

## Submission Guide

### Mid-Term Business Review of SA NT DataLink

#### Terms of Reference

The Terms of Reference (ToR) outlines the background, scope and intended outcomes, process and timing of the SA NT DataLink Mid-Term Business Review. This document will be circulated to stakeholders to assist with consultation and submissions as part of the review.

The review has been authorised by the SA NT DataLink Steering Committee.

#### Background and Introduction

SA NT DataLink was established in 2009, and as part of an Australian wide national data linkage network – the *Population Health Research Network* (PHRN), supports important population based research to inform many areas of policy and service development within South Australia, the Northern Territory and nationwide. It is governed by the Steering Committee, with representation from all of the SA NT DataLink Consortium (Joint Venture) member organisations.

Data linkage (also known as record linkage) involves bringing together two or more sets of records (i.e., individual, household, business) from a number of data sources. Research using de-identified data is more inclusive, representative, efficient and unbiased than conventional studies based on sampling. SA NT DataLink enables the data linkage of administrative and clinical data sets, helping to better inform research, policies and practises in South Australia, the Northern Territory and other jurisdictions.

Given the importance of linked data to researchers in a variety of settings, the infrastructure supporting this capacity should be optimally positioned to be competitive in a dynamic and changing environment. Taking this into account, any current (and potential future) issues relating to the governance, sustainability and service engagement of SA NT DataLink should be considered, and appropriately addressed.

In this regard, the Steering Committee has deemed it important and timely to undertake a mid-term business review of SA NT DataLink. An appointed panel has been tasked with coordinating and delivering the review. As part of the wider review, the panel is now calling on written submissions from stakeholders across government, academia and research institutes.

#### Scope and Intended Outcomes

##### Purpose of review

The Panel shall:

1. Review Item 4: *Intent* and *Objectives* of the Consortium and Item 5: *SA NT DataLink Functions* as described in Schedule 1 of the 2016 - 2020 the *Joint Venture Agreement* (the JVA); and any other clauses in the JVA they consider relevant, with consideration of recommended changes.
2. The Panel shall consider the current operations of SA NT DataLink.

3. With regard to considerations of sustainability, the Panel should consider the operations of SA NT DataLink for a period of 5 years beyond the life of the JVA, i.e. January 2021 to December 2025.
4. In undertaking the review, the Panel will consider the Intent and Objectives of the Consortium and the Functions of SA NT DataLink in the context of:
  - 4.1. SA NT DataLink's financial performance in relation to:
    - Joint Venture Partners' cash and in-kind contributions,
    - NCRIS and other Australian Government grants and contributions, cash payments from research projects and any other sources, and
    - Linkage credits and rebates allowable under the SA NT DataLink *Access and Pricing Policy*.
  - 4.2. Outcomes in terms of:
    - 4.2.1. SA NT DataLink's value in attracting competitive research grants in South Australia and in the Northern Territory, as well as other grants and data related funding opportunities.
    - 4.2.2. Raising public and the research community's awareness of the value of the SA NT DataLink infrastructure including through publications and public presentations supported by SA NT DataLink or directly by JVA partners.
  - 4.3. Any constraints in the JVA that may limit the potential for SA NT DataLink's future development.
  - 4.4. The sustainability of SA NT DataLink's business model and funding sources/structure, including:
    - 4.4.1. The implications of recent external initiatives particularly the 2016 NCRIS Roadmap, the *Public Sector (Data Sharing) Act 2016, (SA)* and the Australian Government's response to the 2016 Productivity Commission's recommendations on Data Availability and Use;
    - 4.4.2. Risks related to reliance on the current funding sources; opportunities from potential increases to Commonwealth national research infrastructure funding (which SA NT DataLink currently receives through the PHRN);
    - 4.4.3. Identifying potential future alternate funding sources and strategies to attract these; and
    - 4.4.4. Potential future demands on the SA NT DataLink infrastructure, technical developments and their implications for the efficacy of the current model of SA NT DataLink, organisational structure and operations, including governance structure and reporting, management, staffing, ICT capacity, and other resources.

## Reporting

The Panel:

1. Will provide a final report by 1 November 2018 for the review by the Steering Committee members prior to the Committee's last scheduled meeting in 2018 on 7<sup>th</sup> December 2018.
2. The final report should include (but not be limited to) recommendations relating to:
  - 2.1. Strategic directions for SA NT DataLink to support the sustainability and growth of integrated data access and use over the proposed period i.e. to 2025. The SA NT DataLink Steering Committee recognises that one of the findings may be that SA NT DataLink, as it is currently configured, may not be sustainable in the medium to long term.
  - 2.2. The most appropriate organisational and governance structure and funding arrangements for SA NT DataLink in the medium to long term.
  - 2.3. Proposed amendments needed to be considered in preparation of an extension to the *SA NT Data Linkage Consortium Agreement (JVA)*.
  - 2.4. Identifying potential future new directions for SA NT DataLink and the strategic approaches and requirements for developing these, including developing research collaborations and

partnerships within and across government, non-government and private sectors, and international collaborations.

- 2.5. Implementing business and technology improvements including improving stakeholder relations, service quality, and delivery of data for approved linkage projects.
- 2.6. Identifying and promoting opportunities for SA NT DataLink and its Joint Venture Partners to deliver educational and promotional collaborative activities (online, workshops, seminars).
- 2.7. Identifying opportunities to attract new SA NT DataLink Joint Venture partners.

### **Process and timing**

The review will be undertaken by a selected panel including Professor Louisa Jorm, Professor Bruce Armstrong, and Professor Sven Silburn.

The review panel will be responsible for developing a report of findings and recommendations against the *scope and intended outcomes* specified above. The process will include research and consultation with academia, government and research institutes, with a comprehensive report to be finalised in late 2018.

The panel comprises:

#### Professor Louisa Jorm

Professor Jorm is the Foundation Director of the Centre for Big Data Research in Health at the University of New South Wales. She is an Australian leader in epidemiological research using large-scale and linked health data, including hospital inpatient, cohort study and Medicare data. Her research spans topics including health system performance, evaluation of health services and programs, maternal and child health, and Aboriginal health. She is a high-profile advocate for more and better use of routinely collected health data for research.

#### Professor Bruce Armstrong

Professor Armstrong is an Emeritus Professor of Public Health in the Sydney School of Public Health, University of Sydney and Senior Adviser in the Sax Institute Sydney. He has been the Director of the Australian Institute of Health and Welfare, Deputy Director of the International Agency for Research on Cancer, and the Commissioner of Health in WA. He is an internationally pre-eminent cancer epidemiologist, acknowledged as a passionate, inspiring leader in cancer research and management. He is an international expert on the causes of skin cancer and melanoma and has made important contributions to the knowledge base on the causes and control of other cancers, heart disease and high blood pressure.

#### Professor Sven Silburn

Professor Silburn is a national leader in clinical, epidemiological and evaluative research in child development and education, youth mental health and suicide prevention. He was a chief investigator on the Western Australian Aboriginal Child Health Survey of over 5600 children, young people and their families. This reported the first independently validated data on the extent of the inter-generational effects of forced separation on the health and wellbeing of the current generation of Aboriginal children and their families. Professor Silburn has served on several national, state and territory advisory boards, and been active in policy advocacy in the areas of developmental health of Indigenous and non-Indigenous children and suicide prevention.

## Questions and contact

For any questions, or queries, contact:

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