

ARDC Leadership Series

Sharing Sensitive and Identifiable Human Data

03 MAY 2022

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ARDC Leadership Series

Panel Discussion: Sharing Sensitive and Identifiable Human Data



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Diamantina Institute
Faculty of Medicine



Prof Sotiris Vardoulakis

Global Environmental Health

The Australian
National University

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PHRN: Linking sensitive data

Presentation to ARDC Sensitive Data Workshop, Sydney, 3 May 2022



PHRN Population
Health
Research
Network

Sensitive linked data about all Australians

**Birth Records/
Perinatal Data**
States/territories

Education Data
States/territories

Hospital Records
States/territories

Disease Registries
States/territories

Death Records
States/territories



GP Records
Commonwealth

Education data
Commonwealth

**Prescriptions
Data (PBS)**
Commonwealth

**Medical Benefits
Data (MBS)**
Commonwealth

**Veterans' Affairs/
Ageing Data**
Commonwealth

Plus clinical trials, clinical registries, cohorts and other research data

National data linkage infrastructure



Data

210

Data collections

>15

Billion records



Linkage

7

Data Linkage Units



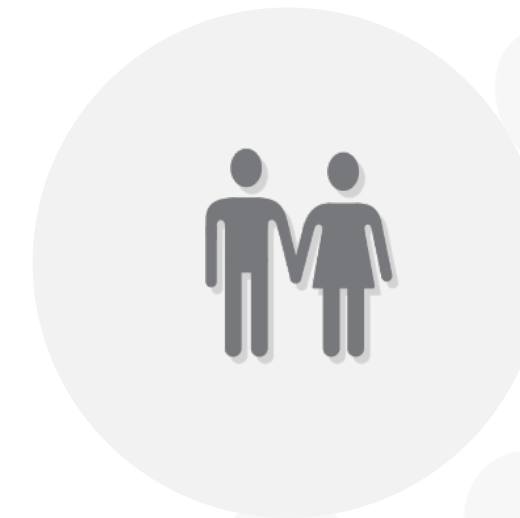
Secure Access

2

Secure Access facilities

Online Application System

Advisory service



Research Impacts

**Better
health and
wellbeing**

Access to sensitive health data

- Use must be lawful, ethical and acceptable to community; informed consent is helpful
- '5 safes' is a useful guide (projects; people; data; settings; outputs)
- Access to health data can be complex but is do-able

HPV vaccine for cervical cancer

- Linked data showed a significant reduction in cancer incidence after vax
- Cancer screening changed (was 2-yearly Pap Smear screen; now 5-yearly HPV screen)



Vitamin D randomised trial

- Low vitamin D is associated with negative health outcomes
- Linked data is supporting 5-year followup of >21,000 people



Further information

www.phrn.org.au

[PHRN Overview YouTube video](#)

<https://www.youtube.com/watch?v=VAsgvP1KaIU>

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Australian
National
University

HEAL National Research Network

*Australian Research Data Commons
Leadership Series: Sharing Sensitive and
Identifiable Human Data*



Professor Sotiris Vardoulakis

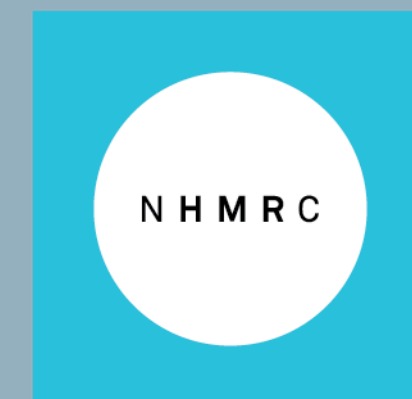
Director, HEAL National Research Network

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Australian Government

**National Health and
Medical Research Council**



We acknowledge Aboriginal and Torres Strait Islander peoples as the first custodians of the land, seas and waterways of Australia. We respect and honour Elders past, present and future; their culture and knowledges that have intrinsically cared for this Country. In this spirit, we commit to building a sustainable future together.





Healthy Environments And Lives (HEAL) Network

AIM

HEAL aims to take leadership in environmental change and health research that will provide the **evidence, capacity and capability**, and **tools** urgently needed to:

1. **Protect and improve community health**, especially at-risk groups and communities disproportionately affected by environmental and climate change.
2. **Strengthen health system resilience**, preparedness and responsiveness to changing environmental conditions and related diseases, and reduce its environmental impact.
3. **Reduce inequities and inequalities** within and across communities and generations.

Policy decision-makers

NSW, NT, VIC, TAS, WA, SA, QLD, ACT and National Health Departments
 National Indigenous Australians Agency
 VIC Dept Environment, Land, Water & Planning
 NSW Dept Planning, Industry & Environment
 VIC Environmental Protection Authority (EPA)
 TAS Environmental Protection Authority
 ACT Sustainability & Environment
 QLD Emergency Management
 NT Climate Change Office

Indigenous organisations

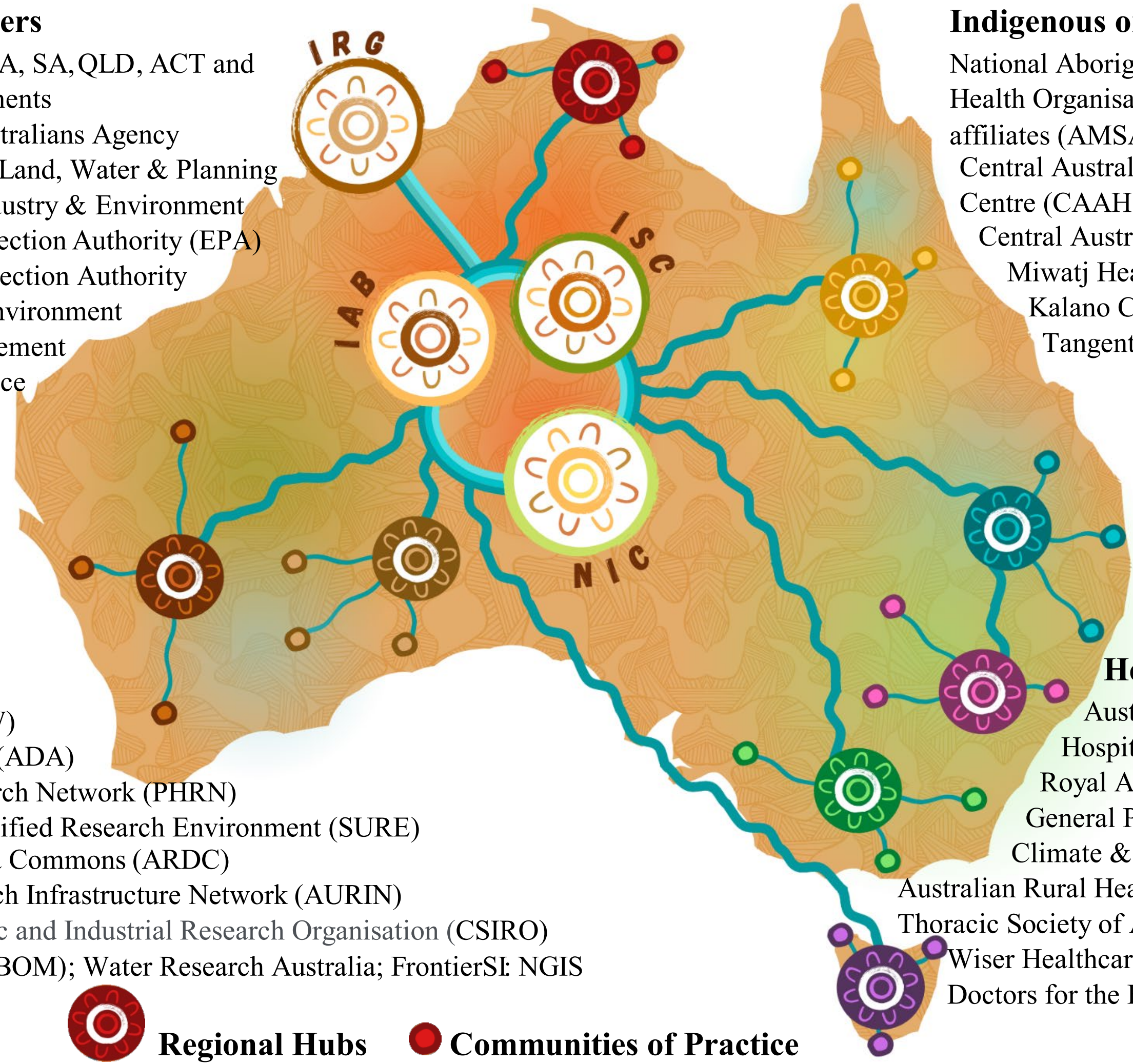
National Aboriginal Community Controlled Health Organisation (NACCHO) & state affiliates (AMSANT; AHCWA, AHCSA)
 Central Australian Academic Health Science Centre (CAAHSC); Lowitja Institute;
 Central Australian Aboriginal Congress
 Miwatj Health Aboriginal Corporation
 Kalano Community Association
 Tangentyere Council; Purple House

Data providers

Australian Institute of Health & Welfare (AIHW)
 Australian Data Archive (ADA)
 Population Health Research Network (PHRN)
 Sax Institute's Secure Unified Research Environment (SURE)
 Australian Research Data Commons (ARDC)
 Australian Urban Research Infrastructure Network (AURIN)
 Commonwealth Scientific and Industrial Research Organisation (CSIRO)
 Bureau of Meteorology (BOM); Water Research Australia; FrontierSI; NGIS

Health sector organisations

Australian Healthcare & Hospitals Association (AHHA);
 Royal Australian College of General Practice (RACGP)
 Climate & Health Alliance (CAHA)
 Australian Rural Health Education Network (ARHEN)
 Thoracic Society of Australia & New Zealand (TSANZ)
 Wisser Healthcare; Asthma Australia (AA)
 Doctors for the Environment (DEA)



IRG: International Reference Group
IAB: Independent Advisory Board
ISC: Indigenous Steering Committee
NIC: National Implementation Centre

 **Regional Hubs**  **Communities of Practice**



Sensitive Environmental Health Data: Challenges & Opportunities

1. Big data are increasingly used in environmental public health research
2. There is a need for findable, accessible, interoperable, and reusable (FAIR) data
3. Ability to create, analyse, and draw conclusions from these data relies on computational tools, e.g. artificial intelligence and machine learning
4. Sharing (or pooling) data from multiple studies enables large, diverse datasets, which creates new opportunities to gain knowledge.
5. But it increases privacy risks for participants who may be re-identified (re-ID) by linking study data to outside datasets.
6. Re-ID is increasingly relevant to environmental health research, because of growing pressures to share data, more personalized exposure measurements, and rapidly expanding repositories of public and commercial data.



ACRF AUSTRALIAN CENTRE OF EXCELLENCE IN Melanoma Imaging & Diagnosis

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REGISTER NOW: 3 May 2022

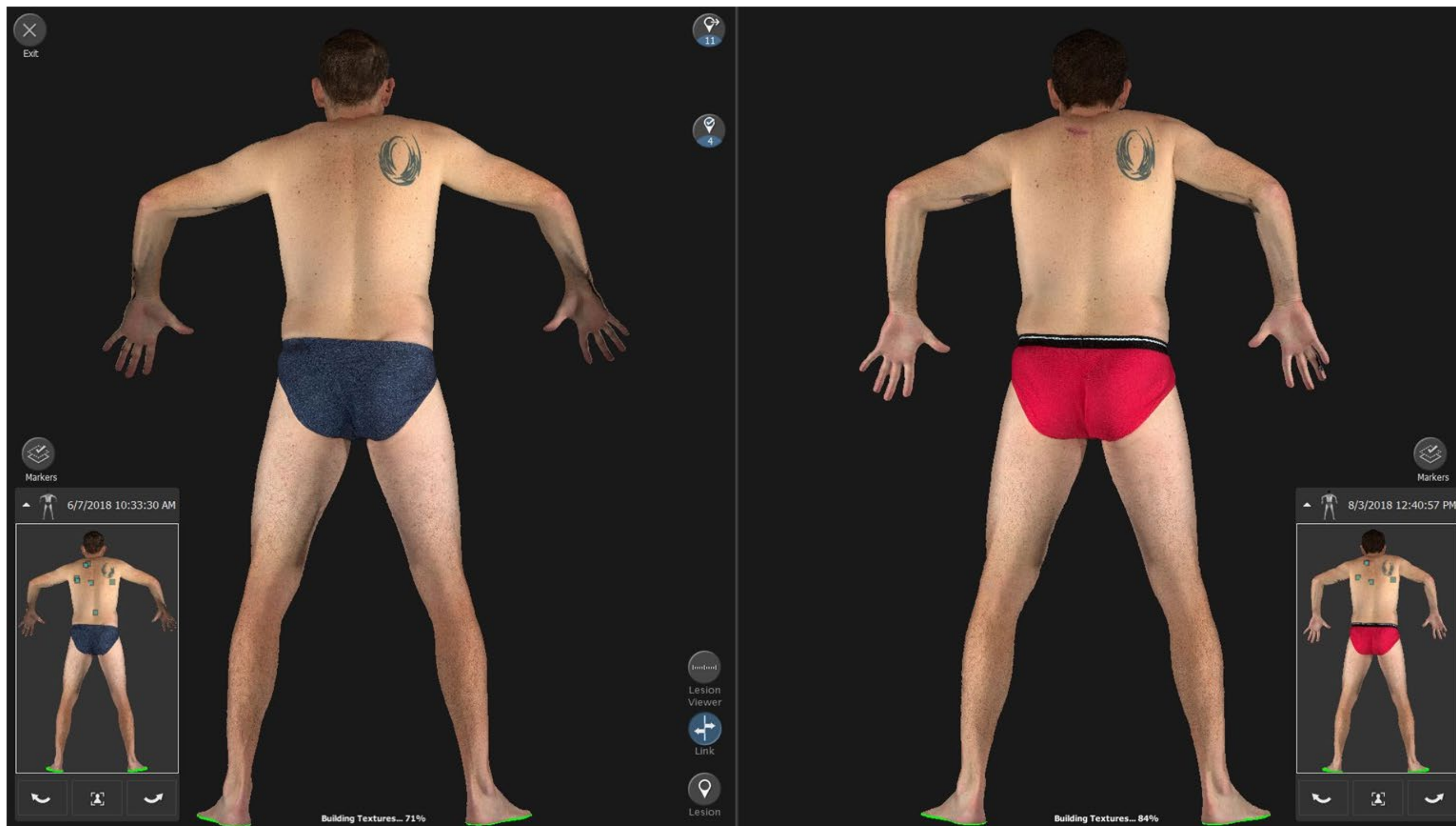


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ACEMID Technology: 3D Total Body Photography



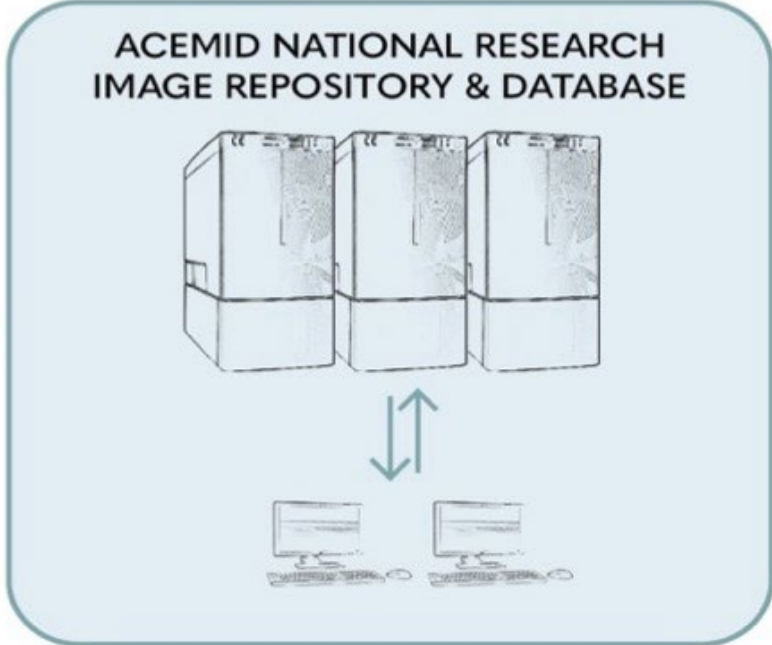
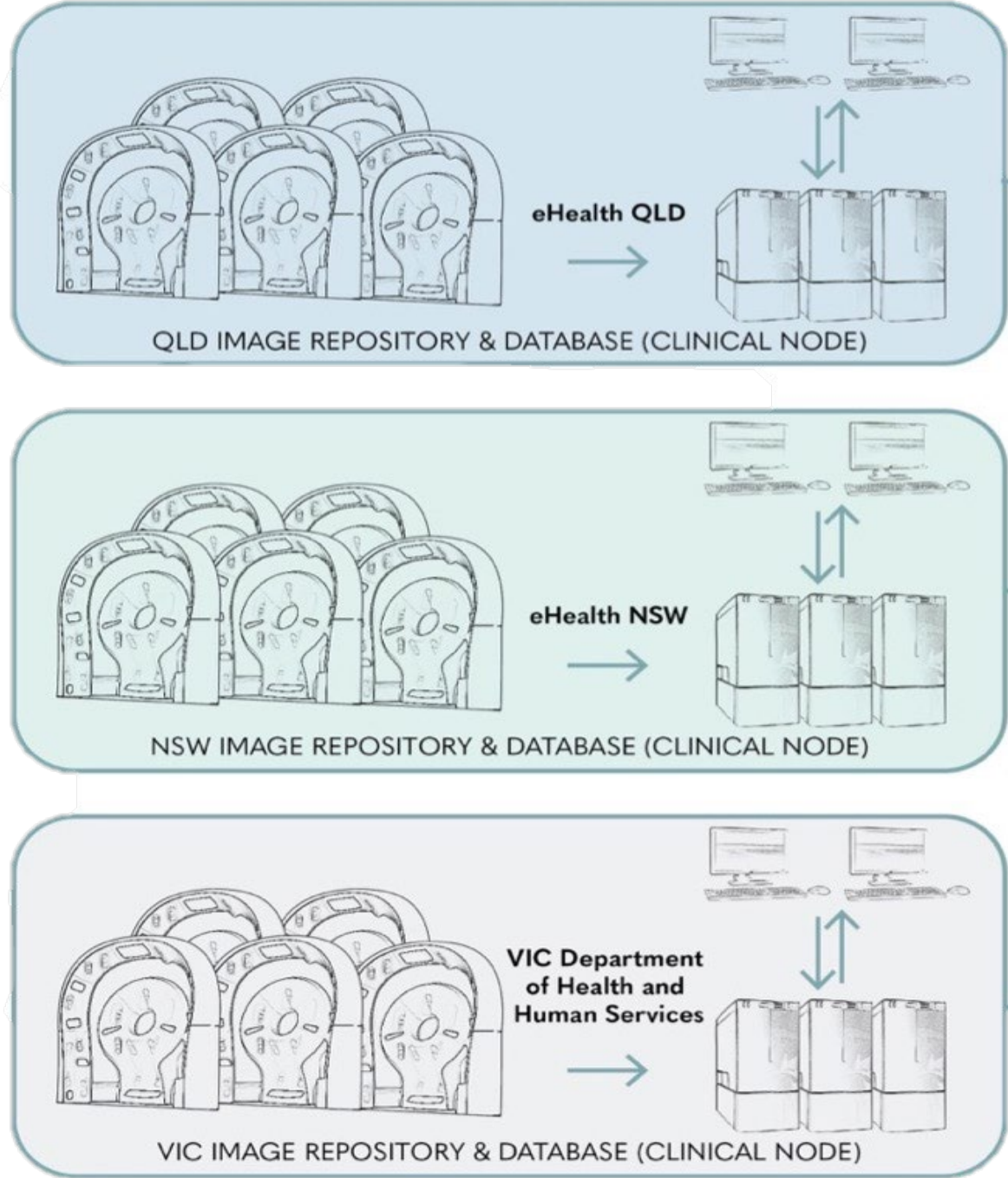
ACEMID Technology: 3D Total Body Photography



Longitudinal Data: Comparing body map images over time to find new & changed lesions

Research & Clinical Network

- 3,000 visits / instrument / year
- 100,000 3D avatars
- >5m lesion images over the next 3 years



Creating the world's largest and most comprehensive skin imaging database



Mission Statement

Mission

Transform melanoma early detection using total body surveillance to enhance individual lesion management

Research aims

Diagnostic Intelligence
Improve early detection and risk stratification using total body images integrated with history, clinical phenotype and genotype.

Health Service Evaluation
Total body imaging will reduce unnecessary biopsies by better 'hit' rate, improving cost for patients and the healthcare system.

Informatics
Integrate total body imaging into a telehealth network and EMR through implementation of image standards.

Critical infrastructure



ACRF funded telemedicine network of 15 total body imaging research nodes

Outcomes

- World's largest, most comprehensive skin imaging database.
- Reliable solutions for melanoma early detection.
- Facilitate artificial intelligence.

- Research-validated ACRF infrastructure underpinning the first nationwide melanoma screening trial.

Thank you for attending

Stay tuned for the upcoming forums

ARDC Leadership Series

Digital Research Skills



14 SEPTEMBER 2022

ARDC Leadership Series

Industry-research
Innovation



26 OCTOBER 2022

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ardc.edu.au/subscribe



Australian Research Data Commons