Data Access Compliance Office (DACO) Annual Report

DATE: Year 2022
*Statistics for this report were calculated on March 01, 2023

1. Background

The purpose of the DACO is to manage access to ICGC's controlled data through application requests (DACO Application for Access to the Controlled Data). Researchers submit their access requests directly to the DACO, who in turn reviews these access requests to ensure compliance with ICGC policies. The Data Access Compliance Office (DACO) was created as an independent body to review access requests for ICGC's controlled data. Operational since July 2010, the DACO evaluates projects to ensure that they comply with the goals and policies of the ICGC. Over 1500 new applications submitted by scientists from more than 37 countries have been reviewed by the DACO in the past 11 years. The office's procedures, the application process and the online submission system have evolved over the years to adapt to the increasing number of applications.

The Data Access Compliance Office is governed and administered by the University of Glasgow. The University as Data Controller (Regulation (EU) 2016/679 (General Data Protection Regulation) governs ICGC operations and management, including data access through the DACO, and data processing through the Data Coordination Centre and associated Regional Data Processing Centres. The duties of the processors are specified in a contract with the University of Glasgow as Data Controller.

2. Progress in 2022

Governance

As of February 2022 the governance of DACO moved to the University of Glasgow and a new DACO officer was appointed. The DACO officer is the University delegate authorised to sign and execute the Data Access Agreement. The Data Access Officer passes the final decision on verdicts passed, related policies, and maintains the general operations of the DACO.

To facilitate the new governance model a revised Data Access Agreement (DAA) was drafted and implemented in May 2022 (Version 2.0 Published February 2022).

ICGC DACO Portal Redevelopment

The original DACO application system (DACO v1) software was approaching end of life and a new system was scoped to better the ICGC ARGO context and practices. A new system was developed, tested and piloted between February and May 2022 (DACO v2). The system formally launched late in May 2022 and containing the new improved following features:

- A better user experience with better functionality and flow, and faster response times.
- Enhanced efficiency within the application lifestyle through reducing errors and response time while maintaining security.
- Enabling electronic sign off
- A clean, flexible and lightweight system that can adapt as ICGC ARGO evolves.

All current approved users were migrated across to the DACO v2 system and from May onwards all amendments and new applications must go through the new v2 system.

In line with the renewed DACO system and processes, Policies and Procedures for data Access and Use were updated. Current DACO policies can be viewed here.

3. Cumulative Statistics

Total applications processed by DACO *(including new, annual renewals and resubmitted applications)*	**441**
Applications Rejected by DACO *(applications are rejected if the research project does not comply with the terms and conditions of the Data Access Agreement)*	1

Application Review Statistics

Number of New Applications Processed	285

|	
Number of Renewal Applications Processed and approved	155 /133
Number of New Applications Approved	175

4. DACO Review Process

The DACO does not have a formal committee structure. It exists as an overarching authority with a range of consultants who oversee proposals on an as needed basis. These consultants have expertise in ethics and law, data management, AI and emerging technologies, computational methods and clinical experience and are called to review sessions as applications require them.

DACO aims to standardise reviews and generally assesses applications across 3 Core components of the application, which consist of:

1. **Qualification of users:** Confirming bonafide researchers with real and current affiliations, credible institutions and track records.
2. **Feasibility and scientific merit:** clear descriptions of objectives, scientific rationale, planned outputs and how ICGC Controlled data will be used.
3. **Ethical considerations:** Potential ethical issues and adherence to ICGC policies, including confirming the project poses minimal risk of re-identifying participants.

5. Application Processed by DACO per Year

Applications Processed by DACO by Year
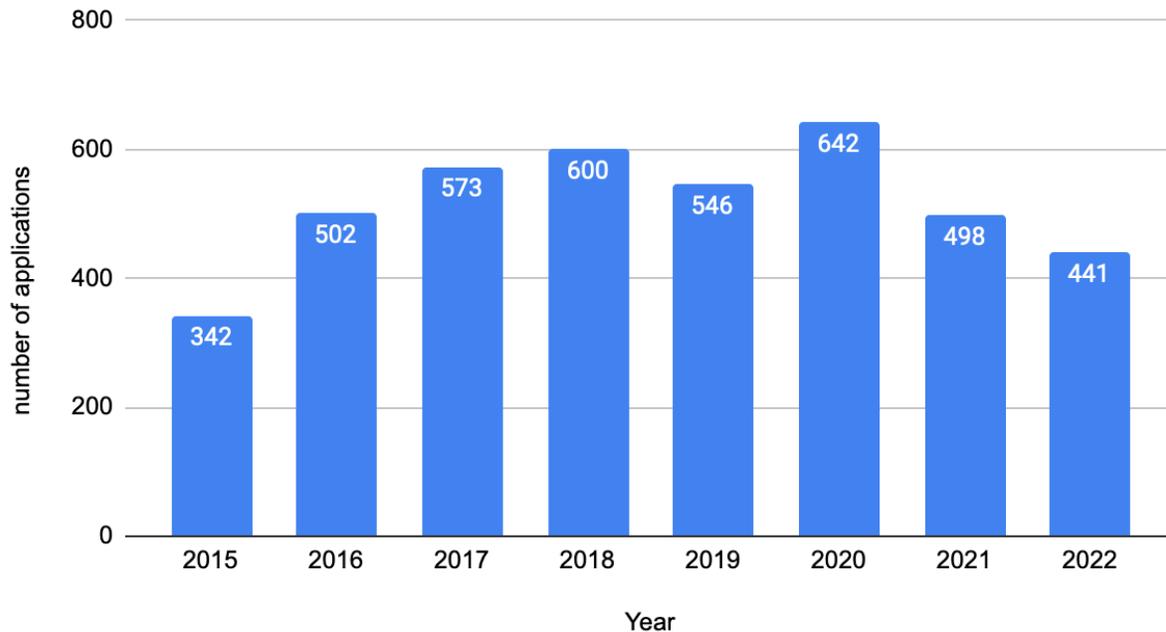
6. Applications Process Time

Average time to process a new application (from the date of reception to initial assessment):
3.5 days (based on the last 10 applications processed).

7. Data Breach

Security incidents or data breaches continue to remain very low within ICGC. 1 breach of the data access agreement was reported to the DACO which involved failure of an approved user to notify DACO of changes to the research team prior to accessing controlled data. The issue was swiftly rectified therefore no further action was required. The event did not result in a data breach, and a report was filed as per the Data Breach Policy procedures.

8. ICGC Data User Demographics

Data from Approved Applications:
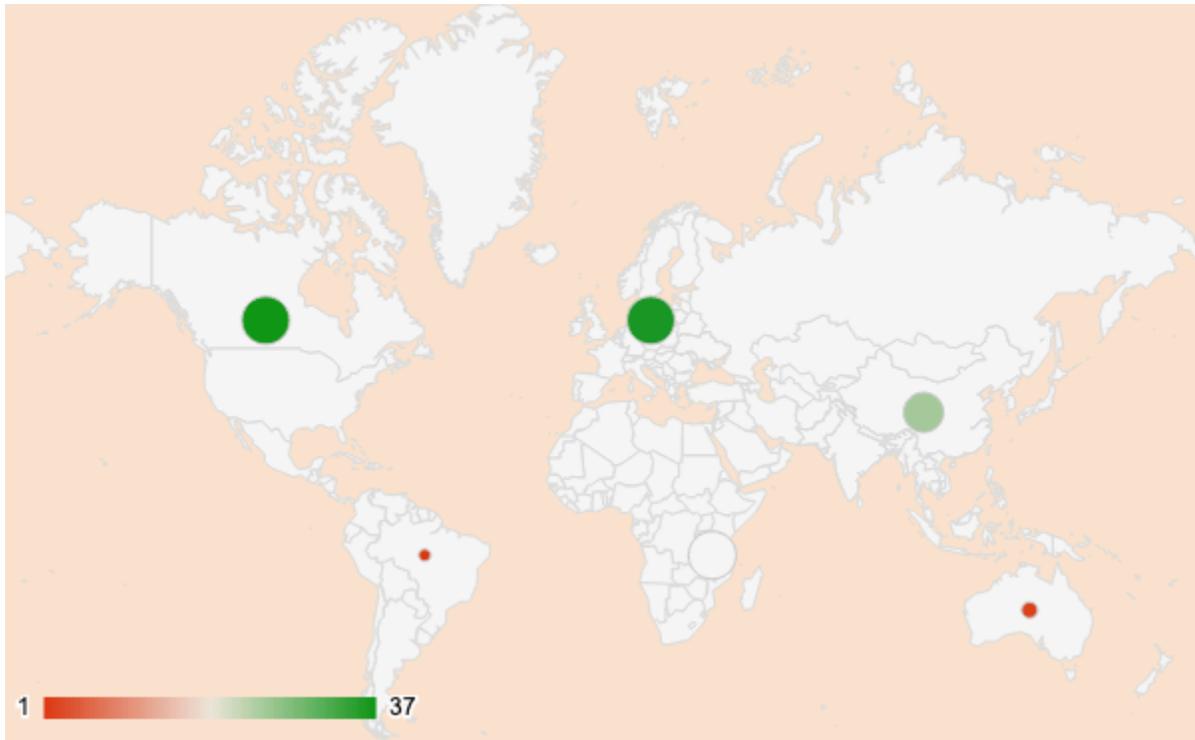
Public VS Private Sector

Public vs Private Sector Applications

Private/commercial
11.0%

Public/academic

Public/academic
89.0%
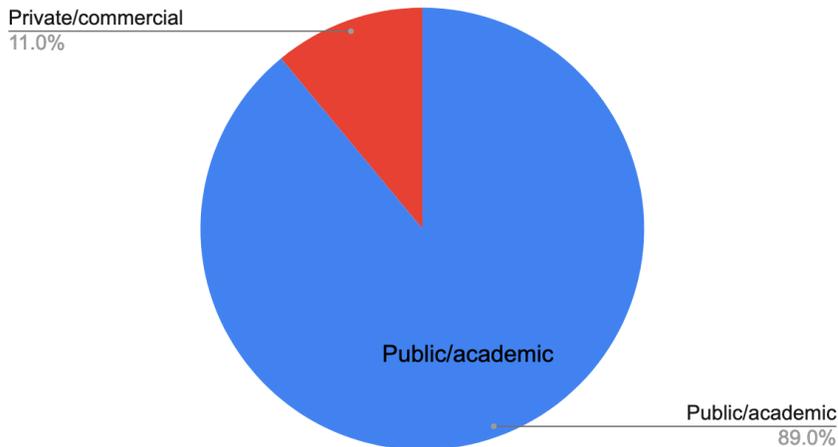
Geographical Location of Approved Applications:

Applications from **38** different Countries

Application Distribution	
North America	37%
Europe	36%
Asia	25%
Australia	2%
South America	1%
Africa	<1%

Top 5 Countries		Number of Approved Applications
1	USA	96
2	China	26
3	UK	25
4	South Korea	16
5	Canada	16

9. List of Applications Approved in 2022

The ICGC DACO is pleased to have provided research organisations access to diverse datasets for a variety of cancer research priorities. You can view the full list of approved studies here.