Improved data protection
- Greater trust
 - data subjects, data users, public
- Improved analytics
- **Reduced burden on data trustees**
- **Non-routine become routine over time**