TRUST Data Access Committee

Annual Report FY2023

TRUST

IMPROVING HEALTH OUTCOMES THROUGH TRUSTED DATA EXCHANGE

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MINISTRY OF HEALTH SINGAPORE

SMART NATION & DIGITAL GOVERNMENT OFFICE

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To our TRUST Stakeholders and Partners

It is my pleasure to introduce the first annual report of the Trusted Research and Real world-data Utilisation and Sharing Tech (TRUST) Data Access Committee (DAC). TRUST, the national platform for health-related research, scaled-up to be a fully operational platform in November 2022, bringing onboard a wide range of datasets to support users and their research.

In FY 2023, researchers could access nearly 40 real-world datasets such as government administrative data, national registries, and national lifestyle programme data through TRUST. During the past year TRUST also supported 107 TRUST users, as part of 17 approved data requests.

Since operationalisation, eight public research organisations (PROs) are onboard as TRUST Partners and TRUST is actively exploring partnerships with seven more PROs. Beyond our initial support of the local research community, we are also establishing a framework to support industry access to TRUST. This is an exciting new phase for TRUST as we look to support more researchers and unlock greater health and social benefits for Singapore and Singaporeans.

The members of the TRUST DAC played an integral role in realising the progress made to date. They undertook this task on a voluntary basis, generously contributing their time, knowledge and perspectives. As some members are finishing their term of service, the positive impact they made for the public interest and social good, will be appreciated across the research and broader healthcare community.

The TRUST DAC Secretariat also deserves special mention. They play an essential part in ensuring the DAC is able to conduct its assessments in a timely and professional manner. They worked hard and successfully to uphold the integrity of processes and the public trust that data is accessed securely to generate valuable insights.

This report covers the data access requests for the first year of operationalisation, which in turn was only possible because of efforts in the preceding three years by colleagues at the Ministry of Health (MOH), the Government Technology Agency (GovTech), the Smart Nation and Digital Government Office (SNDGO) and Synapxe to plan and set up the TRUST platform. The results shared in this report are a testament to their perseverance and ambition.

Whether you are a researcher, data contributor, administrator, or a member of the public, thank you for your support of TRUST.

Philip Ong
Deputy Secretary (Development), Ministry of Health
Chair, TRUST Data Access Committee

Introduction to TRUST and the DAC

TRUST ("Trusted Research and Real world-data Utilisation and Sharing Tech") is a national health-related data governance framework and technical platform that supports health research analytics to improve health outcomes.

TRUST aims to address key data challenges faced by researchers. These challenges include limited access to data due to lengthy negotiations between data sources, varied data standards that hinder data linkage and analytics, and the absence of a secure platform and trusted third party to enable data access and linkage.

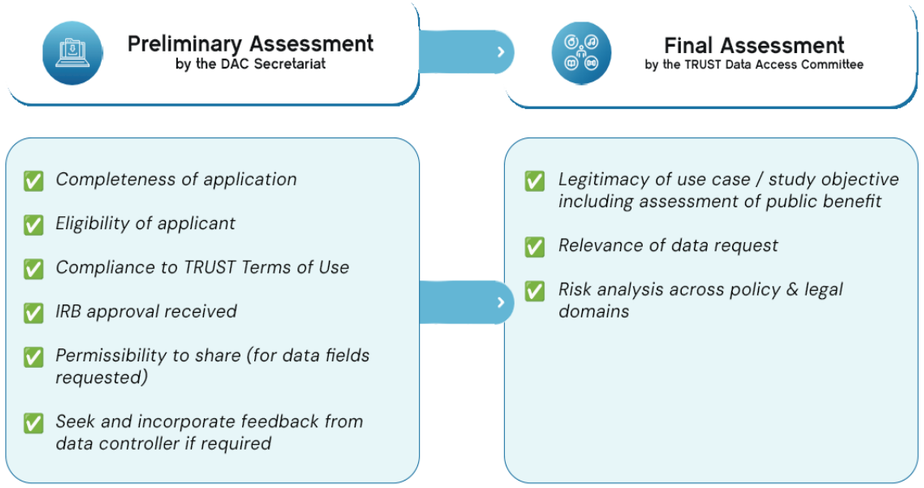
TRUST facilitates safe, expeditious and secure data sharing, linkage and analysis of anonymised health-related research and real-world/administrative data between public institutions and non-government entities.

TRUST Data Access Committee (DAC)
The TRUST DAC was set up to enable expeditious access to data to support research and innovation while upholding data governance according to the pre-agreements between TRUST and the Data Contributors. The TRUST DAC has thus been delegated the authority to approve data access on behalf of the Data Contributors, and serves to ensure that the right balance is maintained between advancing public interest through health innovations that contribute to better health outcomes while protecting individuals' privacy and confidentiality.

The composition of TRUST DAC adopts group representation approach and takes reference from Public Sector Master Research Collaboration Agreement (PSMRCA).

It is made up of the following:

- Business Owner (Chair): MOH
- Government Data Representatives: SNDGO, Department of Statistics
- Performers / Institutional Representatives: SingHealth, National University Health System, National Healthcare Group, National University of Singapore, Nanyang Technological University, Agency for Science Technology and Research, Consortium for Clinical Research and Innovation, Singapore, Duke-NUS Medical School
- Non-institutional Representatives: Ethics, Legal, Lay-person



▲ Figure 1: The DAC assessment process

Note: There is flexibility for TRUST DAC to include other domain experts (i.e. lifestyle, phenotypic, genomic, translational research) in areas not already covered by the above representatives when required.

TRUST Data Request (TDR) Review Process
Complete data requests received by the last Friday of each month will be assessed and reviewed by TRUST DAC within four to six weeks. TRUST DAC meets once a month to review data requests, except for the month of December.

Each data request will undergo two stages of assessment (Figure 1). At the first stage, DAC Secretariat will conduct a preliminary review to ensure that the documentation is complete and all necessary information in the TDR form (e.g. justification for data requested) have been provided.

At the second stage, TRUST DAC will ensure the legitimacy of the research and relevance of the data requested by reviewing the scientific, clinical, and health value of the data request. DAC Members are required to declare any conflicts of interest (e.g. if they form part of the research group submitting the TDR). Any Member who declares a COI will subsequently recuse themselves from the approval process.

TRUST DAC will ensure that the purpose of use fulfils public interest and is assessed to be of social value, and evaluate the risk benefit of the data requested. TRUST DAC can also request more information from the Data Requester after final assessment before making the final decision on the data request. TRUST DAC's decision is final.

Although TRUST DAC is the approving authority for most TRUST data requests, requests for Sensitive Health Information (SHI), rare diseases and data deemed as sensitive by Single Source of Truth (SSOT) would require additional approval from the respective data custodian.

For these, the time to approval would take approximately six to eight weeks.

Following TRUST DAC approval, data is provisioned to the approved users six to ten weeks post-approval (on average). The total time for provisioning could differ depending on the complexity of data requested.

Looking Ahead
In the upcoming year, TRUST aims to widen the reach of the platform and improve operational efficiency through a number of initiatives, including:

1. Expanding partnerships to include a selected number of strategic industry partners through the TRUST Industry Access Framework (IAF);
2. Rolling out a new TDR form to streamline the process for applicants and better define the information required to assess each data request;
3. Reorganising the data catalogue and curating commonly requested datasets. This will make it easier for researchers to find the right data for their studies.

DAC Review Statistics at a Glance

TRUST commenced operations from November 2022 and as of March 2024, we have received a total of 25 data requests, and 17 were approved. We have also supported two collaborative projects that do not require TRUST data but tap on TRUST only as a technical platform.

Total Number of Requests Received (a) + (b) + (c) + (d) = 25	
(a) No. of Requests Approved by DAC / SSOT	**17**
Collaborative projects that do not require TRUST data	2
Request for TRUST Data	15
(b) No. of Requests that Are Not Approved	**1**
(c) No. of Requests that are Out of Scope #	**1**
(d) No. of Requests in Preliminary Assessment Phase^	**6**

A research is deemed out of scope if it falls out of the RIE2025 Health and Human Potential domain, viz (i) Cancer and neoplasms, (ii) Cardiovascular, (iii) Metabolic and endocrine, (iv) Mental health, (v) Infection, (vi) Neurological and (vii) Eye.
^ Requests under this category are pending Data Requesters' response to DAC Secretariat queries, clarification and advice to improve the data request.

Commonly Requested Datasets

This section details the most commonly requested datasets (i.e. top five categories).

Data Categories	Datasets	No. of Datasets	Data Contributor
Health	Accident & Emergency Beds Case & Visit Diagnosis Drugs Laboratory/Radiology National Diabetes Database Operating Theatre & Surgery Polyclinic Patient Management	10	MOH
Health Finance	Community Health Assistance Scheme (CHAS) Finance and Billing Private Insurance	3	MOH
Birth & Death Registry	Birth Registry Death Registry	2	ICA
Socioeconomic Status	Housing Ownership Housing Rental Per Capita Household Income Property Type	4	MOH, HDB
Disease Registry	Cancer Registry Myocardial Infarction Registry Renal Registry Stroke Registries	4	NRDO

List of TRUST Data Requests Approved

Please refer to the Approved Research Projects section of the TRUST website for abstracts of approved TRUST Data Requests.

TDR Reference	Approval Date	Title	Main Applicant
TDR-2022-00001	14 Feb 2023	20-year Trends of Incremental Hospitalizations and Healthcare Costs of asthma and COPD Patients in Singapore	Dr Chen Wenjia, Saw Swee Hock School of Public Health (SSHSPH, NUS)
TDR-2022-00003	8 Mar 2023	Healthcare expenditure costs of women with GDM and their children in the GUSTO (Growing Up in Singapore Towards Healthy Outcomes) cohort	Dr Evelyn Loo, Singapore Institute for Clinical Sciences (SICS, A*STAR)
TDR-2022-00004	28 Mar 2023	Linkage of HELIOS data for Technical Evaluation and Training	Professor John Chambers, Precision Health Research, Singapore (PRECISE, CRIS)
TDR-2023-00001	26 Jun 2023	Developing a Core Real WOrld Dataset for Economic Evaluations of Oncology Therapies (RODEO)	A/Prof Wee Hwee Lin, Swee Hock School of Public Health (SSHSPH, NUS)
TDR-2023-00002	1 Jun 2023	Genomics Risk Factors in COVID-19 Pandemic	A/Prof Barnaby Young, National Centre for Infectious Disease (NCID, NHG)
TDR-2023-00003	30 May 2023	JARVISDHL: Transforming Chronic Care for Diabetes, Hypertension and Hyperlipidemia (DHL) with AI	Prof Wynne Hsu, Institute of Data Science (NUS)
TDR-2023-00004	26 Jan 2024	The Singapore National Steps Challenge – Where We Are Now and Where Do We Go From Here	A/Prof Falk Müller-Riemenschneider, Swee Hock School of Public Health (SSHSPH, NUS)
TDR-2023-00005	31 Jul 2023	AI4HealthyCities Singapore: Using the Power of Data to Improve Cardiovascular Health Outcomes and Equity	Dr Tan Sock Hwee, Cardiovascular Disease National Collaborative Enterprise (CADENCE, CRIS)
TDR-2023-00006	31 Jul 2023	Infectious Disease Modelling and Analytics in the Post-Pandemic Era	A/Prof Alex Cook, Swee Hock School of Public Health (SSHSPH, NUS)
TDR-2023-00007	26 Jan 2024	Long-term Outcomes of Heart Failure Cohort (ATTRaCT) and Health Services Analysis	Dr Roger Foo, National University Heart Centre (NUHCS, NUHS)
TDR-2023-00009	1 Dec 2023	Studying disease progression and complication development in Diabetes, Hypertension and HyperLipidemia (DHL) Patients in SingHealth Polyclinic and TRUST Platform	Prof Tan Ngiap Chuan, SingHealth Polyclinic (SHP, SingHealth)
TDR-2023-00010	1 Dec 2023	National Health Economics on Cancer	Dr Kennedy Ng Yao Yi and Dr Iain Tan, National Cancer Centre (NCC, SingHealth)

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TDR Reference	Approval Date	Title	Main Applicant
TDR-2023-00011	1 Dec 2023	Singapore Microsimulation Model to Assess Interventions to Improve Diet	Asst Prof Chay Junxing, Lien Centre for Palliative Care (Duke-NUS)
TDR-2023-00013	2 Apr 2024	Predicting the Risk of Systemic Diseases Using Eye Images: Clinical and Cost-Effectiveness	Prof Cheng Ching-Yu, Singapore Eye Research Institute (SERI, SingHealth)
TDR-2023-00014	26 Jan 2024	Time to Treatment Initiation and Survival in a Cohort for Different Types of Cancers using Singapore Cancer Registry Data	Stephanie Catharina Charlotte van der Lubbe, Yong Loo Lin School of Medicine (YLLSOM, NUS)
TDR-2024-001	29 Feb 2024	Viral Infections & Cardiovascular Outcome Study	Dr Tan Sock Hwee, Cardiovascular Disease National Collaborative Enterprise (CADENCE, CRIS)
TDR-2024-002	27 Mar 2024 (approval finalised on 2 Apr 2024)	The PRECISE-SG100K Programme	Professor John Chambers, Precision Health Research, Singapore (PRECISE, CRIS)

For Prospective TRUST Data Requestors

To assist prospective TRUST Data Requestors with their TRUST Data Request, a 'Guide to preparing and submitting quality data requests on TRUST' is available in the TRUST Member's Portal. We advise all prospective TRUST Data Requestors to engage TRUST early for advice on the data required for their research and to ensure that their TDR is ready and complete for TRUST DAC review on time.

Requestors should ensure the following before submitting the TDR to TRUST. Any incomplete information and application will lead to delay in review or rejection.

- Public interest and social value and pathway to achieve those are clearly articulated in the TDR;
- Sufficient justification for data requested is provided;
- Institutional Review Board (IRB) application and approval or proof that IRB review is not required (RNR) for the scope of the research, data requested and linkage;
- All administrative fields (e.g. applicant information, DRA number, period of research) are filled, with relevant documents (personal undertaking forms, main applicant CV) provided; and
- Application is endorsed by all relevant parties (e.g. institution, government/agencies, collaborators, co-PIs).