

# Cohort Enrichment and Use Cases through Linkages Request for Proposals (RFP) Roadshow

7 April 2025

# Today's programme

- Opening remarks
  - Dr Xueling Sim, Director, National Cohorts Office
- GUSTO
  - Prof Johan Gunnar Eriksson, GUSTO co-lead
- Request for Proposals (RFP): Cohort Enrichment and Use Cases through Linkages
  - Ms Sharon Wee, Senior Manager, National Cohorts Office
- Q&A

## Opening Remarks

A/Prof Xueling Sim, Director, National Cohorts Office

# Long history of cohorts for health research

## Women, Work and Coronary Heart Disease: Prospective Findings from the Framingham Heart Study

SUZANNE G. HAYNES, PhD, AND MANNING FEINLEIB, MD, DrPH

Journal of Women's Health > Vol. 6, No. 1 >

## The Nurses' Health Study: 20-Year Contribution to the Understanding of Health Among Women

GRAHAM A. COLDITZ, JOANN E. MANSON, and SUSAN E. HANKINSON

Published Online: 25 Apr 2009 | <https://doi.org/10.1089/jwh.1997.6.49>

### Research Article

#### Mortality in relation to smoking: 20 years' observations on male British doctors.

*Br Med J* 1976 ; 2 doi: <https://doi.org/10.1136/bmj.2.6051.1525> (Published 25 December 1976)

Cite this as: *Br Med J* 1976;2:1525



### Atherosclerosis Risk in Communities Study Description

This website is intended for ARIC investigators, researchers, and health professionals. It is maintained for the ARIC participants, health professionals, and the community.

The Atherosclerosis Risk in Communities Study (ARIC), a prospective epidemiologic study conducted in four U.S. communities, is designed to study the development and progression of atherosclerotic disease and its clinical outcomes, and variation in cardiovascular risk factors. To date, the ARIC study has published over 2,000 articles and the Community Surveillance Component.

### OPINION

## Genes, environment and the value of prospective cohort studies

Teri A. Manolio, Joan E. Bailey-Wilson and Francis S. Collins

Comment | [Published: 13 July 2022](#)

## Integrating biomedical and clinical data with BioBank Japan

### UK Biobank: An Open Access Resource for Identifying the Causes of a Wide Range of Complex Diseases of Middle and Old Age

#### Original Article

### Million Veteran Program: A mega-biobank to study genetic influences on health and disease

### Risk factors for long COVID: analyses of 10 longitudinal studies and electronic health records in the UK

### Hypertension prevalence in the *All of Us* Research Program among groups traditionally underrepresented in medical research

[Paulette D. Chandler](#), [Cheryl R. Clark](#), [Guohai Zhou](#), [Nyia L. Noel](#), [Confidence Achilleke](#), [Lizette Mendez](#), [Andrea H. Ramirez](#), [Roxana Loperena-Cortes](#), [Kelsey Mayo](#), [Elizabeth Cohn](#), [Lucila Ohno-Machado](#), [Eric Boerwinkle](#), [Mine Cicek](#), [Jun Qian](#), [Sheri Schully](#), [Francis Ratsimbazafy](#), [Stephen Mockrin](#), [Kelly Gebo](#), [Julien J. Dedier](#), [Shawn N. Murphy](#), [Jordan W. Smoller](#), [Elizabeth W. Karlson](#) & the *All of Us* Research Program Investigators

*Scientific Reports* 11, Article number: 12849 (2021) | [Cite this article](#)

### The Nord-Trøndelag Health Study 1995-97 (HUNT 2): Objectives, contents, methods and participation

Jostein Holmen<sup>1</sup>, Kristian Midthjell<sup>1</sup>, Øystein Krüger<sup>1</sup>, Arnulf Langhammer<sup>1</sup>,  
Turid Lingaas Holmen<sup>1</sup>, Grete H. Bratberg<sup>1</sup>, Lars Vatten<sup>2</sup> and Per G. Lund-Larsen<sup>3</sup>

## The Dunedin Multidisciplinary Health and Development Study: a 15 year longitudinal study

Phil A. Silva

First published: January 1990 | <https://doi.org/10.1111/j.1365-3016.1990.tb00621.x> | Citations: 176

1940

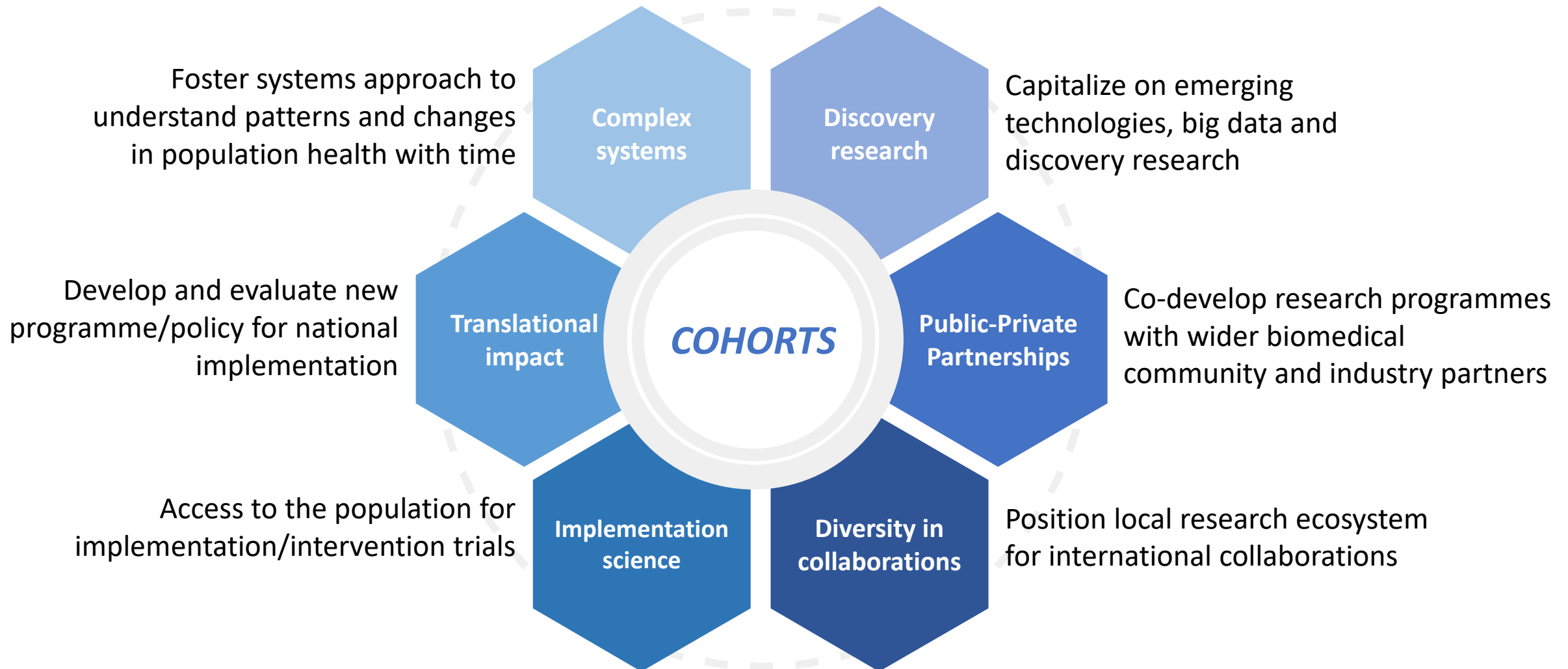
1990

2000

2010

2020

# Cohorts are valuable *infrastructure* for health research



# National Cohorts Office (NCO)

- Enabler of a cohort ecosystem supported by open sharing mechanisms
- Funding administrator (Requests for Proposals RFPs)

NCO mission: To maximise utility, value and impact of population cohorts in Singapore

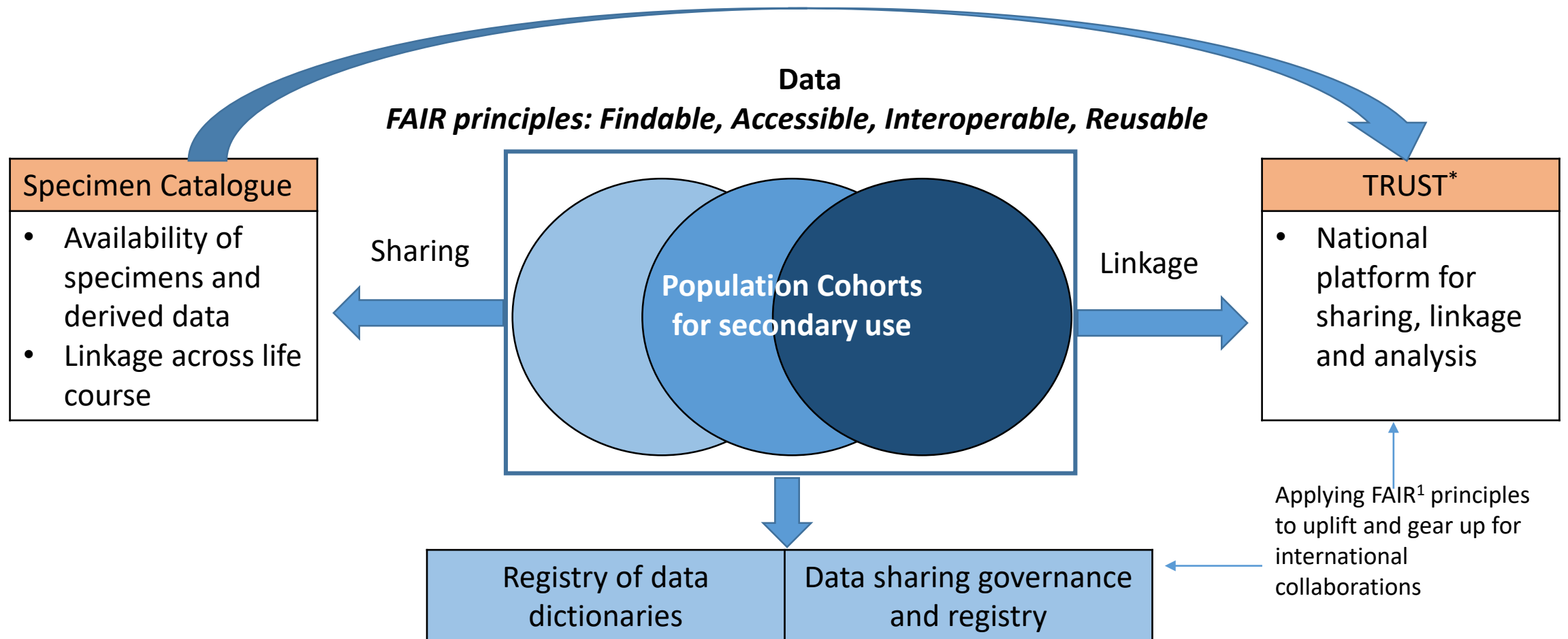
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## The National Cohorts Office

Ecosystem Facilitator	Cohort Advocator	Competency Building	Methodological Innovation	Funding Administration
Connect across cohorts and other stakeholders to build a collaborative ecosystem	Highlight needs of cohorts at the national level	Establish and encourage best practices	Promote development, evaluation and dissemination of relevant methods	Launch and administer requests for proposals

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# Ecosystem supported by open sharing mechanisms



\*Trusted Research and Real world-data Utilisation and Sharing Tech

<sup>1</sup>Wilkinson, Mark D., et al. "The FAIR Guiding Principles for scientific data management and stewardship." Scientific data 3.1 (2016): 1-9.

# Putting FAIR principles into practice

Principles	Guidelines	Output
<b>Findable</b>	Data and supplementary materials to have identifiers that are findable by human and computational resources	Online data dictionary
<b>Accessible</b>	Data to be deposited in a trusted repository that is accessible and shared	Data access governance
<b>Interoperable</b>	Data to use a formal, accessible and broadly applicable language for knowledge representation	Consensus standards aligned to data dictionary
<b>Reusable</b>	Data and collections have a clear usage licences and provide accurate information on provenance	Cohorts with consent for secondary use and traceable record linkage

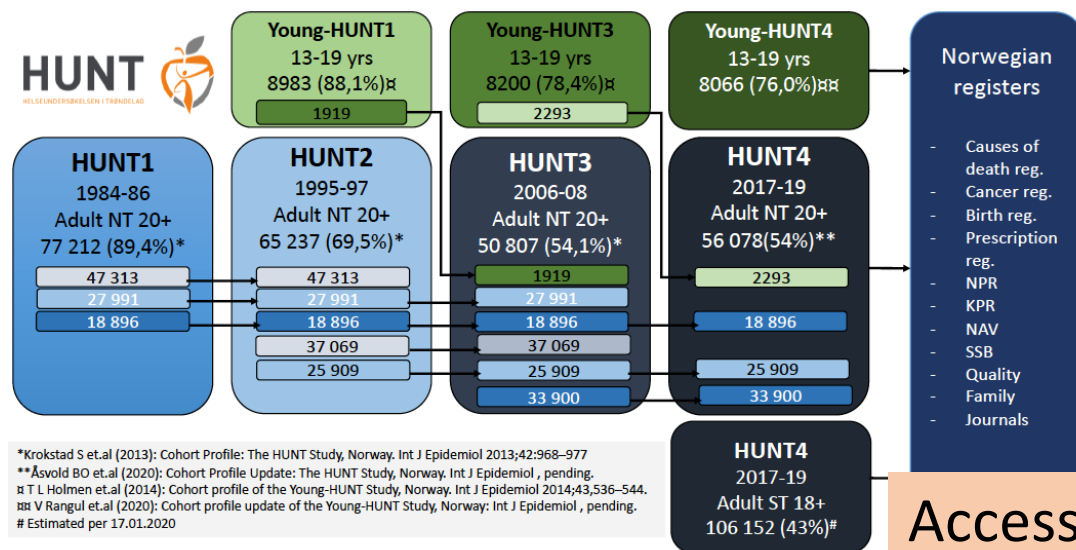
Wilkinson, Mark D., et al. "The FAIR Guiding Principles for scientific data management and stewardship." Scientific data 3.1 (2016): 1-9.

Garcia-Closas M, Ahearn TU, Gaudet MM, Hurson AN, Balasubramanian JB, Choudhury PP, et al. Moving Toward Findable, Accessible, Interoperable, Reusable Practices in Epidemiologic Research. Am J Epidemiol. 2023;192(6):995-1005.



# HUNT since 1984

<https://www.ntnu.edu/hunt/>



## HUNT application process



Accessible, Findable

The screenshot shows the HUNT Databank interface. It includes a search bar, login/sign up options, and a variable list. The variable list shows 9974 hits matching the search criteria. The variables are listed in the order they were asked in the study.

Variable name	Variable	Study part	n
Hei@NT1BLM	Height	HUNT1 Measurements	74 369
Wei@NT1BLM	Weight	HUNT1 Measurements	74 347
HeiWeiDev@NT1BLM	Height Weight Deviation	HUNT1 Measurements	2 344
Bmi@NT1BLM	Body Mass Index	HUNT1 Measurements	74 333
Puls1@NT1BLM	Pulse 1	HUNT1 Measurements	74 911
BPDias1@NT1BLM	Blood Pressure Diastolic 1	HUNT1 Measurements	74 892

Interoperable

The screenshot shows the NTNU website. It includes a search bar, navigation links, and a section titled "Research projects using HUNT material". The section provides an overview of research projects using HUNT material and includes a list of research projects.

**Research projects using HUNT material**

An overview of [research projects using, or having used, HUNT material can be found here](#) (Norwegian). You will also find short summaries in Norwegian and information about project leader and the research institution.

**Research**

- Data access
- HUNT Databank
- Participation numbers
- Research projects using HUNT material
- HUNT Cloud
- Collaboration projects
- GWAS
- HUNT Biobank
- About HUNT
- Collaboration

Reusable

**NTNU**  
HUNT forskningscenter

**Address**  
HUNT Research Centre  
Forskningsveien 2  
7600 Levanger

**Phone**  
+47 74 07 51 80 | +47 74 01 92  
40 | +47 916 83 253

**Email**  
[kontakt@hunt.ntnu.no](mailto:kontakt@hunt.ntnu.no)

# First RFP – Strategic Cohorts in September 2022



# Engagements with cohorts

## Engagement with cohorts

- **Landscape review** of population cohorts
- Understand strengths, needs, and challenges



# Insights from talking to you

<p>“I have diverse data generated on the cohort at different times, and they are in different places .. we pull out what we need and organizing them requires some data management ”</p>	<p><i><b>Need for data organization and structure</b></i></p>
<p>“We used to link our data to the MOH micro-access lab, but it has now closed .. We need to find other ways to link our data passively to enrich the data for more hypotheses”</p>	<p><i><b>Data linkage to health and other administrative data on TRUST</b></i></p>
<p>“On hindsight, I have the relevant data that would have been helpful to another study, and we could have worked together .. except that we both didn’t realize we have common data”</p>	<p><i><b>Findable structured meta-data and data dictionary for collaborations</b></i></p>

# Gearing up the ecosystem

Build community, enable sharing, increase visibility, maximise utility

## Website

Increase visibility and signpost researchers to cohort resources. Create platform to share findings.

## Landscape scan

Continue engaging with more cohorts to discover strengths and needs while promulgating best practices

**What has worked and what do you need to even better utilise your cohorts?**



NCO website: <https://nco.nus.edu.sg>

## Harmonisation

Facilitate harmonisation via sharing of tools and standards to open up more data for secondary use

## Build user base

Support more use cases to demonstrate the value of cohort studies and build critical mass of researchers

**Are there research use cases that can be enabled through linkage on TRUST?**

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

TRUST statistics as of Aug 2024

- 01 DATA REQUESTS**  
Approved TRUST Data Requests through the Data Access Committee **22 total**
- 02 USERS**  
Total Users on TRUST supported research projects **172 users**
- 03 DATASETS**  
Anonymised datasets available through TRUST **40+ 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

Anonymised and transfer

Real-World Data  
in Vault or Govt agencies' repository

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***

# 2025 RFP Objectives

1

Maximise utility, value and impact of existing population cohorts by uplifting to FAIR<sup>1</sup> principles  
(Findable, Accessible, Interoperable and Reusable)

2

Support existing population cohorts to prepare their data and processes to enable linkage and secondary use

3

Enrich and generate new insights from use cases through data linkage of existing population cohorts with other datasets on TRUST<sup>2</sup>

<sup>1</sup>FAIR principles: Findable, Accessible, Interoperable and Reusable. Wilkinson, Mark D., et al. "The FAIR Guiding Principles for scientific data management and stewardship." Scientific data 3.1 (2016): 1-9.

<sup>2</sup>Trusted Research and Real world-data Utilisation and Sharing Tech (TRUST) is a national linkage platform for health-related research.

# Why make my data FAIR?



## **Increase visibility:**

FAIR data can be easily found and cited by others



## **Better Data Management and Longevity:**

FAIR data management practices lead to better organized and preserved data, which can be used for future research and long-term studies



## **Efficiency in Data Sharing:**

Clear metadata and standardized formats facilitate sharing and data use across platforms, speeding up collaboration efforts



## **Attract new partnerships and collaboration:**

FAIR data is well-documented and facilitates secondary use, accelerating research impact of the data



## **Practice good stewardship:**

FAIR data maximises the potential of the data



# GUSTO

Prof Johan Eriksson, GUSTO co-lead



**Before**

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No clarity about available data

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People working in silos – no data sharing

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Overlap of projects

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Data governance – Form A



**Today**

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Cohort-wide data management

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Dedicated data management team

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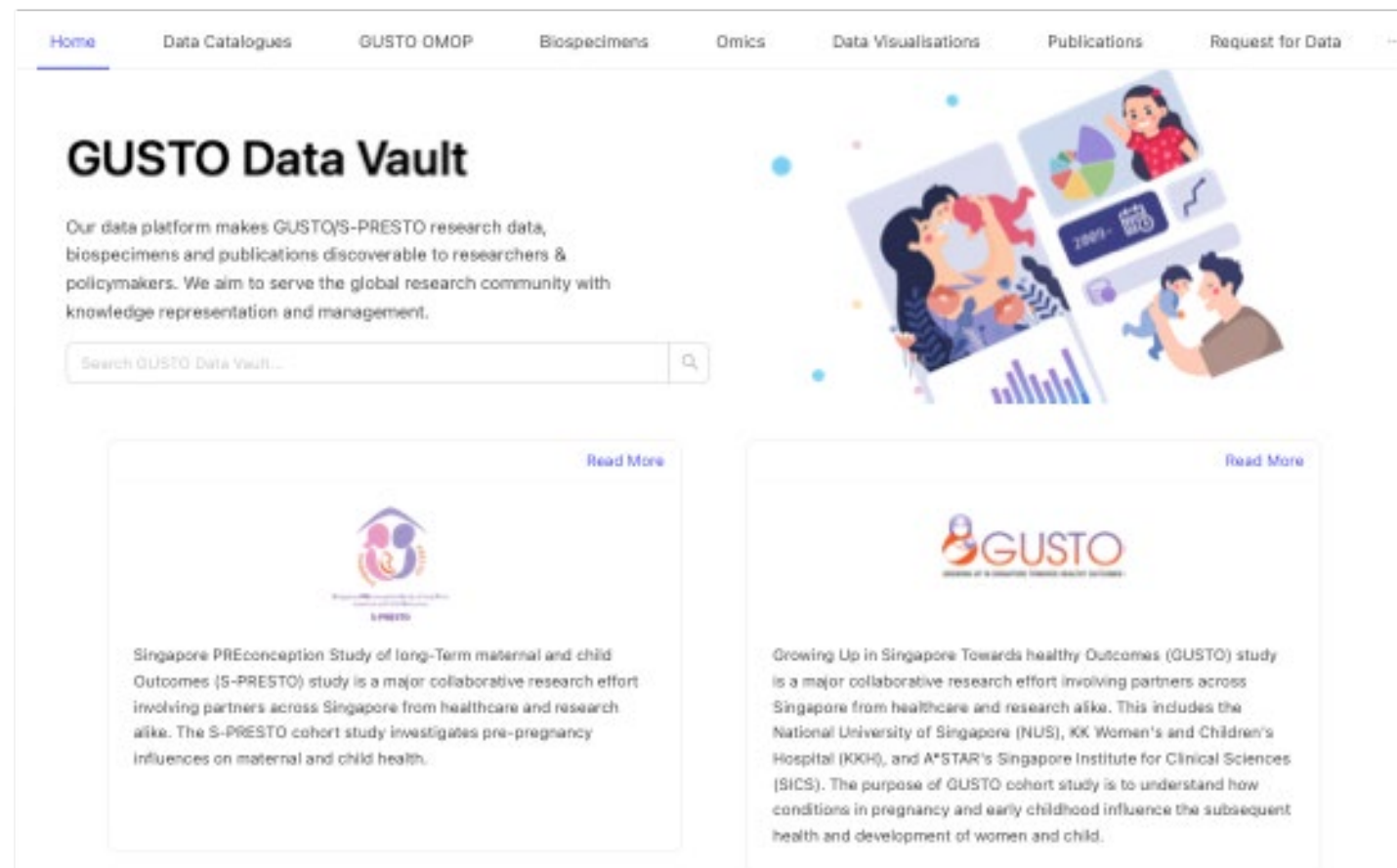
Professional website

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Data governance – Form A, Form B, Form C, Form G



# Today



[gustodatavault.sg](https://gustodatavault.sg)



# Advantages

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Accelerated research

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Accelerated collaborations

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Professional set-up

– linkage to MOH-trust

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AI-function to be introduced

## Request for Proposals (RFP): Cohort Enhancement and Use Cases through Linkages

Ms Sharon Wee, Senior Manager, National Cohorts Office

# 2025 RFP Objectives

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<sup>2</sup>Trusted Research and Real world-data Utilisation and Sharing Tech (TRUST) is a national linkage platform for health-related research.

# Scope of award

Within scope	Out-of-scope
✓ Existing population cohort	✗ New Cohorts
✓ Population cohort: Recruitment of healthy volunteers from the community	✗ Disease cohorts <i>May be considered if the disease is of national significance and the cohort can demonstrate utility for multi-disciplinary research but the priority is to fund population cohorts</i>
✓ Participants consented to secondary use, record linkage and data sharing with third parties	✗ No consent for secondary use, record linkage or data sharing <i>May be considered if waiver is tenable</i>
✓ Participants full NRIC	✗ No or partial NRIC <i>Without full NRIC, the data cannot be used for record linkage</i>
✓ Research use case that includes data linkage and analysis on TRUST	✗ Research use case that does not require data linkage and analysis on TRUST
✓ Cohort data has been published in a scientific journal	✗ No cohort publication <i>Cohort might be too nascent for third party sharing; can be considered if cohort has data sharing experience with third party</i>



# Using cohort data for research

## Participants consent checklist:

- Participants' personal identifiers are retained
- Recontact: Consent is obtained to allow recontact of participants
- Data linkage: Consent is obtained to allow data linkage to other data sources
- Secondary use: Collected data (and biological materials) may be used for purposes beyond the initial research scope
- Sharing: Data (and biological materials) may be shared with third partners including commercial companies

## Process Checklist:

- Dataset(s) has the relevant data of interest
- Appropriate consent governing secondary use of data and/or biological materials
- Legal agreements on the use of data and/or biological materials
- Minimise possibility of re-identification of participants through the data
- If linked to external datasets, de-identified data to be provision for research use with the appropriate approvals and security controls
- Cost related to access and analysis

# Application Form and Evaluation Criteria

Principle	Question	Evaluation Criteria
Value	<p>Why this cohort?</p> <ul style="list-style-type: none"> <li>Value proposition and description</li> <li>Documentation and processes for data management, quality assurance and participant and public involvement and engagement (PPIE)</li> </ul>	<ul style="list-style-type: none"> <li>Documentation: published description of cohort (e.g., sampling frame, demographic description, acceptance rates, attrition etc.)</li> <li>Cohort has significant contribution to ecosystem (e.g., key publications, policies, collaborations including with industry)</li> </ul>
FAIR-ness	<p>To what extent is the cohort FAIR?</p> <ul style="list-style-type: none"> <li>Online presence (F), data access framework (A), data standards and consortia memberships (I), data dictionary and data use register (R)</li> <li>Describe the delta and plans to establish/ improve governance framework, data dictionary and website</li> </ul>	<ul style="list-style-type: none"> <li>Planned activities are aligned to FAIR principles</li> <li>Data access principles facilitate data sharing</li> <li>Previous data linkages (e.g., with NRDO, Omnibus, TRUST)</li> </ul>
Utility	<p>How will a linkage use case enrich the cohort?</p> <ul style="list-style-type: none"> <li>Research objectives</li> <li>Data and resources required</li> <li>Perceived impact (possible achievements due to this funding)</li> </ul>	<ul style="list-style-type: none"> <li>Use case addresses an important health(care) issue</li> <li>Use case requires data linkage and analysis on TRUST</li> <li>Use case builds new capabilities for the cohort</li> </ul>
Feasibility	<p>How feasible is the plan?</p> <ul style="list-style-type: none"> <li>Team composition and Gantt chart</li> </ul>	<ul style="list-style-type: none"> <li>Applicants have the required expertise</li> <li>Plans can be executed within the funding duration</li> </ul>
Collaboration	<p>Why is the collaboration required?</p> <ul style="list-style-type: none"> <li>Synergy and collaborative outcomes</li> </ul>	<ul style="list-style-type: none"> <li>Proposal outlines an effective collaboration</li> </ul>

# Milestones-based Funding

- To incentivise desired behaviours and good stewardship of public funds
- Milestones are important achievements along the trajectory to project success
- Successful applications will be reimbursed based on milestones achieved
  - For example, 10% of the approved budget is released for reimbursement upon receiving signed letter of acceptance

## Expected milestones for successful applications

S/N	Milestone
0	Signed Letter of Acceptance
1	Cohort is listed on NCO cohort directory
2	Machine readable Data dictionary is hosted on cohort website
3	Data access forms are accessible on cohort website
4	Data is ready for ingestion on TRUST
5	Dataset linked on TRUST for analysis
6	<i>For collaborative applications only:</i> Harmonised variables in an area of measurement (e.g., hours of sleep, mood)

# Funding support from NCO for data

## Organise

Organise cohort data  
e.g., data dictionary  
and data  
documentation

Create and host  
website, data  
dictionary, data and  
data request forms

## Standardise

Standardise across  
timepoints, cohorts  
or to international  
standards

Establish TTP or  
process to link de-  
identified data

## Link

Emplace ethical  
and/or legal  
agreements for data  
sharing

Establish data access  
governance e.g. data  
access committee

## Analyse

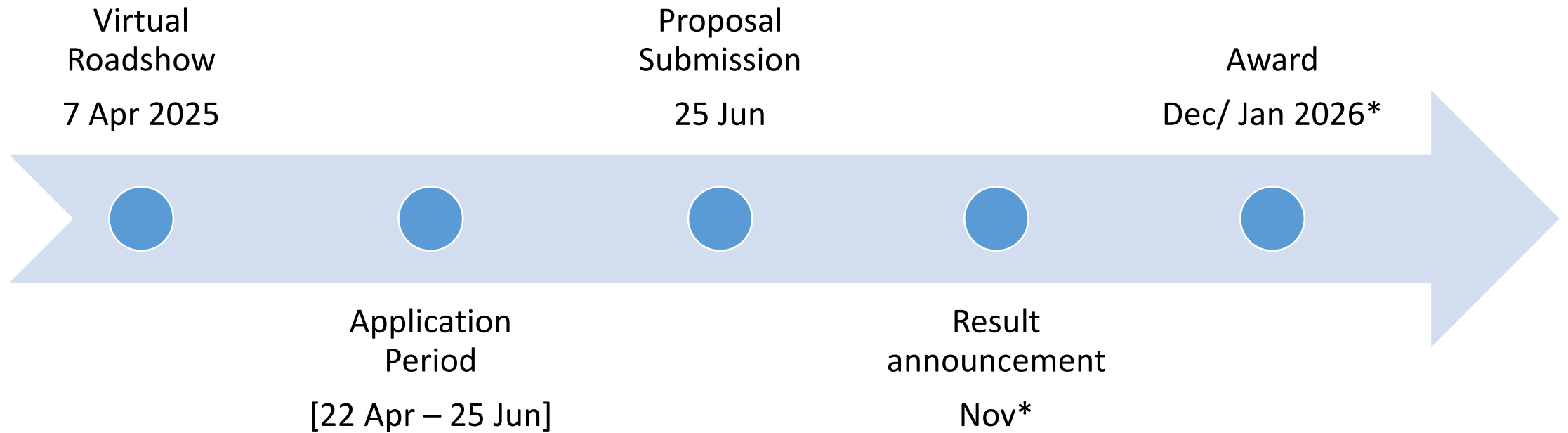
Prepare cohort data  
for linkage and  
analysis

Generate research  
insights using linked  
data e.g. compute  
cost

### Non-fundable

- ✗ Collecting new or additional measurements
- ✗ Recruiting participants
- ✗ Maintaining biospecimens, e.g., freezers

# Timeline



\* tentative

# Preparing your Proposal

You must demonstrate that your proposal has:

- A population cohort that has consent for secondary use and record linkage
- A framework or mechanisms for sharing
- Evaluated what is the delta that you can address in 12 - 18 months
- Opportunities for third parties to access the collection
- A good use case requiring data linkage
- Potential to unleash scientific inquiry and accelerate science

***Multi-cohort collaborative applications are encouraged***

# Applicant Eligibility

- Cohort lead must be the corresponding applicant.
- One Corresponding Applicant per application. Collaborative applications should appoint one cohort lead to be the corresponding applicant.
- At point of application, cohort lead should:
  - a) Hold a primary appointment in a local publicly funded institution and salaried by the institution.
  - b) Have PhD or MD/MBBS/BDS qualifications. (*Exceptions can be made on a case-by-case basis*).
  - c) Is an independent investigator (with PI status in institution) with a demonstrated track record of research, as evidenced by the award of nationally competitive funding (international funding to be considered on a case-by-case basis), and substantial publication record in the past 3 years.
  - d) Has a laboratory or clinical research programme that carries out research in Singapore
  - e) Hold a minimum of 9 months employment (per calendar year) with local Singapore institution(s). Upon award, the applicant must agree to fulfil at least 6 months of residency in Singapore for each calendar year over the duration of the award.
  - f) Has no outstanding report from previous BMRC, NMRC grants, and other national grants.
- Letter of support from Host Institution for data sharing

# Eligibility of co-applicant and collaborator

- Co-applicants need to hold at least an adjunct position in a local publicly funded institution.
- Researchers from overseas institutions or private companies can only participate as Collaborators.
- Research Fellow/Associate/Assistant/Officer/Scientist
  - salaried by institution can participate as Co-applicant or Collaborator
  - salaried by project grants can only participate as Collaborators
  - to be salaried under this current application cannot be Co-applicant or Collaborator



# Key Details

<b>Application period:</b>	22 Apr – 25 Jun 2025
<b>Funding quantum:</b>	S\$750,000; \$1.5M for 2 or more cohorts
<b>Indirect Research Cost (IRC):</b>	Not applicable
<b>Funding duration:</b>	18 months
<b>Funding period:</b>	1 Feb 2026 – 31 Ju1 2027
<b>Eligibility criteria:</b>	Existing population cohorts with NRIC and consent for record linkage and secondary use
<b>Application format:</b>	5-page write-up and annex tables Application package will be emailed to roadshow attendees and also available on NCO website from 22 Apr 20205
<b>Submission:</b>	Email to <a href="mailto:cohorts@nus.edu.sg">cohorts@nus.edu.sg</a> by 25 Jun 2025, 12 pm

# Enquiries

- [cohorts@nus.edu.sg](mailto:cohorts@nus.edu.sg)
- Information and application forms will be accessible on NCO's website (<https://nco.nus.edu.sg/funding-opportunities/>) from 22 Apr 2025

Q&A

Question	Response
We have an IRB-approved proposal pending TRUST linkage, are we eligible to apply?	A linkage use case is only part of the requirements for this RFP. This RFP is also to fund cohort uplifting. If you are prepared to open the cohort to secondary use and third party sharing, you may proceed to apply.
Do we need to have already collected NRIC and secondary usage consent before applying for this grant? Can we get the NRIC when we seek consent?	Yes, ideally you should already have collected NRIC, because participants full NRIC is required for linkage via TRUST. You may obtain the NRIC when you seek consent, but this RFP will not cover costs related to re-contacting participants.
When requesting consent for secondary use, is there specific language that is needed to qualify for TRUST? Do you have a template or example that researchers can use?	IRBs e.g. CIRB, DSRB NUS-IRB etc. have templates for consent clauses and you can reference the institutions' IRB.
Is there an expected cohort/ cohorts size per application?	No sample size threshold has been defined, and NCO is looking for population cohorts across all age groups and domains that allows secondary analyses. It is up to the study team to make their case and for the reviewing committee to evaluate.
Are there any priority areas e.g., healthcare, human health, population etc.?	

Question	Response
<p>I have a DSRB-approved standing registry for a disease cohort that is prospective and is consent-waived. Is this eligible?</p>	<p>The priority is to fund population cohorts. Disease cohorts may be considered if the disease is of national significance and the cohort can demonstrate utility for multi-disciplinary research. If there is patient consent for secondary use and record linkage, and the deidentified dataset can be made available for secondary use, you are eligible to apply. Do note that TRUST still requires a Review Not Required (RNR) from IRB.</p>
<p>Will a big cohort with healthy control subjects that went through some sort of lifestyle intervention with longitudinal follow up be eligible for this?</p>	<p>Yes, as long as you have collected NRIC and have consent for secondary use and record linkage.</p>
<p>Will cohorts that recruit both healthy and diseased subjects be eligible?</p>	
<p>Will cohorts with bio-samples e.g., genomics be viewed more favourably?</p>	<p>The more data available for sharing, the better.</p>

Question	Response
Does the cohort require subject recruitment to be completed before putting in an application?	Yes, as awardees are expected to make their data shareable by the end of the funding period, cohorts that are too nascent may not be ready for third party sharing. Published cohort description is one of our eligibility criteria.
Is there a maximum number of cohorts that will be funded and will the funds be split across them?	A single cohort application will be funded \$750,000. An application can be a consortium where the corresponding applicant can ask for \$1.5M to split across cohorts. Funding will be split across sites for collaborative proposals that are submitted as one application.
Is an international consortium of cohorts based in Singapore eligible?	Yes, work required to uplift the Singapore cohort(s) will be eligible, including the proposed use case linked via TRUST. Furthermore, multi-cohort collaborations are highly encouraged.
We are currently working on cluster wide database to go-live by end of year. Will there be a similar RFP in future years, for cohorts that are planning to go live in the next few years and help with TRUST linkage?	We cannot promise that there will be similar RFPs. It will depend on the ecosystem priorities/ needs and our funding objectives in RIE2030. We will continue to engage the community to understand the needs.