TRUST

IMPROVING HEALTH OUTCOMES THROUGH TRUSTED DATA EXCHANGE

trustplatform.sg

"Trusted Research and Real world-data Utilisation and Sharing Tech"

Koh Mingshi
Director, TRUST Office, MOHT

SCRI Clinical Trial Symposium, 31 Jul 2024

Jointly developed by:

MINISTRY OF HEALTH SINGAPORE

SMART NATION & DIGITAL GOVERNMENT OFFICE

synapxe

GOVTECH SINGAPORE

Agenda

- What is TRUST?
- How we enable safe and efficient data linkage and analytics
- What is on the horizon
- Supporting clinical trials design and research

TRUST

IMPROVING HEALTH OUTCOMES THROUGH TRUSTED DATA EXCHANGE

What is TRUST

‘Trusted Research and Real world-data Utilisation and Sharing Tech’

How TRUST addresses key data challenges faced by researchers

UNCLEAR DATA ACCESS RULES

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CLARIFY PERMISSIBILTY OF USE; OPEN UP ACCESS

- Data permissibility rules and governance for key datasets has been clarified.
- Streamlined **pre-agreements** with data custodians and users.
- Established **central Data Access Committee** for streamlined and efficient data approval.

VARIED DATA SECURITY & INFRASTRUCTURE

↓

NATIONAL DATA-EXCHANGE PLATFORM

- Established **secure environment on Government Commercial Cloud** for data linkage, access and analysis
- Established **Trusted Third Party to enable linkages across datasets** and anonymisation tool according to MOH anonymisation standards.

LACK DATA STANDARDS

↓

DATA CATALOGUE & INTEROPERABILITY

- Adopted **internationally recognised data standard** (e.g. OMOP*).
- A central data curation team has been set up and OMOP mapping work is ongoing.

*Observational Medical Outcomes Partnership (OMOP)

TRUST is a data framework and platform to enable health analytics across datasets

One stop to request, access and analyse data

TRUST

IMPROVING HEALTH OUTCOMES THROUGH TRUSTED DATA EXCHANGE

Secure cloud analytical environment within Government Commercial Cloud

Real-World Data
in Vault or Govt agencies' repository

Anonymised and transfer

Real-World Data

Strategic Research Data

Anonymised and transfer

Strategic Research Data
in their own repositories or data aggregators e.g. A*STAR BiomedDAR

Anonymised linked datasets for analysis

"Trusted Research and Real world-data Utilisation and Sharing Tech" Platform

TRUST have enabled high value health-data analytics research

Project #1: Linkage of Genomic-phenotypic-clinical data for Precision Medicine studies

HELIOS Health for Life in Singapore

PRECISE

Support development of analytical pipelines to enable next phase of Precision Medicine studies in diseases such as cardiovascular, metabolic, neurological, psychiatric, ophthalmologic, as well as rare diseases.

Project #2: Linkage of Clinical-lifestyle-social data for better understanding of the social determinants of health to improve cardiovascular health outcomes

CADENCE Cardiovascular Disease National Collaborative Enterprise

Generate new insights into determinants that influence cardiovascular health and equity, to better design interventions for impactful and sustainable cardiovascular outcomes.

Project #3: Linkage of clinical-lifestyle data for transforming Chronic Care for Diabetes, Hypertension & Hyperlipidemia (DHL)

JARVIS

Reduce complication rate in DHL patients by 20% over 5 years through AI models that are built on local real-world data, develop preventive measures and treatment optimization.

Project #4: Linkage of Genomic-clinical data for COVID-19 genomic risk factor study

Agency for Science, Technology and Research SINGAPORE

PREPARE

Assess the prevalence and allele frequencies of host genetic variants determining the susceptibility and severity of SARS-CoV-2 infections in Singapore residents.

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IMPROVING HEALTH OUTCOMES THROUGH TRUSTED DATA EXCHANGE

Currently, TRUST offers ~40 datasets across the following domains

List updated as of July 2024

Population

- Birth & Death
- Passes & Permits
- Citizenship & Residency

Social

- Economic
- Housing
- Education*

*subject to MOE approval

Health

- Polyclinic
- Patient Management
- Surgery
- Laboratory
- Accident & Emergency
- Case & Visit
- Drugs
- Diabetes
- Comorbidity
- Beds
- Radiology

Lifestyle / Preventive Care

- iQuit Smoking
- Leisure Time Activity
- Sleep Tracking
- Steps Challenge
- Screening
- Immunisation

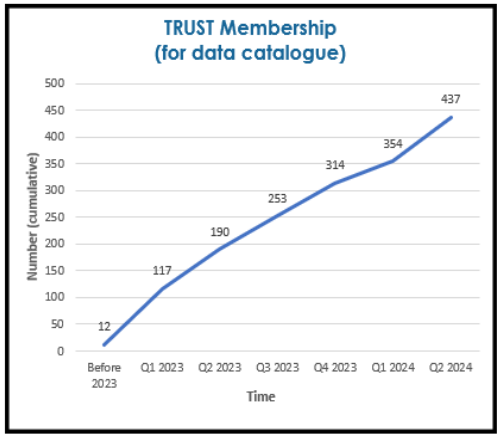
Health Finance

- Community Assistance
- Billing & Subsidy
- Medical Claims

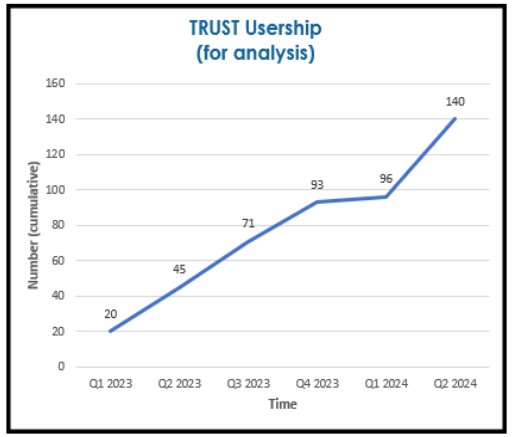
Disease Registry

- Myocardial Infarction
- Stroke
- Cancer
- Renal

TRUST growing usership



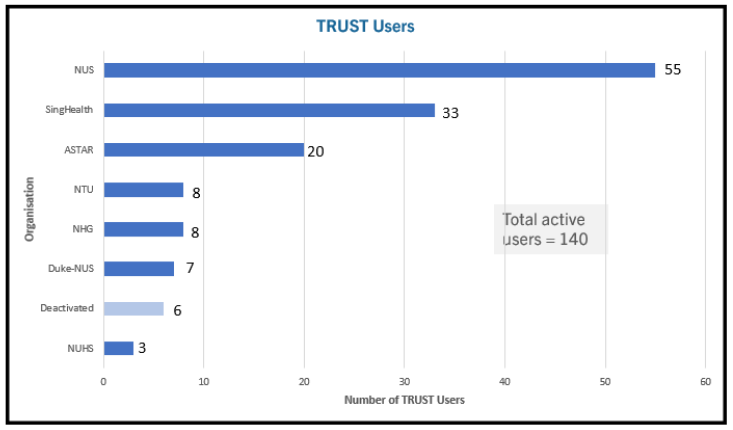
- For access to data catalogue, training materials and TRUST data request application forms
- TRUST Membership grew with an average of **~65 new members each quarter** in 2023
- Q2 2024 data up to 7 June 2024
- Does not include TRUST staff and deactivated accounts



- For access to data analytics portal based on approved TRUST Data Request by TRUST DAC
- TRUST Usership grew with an average of **~24 new users each quarter** in 2023 and **had the highest jump of 44 users** from Q1 to Q2 2024
- Q2 2024 data up to 7 June 2024

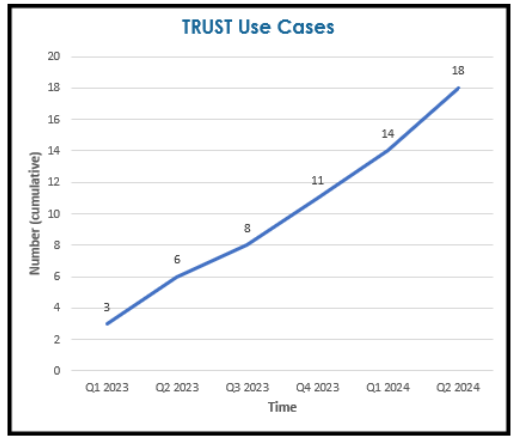
3. TRUST Usership

Breakdown of usership by institution

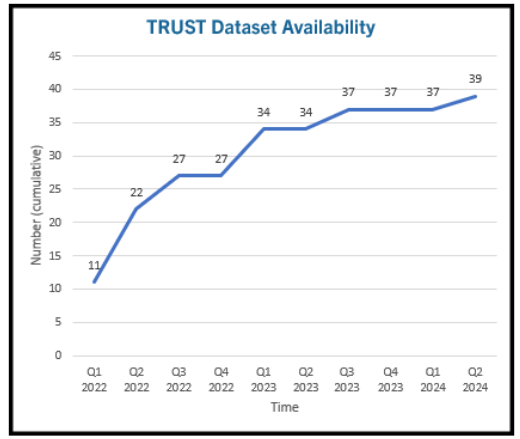


- Majority of TRUST Users come from **NUS** (39%)
- Data is accurate up to 7 June 2024

Notes:
- *Does not include TRUST staff*
- *Deactivated accounts are due to staff resignations from Organisation*



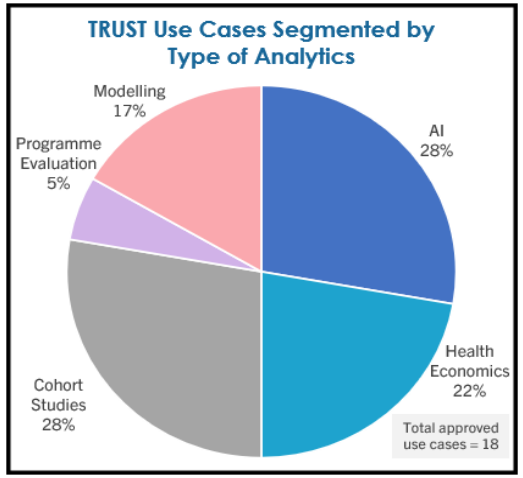
- TRUST use cases grew with an average of **~3 new use cases each quarter** in 2023
- Q2 2024 data up to 7 June 2024



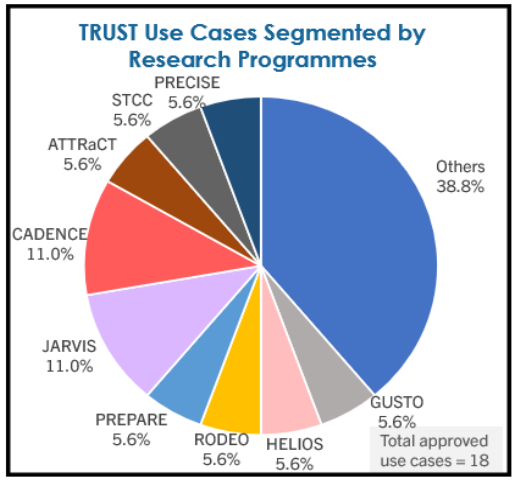
- Available TRUST datasets grew most significantly in **2022 by 20 datasets** when TRUST was gearing up for operation.
- Data up to 7 June 2024

TRUST Use Cases

Approved TRUST Data Requests by TRUST DAC



- Majority of TRUST Use Cases support analytics for **health economics, data-driven health management and AI**



- Majority of TRUST Use Cases come from **large national research programmes**

Key highlights in current phase of development to facilitate data access and sharing

Promulgated data sharing principles and best practices

Established pre-agreements with 12 Public Research Organisations to enable expeditious data access (af 22 April 2024)

Agency for Science, Technology and Research (A*STAR) · Duke-NUS Medical School · CRIS · MOHT (MOH Office for Healthcare Transformation) · Nanyang Technological University Singapore · National Healthcare Group · NUHS National University Health System · National University of Singapore · Singapore Institute of Technology · SMU Singapore Management University · SUSS Singapore University of Social Sciences · SingHealth

Support more genomics & low/no code analysis by 2H 2024

lifebit

Initiated National level effort to harmonise data standard

- **~60% clinical data mapped to** OMOP CDM*
- **Established national partnerships and curation team** on OMOP mapping

*Observational Medical Outcomes Partnership (OMOP) Common Data Model (CDM)

How do we enable safe and efficient data linkage and analytics

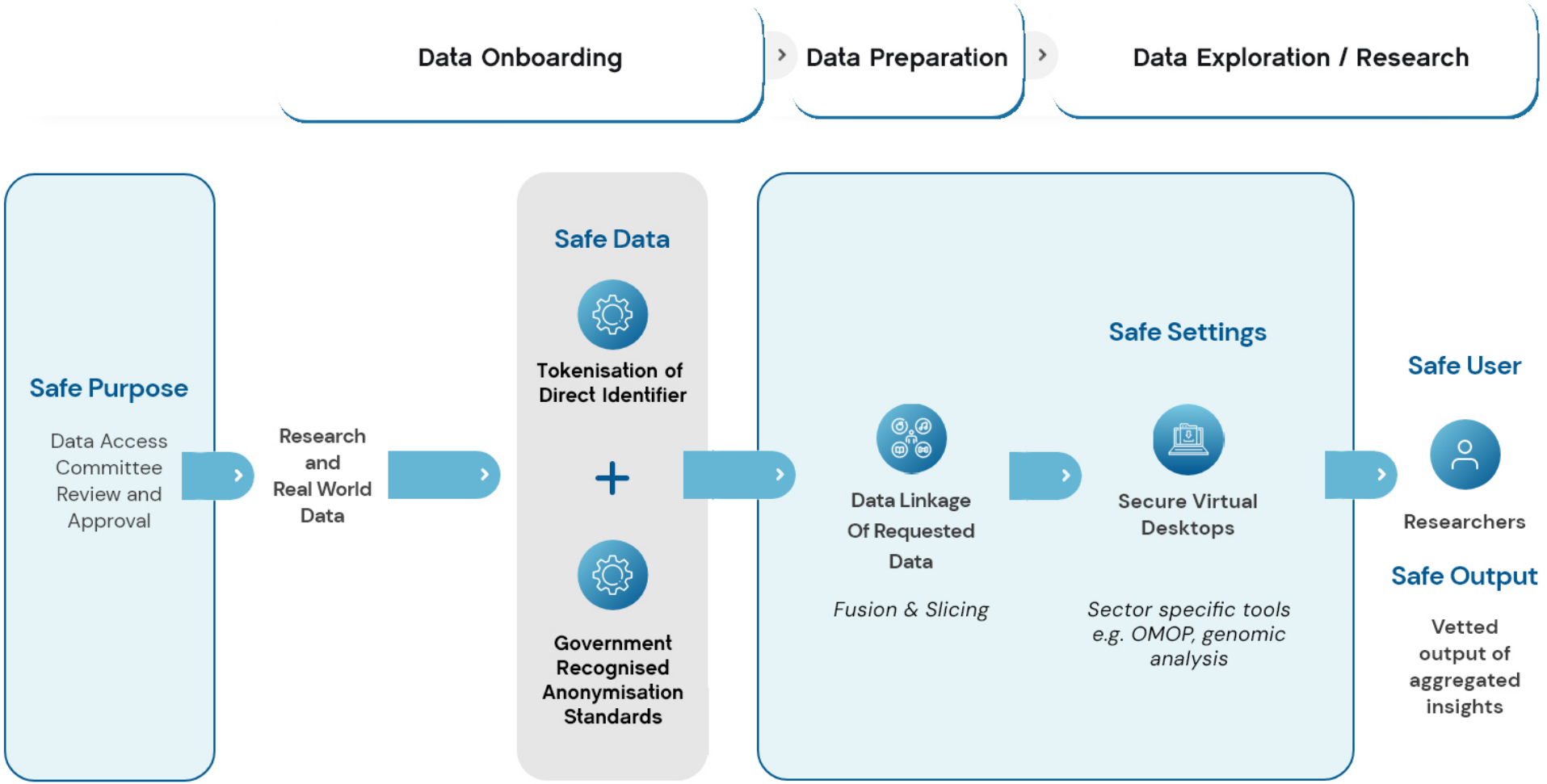
TRUST's core features are built on the 5 Safes Framework, ensuring safe data access

Deploy synergistic policy and technical solutions across the data lifecycle

Balance privacy & public interest with safe use of data

Improved health outcomes & better care delivery

TRUST adopts the Five Safes Framework



TRUST DAC

Mr Philip Ong (Chair)
DS (Development), MOH

Mr Lai Kai Bin
DD, GDO, SNDGO

Ms Lim Yi Ding
D, DOS/TC

A/Prof Yeo Khung Keong
Dy GCMIO (Research), SHS

A/Prof Ngiam Kee Yuan
GCTO, NUHS

A/Prof Tan Cher Heng
GCRO, NHG

Prof Chng Wee Joo
Vice President (Biomedical Science Research), NUS

Prof. Roger Vaughan
D, CQM & CSSD, Duke-NUS

Dr Sebastian Maurer-Stroh
Executive Director, BII, A*STAR

Prof John Chambers
Prof, CVD Epi, NTU
CSO, PRECISE

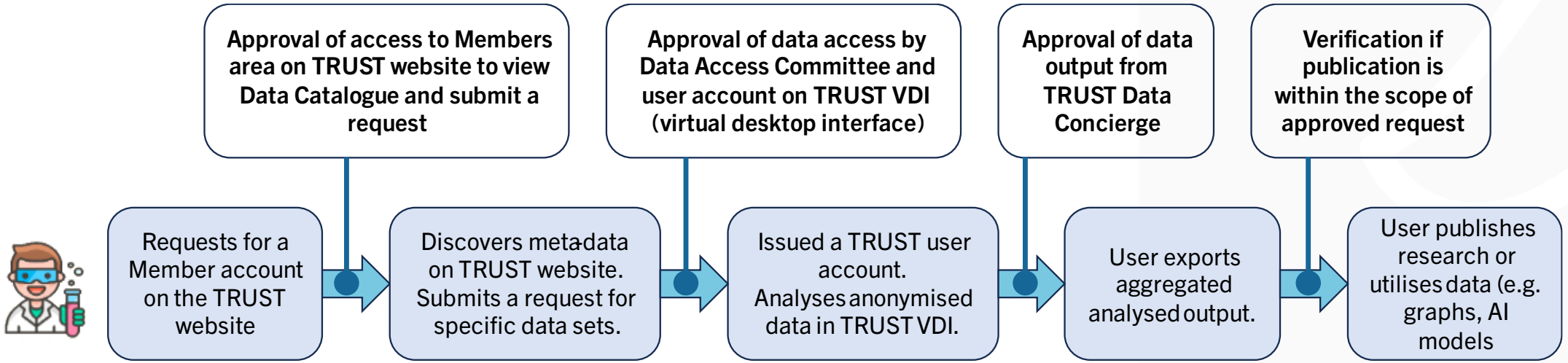
Prof Julian Savulescu
D, Centre for Biomedical Ethics (Ethics Domain)

Prof Simon Chesterman
Vice Provost (Educational Innovation), NUS (Legal Domain)

Ms Ai Ling Sim-Devadas
DD (Advocacy & Engagement), LKCSOM, NTU

Mr Rajakanth Raman
ED, Rainbow Across Borders

Ensuring Data User's expeditious and safe access



a. Approval of data output by TRUST Data Concierge.

- All output must comply with TRUST's output policy, which states that **these must be aggregated/de-identified, generated based on data from at least 5 individuals.**

b. Verification that public release of analysis is within scope of approved request.

- Researchers who wish to publish insights generated from their research on TRUST are required to **submit their publications to TRUST DAC secretariat for pre-publication review.**

TRUST portal as launch point for user to access various features and functions

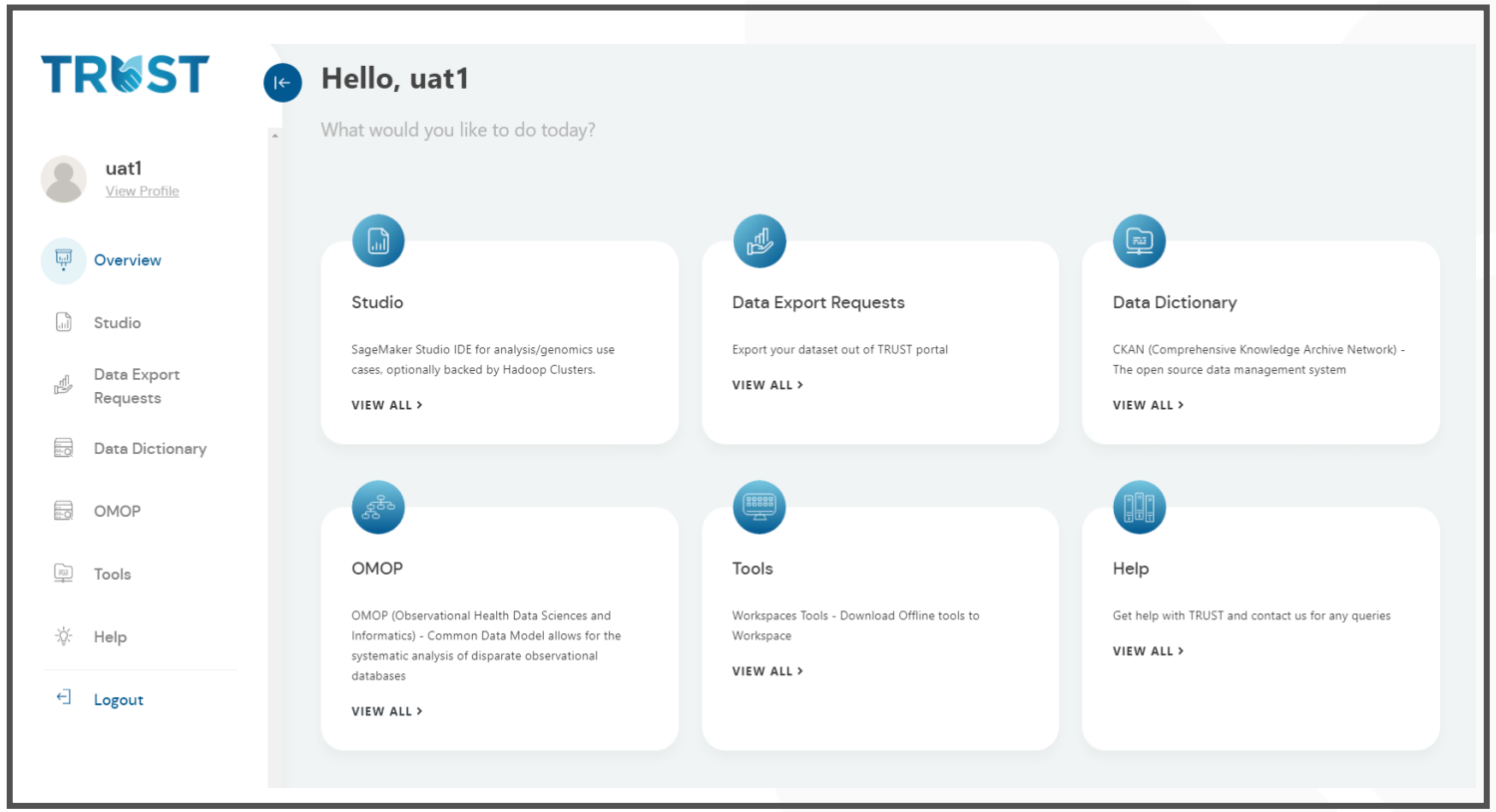
Key Features and Function

- Access to Jupyter Lab via Sagemaker Studio
  - Support on Python, R, Pyspark, and SparkR

- Genomic Tools (2H 2024)
  - Hail in Sagemaker Studio
  - Lifebit genomic platform
    - Cohort Browser for minimal code experience
    - Genomic analysis pipelines

- Export analytical insights and findings with just a few clicks

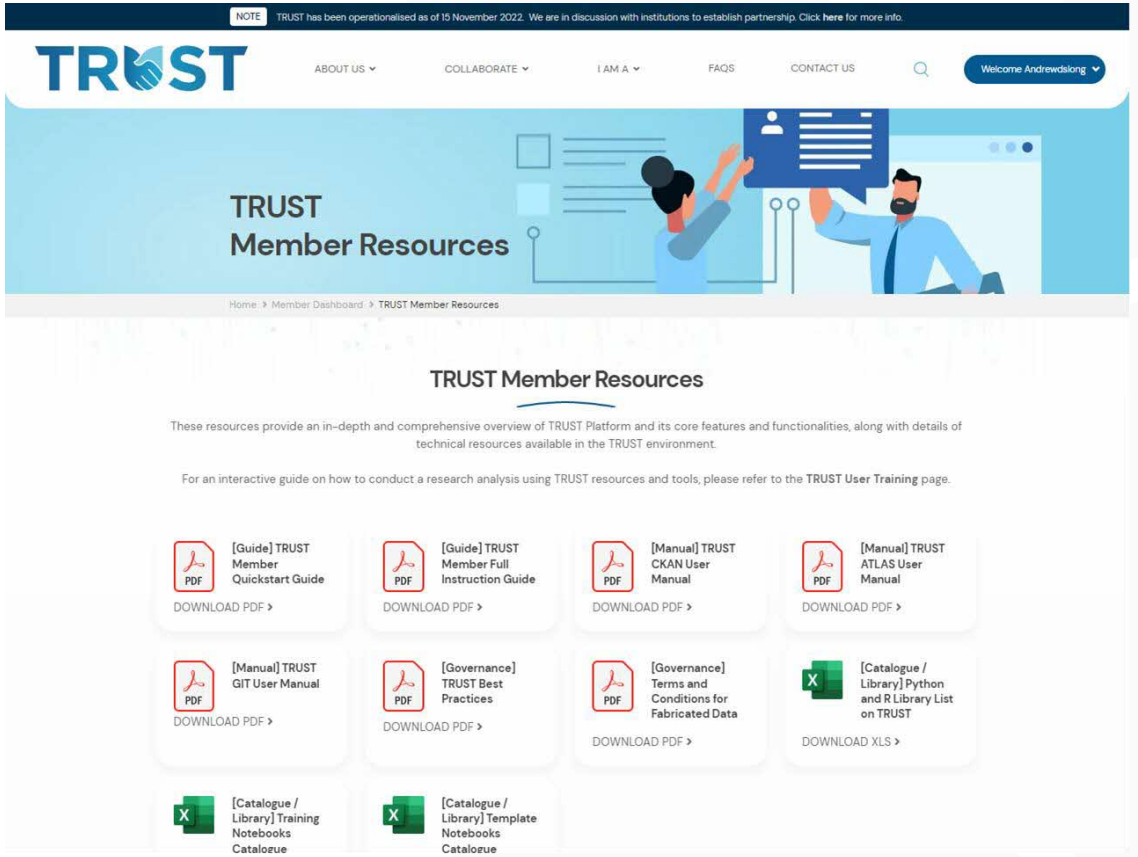
- Send your enquiries from within the portal



User Onboarding, Training and Support

- Since launched, TRUST has made available **~40 datasets**, approved **~20 data requests** and supported approximately **~150 users** on their research analytics.
- We are actively engaging researchers to understand their research questions and to support their data needs.
- Users are supported with an onboarding programme by the TRUST team, augmented with additional resources available through the TRUST portal
  - User guides and Onboarding sessions
  - Step-by-step video tutorials
  - Community / peer forum*

*to be launched in 2H 2024



A *TRUST Data Concierge* team supports users throughout their journey

> *"We are extremely grateful towards the TRUST Support team for their generous support and great responsiveness and guidance, thank you!"*
> **- Dr Chen Wenjia, SSHSPH, NUS (first batch of TRUST users)**

Whats on the horizon

New opportunities

Increasing Impact

- Enable unstructured data (e.g., free text clinical notes, retinal images) and broaden data types (e.g. geospatial)
- Support strategic industry partners

- Future-proof with Privacy Preserving Tech (e.g. federated analysis)
- Enhance interoperability with other Trusted Research Environments local and internationally

Increasing Interoperability

Enhancing experience

- Scaling and automation (e.g. output checking)
- Enable self-serve (e.g. data exploration & visualisation)
- Develop “TRUST academy” training programmes (e.g. data governance, best practices for data sharing and management)

Further interoperability with the wider ecosystem to further health data innovations

Supporting clinical trials design and research

Supporting clinical trials design and research with real world data

- **Support hypothesis generation –**
  - Identify trends to inform the design of new trials e.g. uncover patterns of treatment responses or adverse effects based on multi-modal datasets
  - Refine the inclusion/exclusion criteria, ensuring the trial is more focused and relevant.
  - Historical data can provide a baseline comparison for new trial results, helping to establish benchmarks and norms.

- **Support more efficient and effective clinical trials -**
  - Analysis of past anonymized data can highlight potential risks and adverse effects, allowing for better mitigation strategies in the trial design.
  - Support simulations and power analyses to determine the optimal clinical trial sample size needed to detect a meaningful effect, optimizing resource allocation.
  - Track participants longitudinally without compromising their privacy to observe health outcomes and treatment effects.

Using real world data with care

- Trial and real-world populations are different, should be cognizant of the efficacy-effectiveness gap;
- Confounding factors influencing the outcome need to minimized e.g. careful study design or through data analysis.
- Selection biases may be introduced e.g. when the observed subgroup of patients is not representative of the broader population of interest and need to be adequately dealt with.

Thank you

Questions?

www.trustplatform.sg