



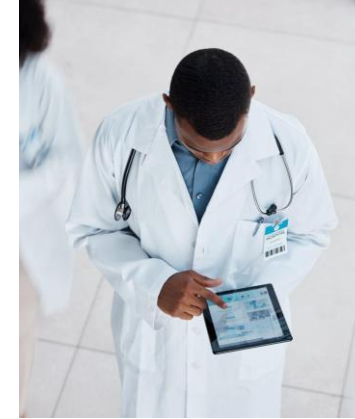
Australian Research Data Commons

Health Studies National Data Asset (HeSANDA)

Health Data Australia

eResearch Australasia Conference 23rd Oct 2025

Kathy Dallest, Katie Ozdowska, Olya Ryjenko



ARDC is enabled by NCRIS



Acknowledgement of Country

We acknowledge the Traditional Owners of the unceded land on which we work, learn and live, and we pay our respect to their elders past and present.



Image credits clockwise:

Federico-Garcia - MQxP65uEfJE / unsplash.com

Tristan McKenzie - 715v3NOIVhU/ unsplash.com

René Riegel - 0VFr6ub7HIA / unsplash.com



This project received investment from the NCRIS enabled ARDC Infrastructure

HeSANDA

Health Studies National Data Asset

National infrastructure to allow researchers to access and share data from health studies

Focus

- Consultation and co-design with the Australian research community
- Metadata standards and harmonization
- Consistent procedures
- Policy development
- Infrastructure (Health Data Australia)

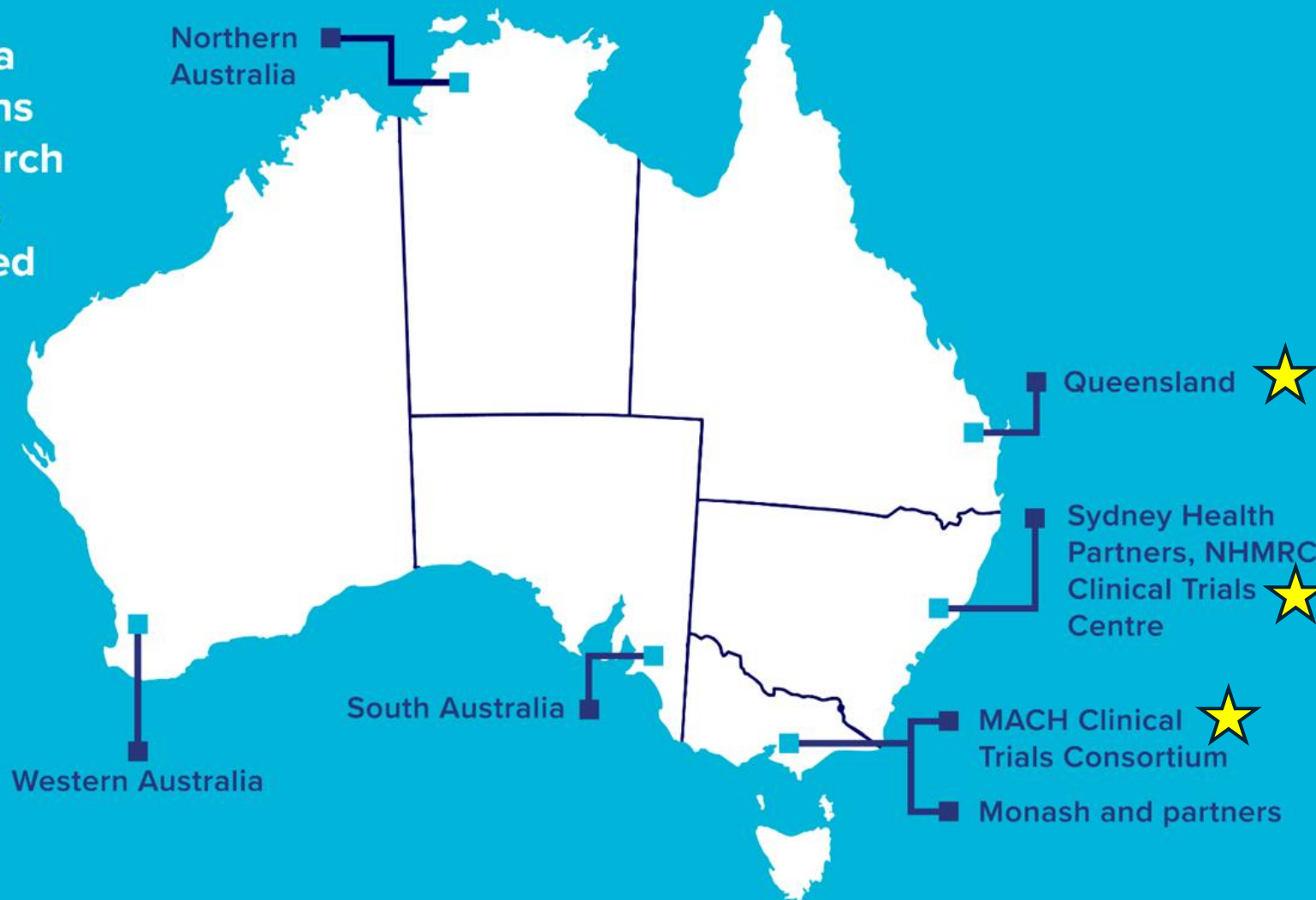


visit - researchdata.edu.au/health/ ►

Health Data Australia contains contributions from 72 health research organisations across the country, organised into 9 nodes

National Networks

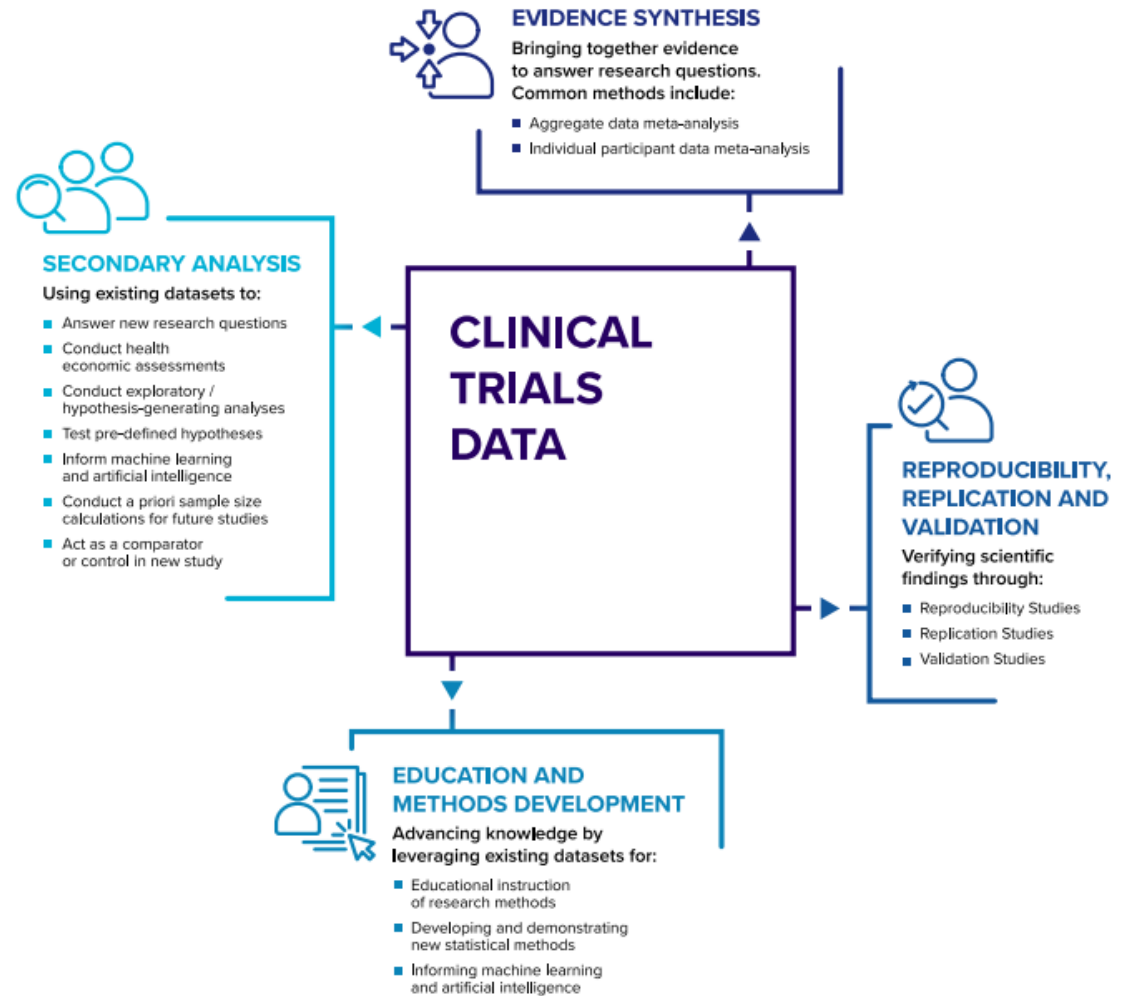
- Mental Health
- Cancer Cooperative Trials Groups

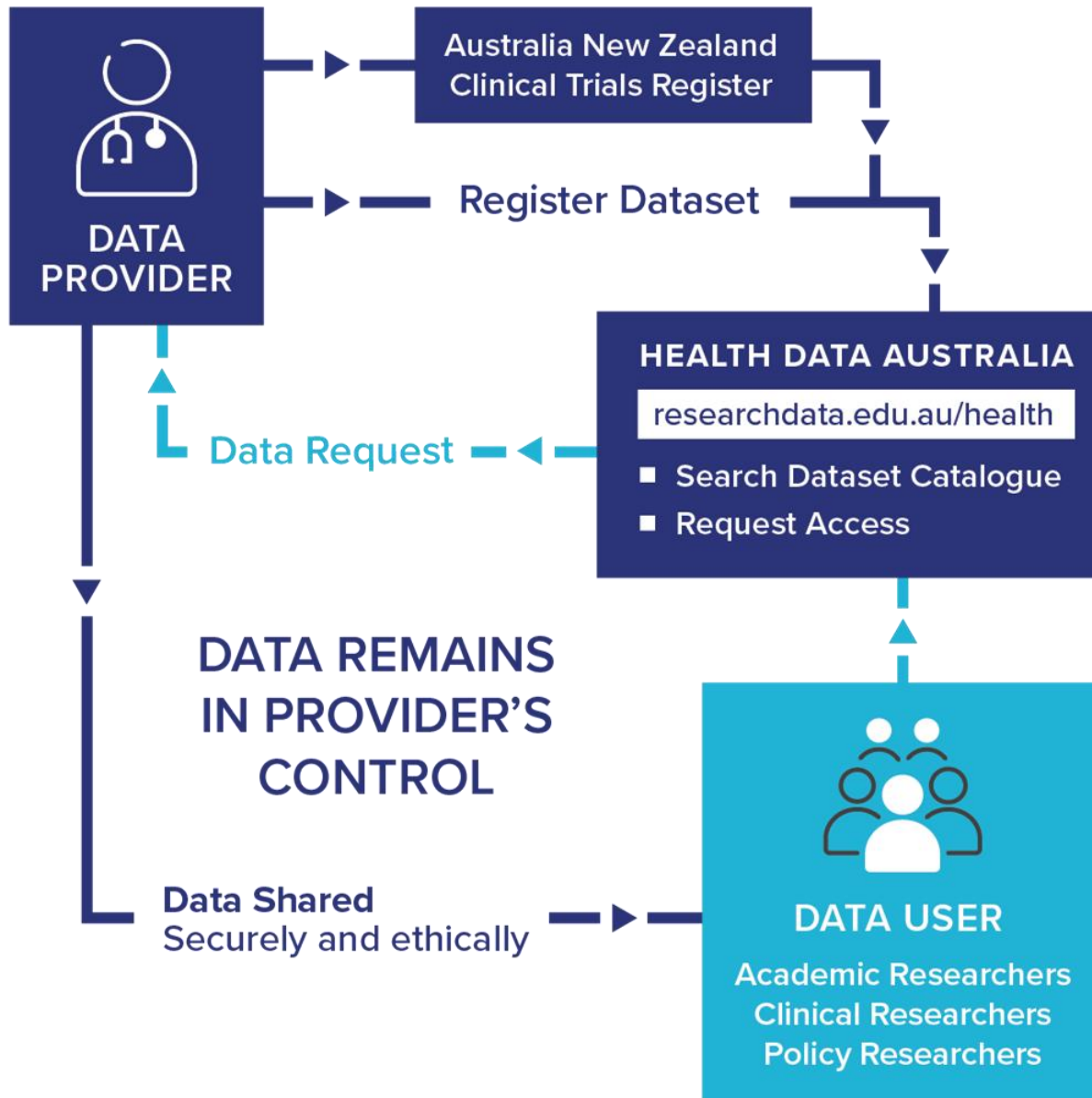


Scan QR code for more information & HeSANDA node contact details.

Why HeSANDA

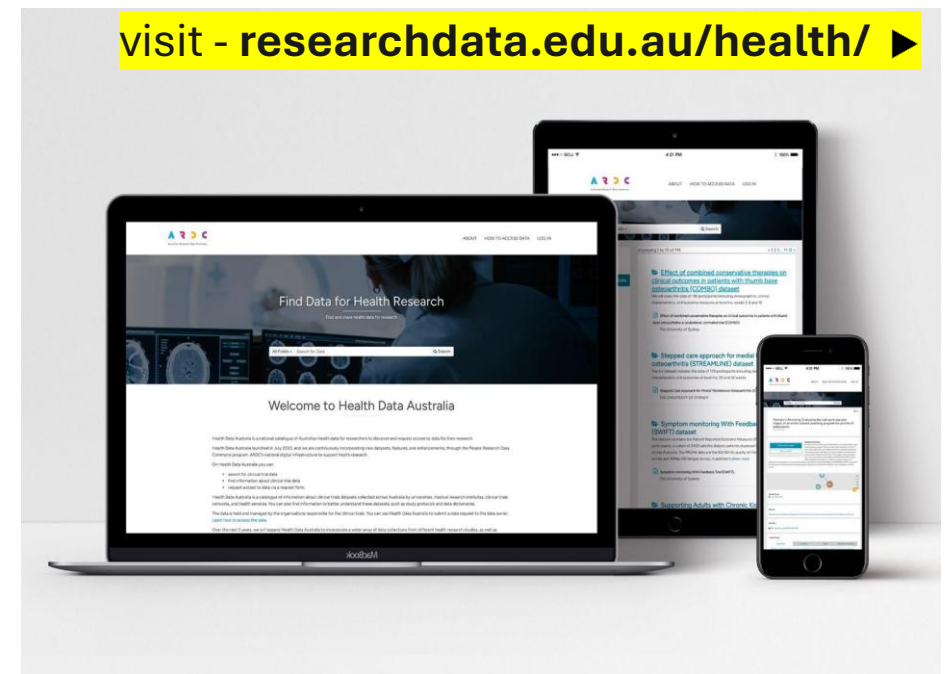
- To improve the quality and productivity of research
- Encouraged and/or required by publishers and funders
 - National Health Medical Research Council (NHMRC)
 - Medical Research Future Fund (MRFF)
 - Australian Research Council
- To align with the international data sharing research community





Health Data Australia

Discover and request clinical trial data from around Australia

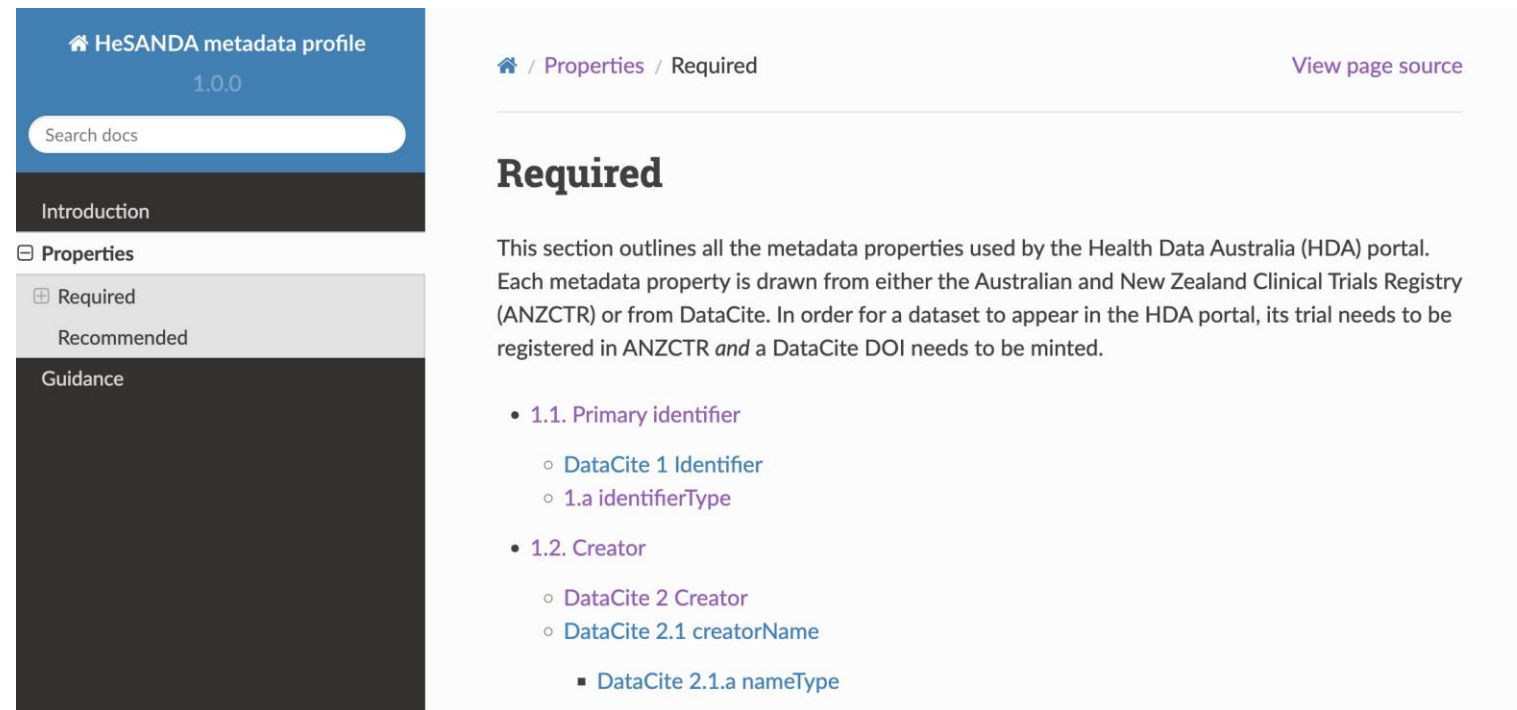


Building national capability in 3 key areas

- **Coordinated data services**
 - A national network of infrastructure nodes supplying clinical trials metadata and research outputs according to the coherent data practices
- **Coherent data practices**
 - Research community and stakeholder-defined data sharing practices for minimum information requirements, metadata design, data access, and ethics and consent
- **Federation services**
 - Interfaces, applications, and services that allow research and data discovery, data request and access, and additional functionality across the node network

Coherent Data Practices

About the dataset



The screenshot shows the HeSANDA metadata profile page for version 1.0.0. The left sidebar contains navigation links for Introduction, Properties (with sub-links for Required and Recommended), and Guidance. The main content area is titled 'Required' and includes a 'View page source' link. The text explains that metadata properties are drawn from the Australian and New Zealand Clinical Trials Registry (ANZCTR) or DataCite. A list of required properties is provided:

- 1.1. Primary identifier
 - DataCite 1 Identifier
 - 1.a identifierType
- 1.2. Creator
 - DataCite 2 Creator
 - DataCite 2.1 creatorName
 - DataCite 2.1.a nameType



About the clinical trial



A database of clinical trials and their results from Australia, New Zealand, and other countries.

Set requirements for trial registration from the International Committee of Medical Journal Editors (ICMJE) and World Health Organization (WHO) Trial Registration Data Set.

Federated Services



DATA ACCESS ABOUT LOG IN

Find Data for Health Research

Find, access, and re-use health data for research

All Fields ▾ Search for Data

Q Search



Scan QR code
for more
information &
HeSANDA node
contact details.

Welcome to Health Data Australia

<https://researchdata.edu.au/health/>

Log in to Save Clear Search

displaying 31 to 40 of 85

< 1 2 3 4 5 ... 8 9 >

Current Search Data

Current Selection

Viewing all documents!

Subjects

- Chemotherapy (23)
- Cancer therapy (excl. chemotherapy and radiation therapy) (15)
- FOS: Medical and health sciences (4)
- Infectious diseases (4)
- Radiation Therapy (4)
- [show more](#)

Publishers

- Australasian Leukaemia and Lymphoma Group (ALLG) (32)
- The University of Sydney (7)
- University of Melbourne (7)
- Breast Cancer Trials (BCT) (6)
- South Australian Health and Medical Research Institute (SAHMRI) (4)
- [show more](#)

ANZCTR Condition Codes

- Cancer (46)
- Leukaemia - Acute leukaemia (13)

Randomised, double blind control trial of megestrol acetate, dexamethasone and placebo in the management of anorexia in people with cancer

Data set includes: - One hundred and ninety participants were included in intention-to-treat analysis (61 receiving megestrol acetate, 67 receiving dexamethasone, and 62 receiving placebo) The treatment period was for four weeks whilst outpatient, with an optional extension for a further 4 weeks ([st show more](#))

Randomised, double blind control trial of megestrol acetate, dexamethasone and placebo in the management of anorexia in people with cancer
Cancer Symptom Trials (CST)

Benefits Of Oxygen Saturation Targeting Study (BOOST-II) dataset

This dataset includes 1135 participants receiving either a lower (85 to 89%) or a higher (91 to 95%) oxygen-saturation range in 15 centres in Australia. Baseline data will include demographics, antenatal glucocorticoid treatment, method of delivery and temperature at admission to the neonatal unit. [show more](#)

BOOST II: Benefits Of Oxygen Saturation Targeting Study
The University of Sydney

AYAPK Pharmacokinetics and Pharmacodynamics of Doxorubicin in Children, Adolescents and young adults with Newly Diagnosed Osteosarcoma, Ewing Family of Tumours and Hodgkin Lymphoma A Multi-Institutional Cross-Discipline Non-Therapeutic Study

The dataset contains individual patient data for 66 participants. This includes data chemotherapy drug dosage, drug dose modification, site of disease and extent, disease progression, medical history and adverse events.

Pharmacokinetics and Pharmacodynamics of Doxorubicin in Children, Adolescents and young adults with Newly Diagnosed Osteosarcoma, Ewing Family of Tumours and Hodgkin Lymphoma A Multi-Institutional Cross-Discipline Non-Therapeutic Study
Australia and New Zealand Sarcoma Association(ANZSA)

Help Feedback

A Phase III, randomised trial of adding nitroglycerin to first line chemotherapy for advanced non-small cell lung cancer

Thoracic Oncology Group Australasia (TOGA)

[Access the data](#)

[Save to MyHDA](#)

Dataset description

Background: We sought to determine whether the substantial benefits of topical nitroglycerin with first-line, platinum-based, doublet chemotherapy in advanced nonsmall-cell lung cancer (NSCLC) seen in a phase II trial could be corroborated in a rigorous, multicenter, phase III trial. Patients and methods: Patients starting one of five, prespecified, platinum-based doublets as first-line chemotherapy for advanced NSCLC were randomly allocated treatment with or without nitroglycerin 25 mg patches for 2 days before, the day of, and 2 days after, each chemotherapy infusion. Progression-free survival (PFS) was the primary end point. Results: Accrual was stopped after the first interim analysis of 270 events.

Chemotherapy was predominantly with carboplatin and gemcitabine (79%) or carboplatin and paclitaxel (18%). The final analysis included 345 events in 372 participants with a median follow-up of 33 months. Topical nitroglycerin had no demonstrable effect on PFS [median 5.0 versus 4.8 months, hazard ratio (HR) = 1.07, 95% confidence interval (CI) 0.86-1.32, P = 0.55], overall survival (median 11.0 versus 10.3 months, HR = 0.99, 95% CI 0.79-1.24, P = 0.94), or objective tumor response (31% versus 30%, relative risk = 1.03, 95% CI 0.82-1.29, P = 0.81). Headache, hypotension, syncope, diarrhea, dizziness, and anorexia were more frequent in those allocated nitroglycerin. Conclusion: The addition of topical nitroglycerin to carboplatin-based, doublet chemotherapy in NSCLC had no demonstrable benefit and should not be used or pursued further.



Funded by



Dataset Requested

Applicant Details

Project Administration

Project Design

Project Outputs

Ethics

Dataset DOI:*



Dataset Title:*



Data Access Requirement:*



Bio Sample:



Save

Next

Data Access Request

Secondary data use for education, replication, reproducibility

- Dataset contains IPD for 60 participants, all demographic and clinical data variables collected at baseline, week 6, week 12
- Secondary Use – to improve analytical skills of early/mid careers researchers to conduct independent analysis, replicate results.

Dataset Requested	
DOI	http://doi.org/10.25910/KWKH-HJ77
Title	T2DM probiotic intervention clinical data
Reason for request	Our group would like to use the data for research training purposes (early career researchers at the Faculty of Health and Medical Sciences), as we are planning to expand work in the field of clinical trials. The dataset will be used to replicate the results in the published paper.
Bio Sample	No biological samples, only the de-identified dataset.
Applicant Details	
Researcher Name	[REDACTED]
Researcher Email	[REDACTED]
Researcher Position	[REDACTED]
Researcher ORCID	[REDACTED]
Researcher organisation	[REDACTED]
Project Details	
Project Administrative	
Project Identifier	0001
Project Title	Clinical trial research training for early and middle career researchers
Start Date	2024-03-01
End Date	2025-12-31
Funding Sources	No funding is available
Conflict of Interest/Relevant disclosures	N/A
Project Design	
Background or Rationale	Early and middle career researchers at the Faculty of Health and Medical Science at the [REDACTED] lack the analytical skills to complete analyses in their studies. They have requested the provision of additional training resources using real health data from clinical trials.
Aims	To improve analytical skills of early and middle career researcher to conduct data analysis independently
Hypotheses	The use of real data and replication of results in previous studies is the best approach to improve analytical skills
Outcomes and Endpoints	At least 20 early and middle-career researchers completed 3 levels of research and analytical training using statistical software.
Data Security Strategy	All data will be stored in the internal servers at the [REDACTED] and only academics attending these session will get access to de-identified data as part of the training sessions. The data will not be used for secondary purposes.
Project Outputs	
Output Type	No any paper or Ip will be developed using this data
Output Title	No output will be obtained
IP Arrangements	There are no outputs requiring IP arrangements
Output Completion Date	2025-12-31
Ethics Information	
Ethics Approval Obtained	NO

Governance



Governance

- Ethics
- Regulatory & legal
- Standards & best practice
- Institutional policies



Governance achievements

- Research community consultation report
- Draft report on ethical & responsibilities
- Ethics committee benchmarking
- PICF template for data sharing
- Institution-specific policies & guidelines



CT-IQ InFORMed PICF Template
12 June 2024
Page 1 of 13

<Insert protocol number and date>

Awareness and training

- Free resources (e.g. Science Scenarios, ARDC Practical Guide)
- Node- and institution-specific training and guides for researchers



Secondary Use of Clinical Trials Data in Health Research A Practical Guide (Version 2.0)

By Kylie Hunter, Jonathan Williams, Talia Palacios, Aidan Tan, Kristy Robledo, Angelina Tjokrowidjaja, John Simes, Angela Webster, Amany Gouda-Vossos, Kristan Kang, Anna Lene Seidler

For the *Australian Research Data Commons*

February 2025



Text only.



Understanding barriers to data sharing in HDA

- Current project
- Barriers and enablers to data sharing using HDA
- Survey link and QR code

