

# Terms of Reference

## A review of data linkage capabilities in Western Australia to enhance the next generation of whole-of-Government data linkage

This Terms of Reference document sets out the background, scope and intended outcomes of the review of data linkage activities and capabilities in Western Australia (WA). This document will be made public and circulated to stakeholders to assist with consultation and submissions as part of the review. This document also sets out an overview of the review process and the advisory group.

This review has been authorised by Mr Peter Conran, Director General of the Department of the Premier and Cabinet (DPC).

### Background and introduction

It has been well acknowledged that WA has been a world leader in data linkage for many decades, especially in relation to datasets contributing to population health research. Projects and research using linked data have contributed to a range of policy, legislation and investment measures that have improved the health and wellbeing of Western Australians.

However, there is mounting evidence that WA's position as a leader in data linkage is declining, with reports of linked data users facing barriers, such as long wait times and high costs. These barriers are limiting access to linked data for important health and social welfare research. This in turn reduces the ability to make evidence-based decisions, secure competitive research grants, and attract/retain skilled workers with and expertise in data linkage. Ultimately, this results in lost opportunities to improve outcomes and deliver important benefits to citizens.

Data linkage is a technique that connects pieces of information that are thought to relate to the same person, family, place or event. Data linkage can provide many insights, including intervention programs that are working or failing, areas that need greater resources, trends to promote novel intervention strategies, and information regarding risk or preventative factors. Linking data across government agencies and services can provide a powerful resource for understanding complex issues, as well as developing new multi-disciplinary approaches to improve the WA community.

Over recent years there has been a rapid increase in the demand for linked data for research, government planning and commercial purposes, with an expansion beyond the health sector. Much of this is in response to a realisation that many "wicked problems" facing modern democracies require a whole-of-government response (for example: social health determinants, climate change, inequalities, youth incarceration, mental health problems, youth disengagement and educational problems). A whole-of-government data capacity can enable the best information on these problems and an ability to evaluate whether current or proposed services and policies are working or likely to.

In April 2015 the Premier released [A Science Statement for Western Australia](#) (the Science Statement) which recognises data and data intensive science as areas of opportunity for the State to help broaden its economy and create a new generation of jobs. The Science Statement acknowledged WA's competitive advantages in health and population-level data linkage, together with longitudinal studies such as the Busselton Health Study and Raine Study. One significant commitment under the Science Statement was the development of a new data linkage model that builds on these strengths.

The [WA Whole-Of-Government Open Data Policy](#) was also released in 2015. In addition, the WA Government Chief Information Officer (GCIO) was appointed and a supporting office, the Office of the GCIO (OGCIO), was established. These important initiatives form part of the Government's plan to transform the way public sector data is managed, accessed and used in order to remain competitive in an increasingly digital economy. The OGCIO is working to build the foundations and capabilities necessary to generate a sophisticated and efficient approach to data utilisation across the public sector.

It is, therefore, important and timely to review WA's current data linkage activities to ensure the State maximises this unique resource. It is essential that this capability meets the growing demand and increasing scope of data linkage, if it is to continue delivering social and economic benefits to Western Australians.

## Scope and intended outcomes

It is intended that the review of WA's data linkage capabilities will provide Government with the information necessary to meet the growing demand for data linkage and enhance the next generation of whole-of-Government data linkage for WA.

The key focus areas of the review are to examine:

- i. the State's strengths, capabilities and capacities in data linkage and consider how they can best be utilised and developed;
- ii. the barriers and impediments to data linkage, and address how they can be improved;
- iii. examine the data linkage systems, infrastructure and processes to determine whether they drive efficient, high quality and secure outcomes; and
- iv. examine the governance and funding arrangements for data linkage and assess what is required to meet increasing demand beyond just health.

The review will have regard to:

- current and future requirements for data linkage in WA, including needs, technological advances and trends in service delivery; and
- State and national government policies, and data linkage models and practices nationally and internationally.

The key outputs of the review are to provide:

- recommendations to Government for immediate improvements to data linkage that will bolster the State's competitive advantage; and
- options for enhanced data linkage models for the next generation of whole-of-Government data linkage.

## Process and timing

The review will be undertaken by the Data Linkage Expert Advisory Group, comprising the WA Chief Scientist, Professor Peter Klinken (Chair), the WA GCIO, Mr Giles Nunis, and Professor Fiona Stanley, Patron and Founding Director of the Telethon Kids Institute and Professor of Child Health at The University of Western Australia (UWA). More information about members of the advisory group is provided below.

The advisory group will be responsible for developing a report of findings and recommendations against the *scope and intended outcomes* outlined above. The process will include research and consultation across Government and the research sector. The review process will also provide an opportunity for written submissions to be made against the terms of reference of the review.

The advisory group will report to the Director General of the Department of the Premier and Cabinet, with a final report to be submitted to the Director General by August 2016. The report will inform government on how to proceed, in both the short and longer terms, to meet the growing demand for data linkage and achieve the next generation of whole of government data linkage for WA.

Given the WA Data Linkage System is managed by the Department of Health, and WA's strong data linkage foundations in the health sector, Dr David Russell-Weisz, Director General of the Department of Health has endorsed the review and terms of reference.

Information about the review will also be made available on the Department of the Premier and Cabinet website, including opportunities to provide information and submissions:

<https://www.dpc.wa.gov.au/Consultation>

## Data Linkage Expert Advisory Group

The advisory group comprises:

**Professor Peter Klinken (Chair)** – Professor Klinken was appointed to the role of WA Chief Scientist in 2014. Professor Klinken is a leading WA medical research scientist, highly regarded for advancing the understanding of genes involved in leukaemia, cancer and anaemia. His many research achievements include the discovery of a gene that suppresses the growth of tumours.

Professor Klinken's previous roles have included Professor in Clinical Biochemistry at UWA; Director of Research at the Royal Perth Hospital; and Director of the Harry Perkins Institute of Medical Research (previously the WA Institute for Medical Research). Under his stewardship, the Perkins Institute attracted world-class national and international researchers to WA and made numerous acclaimed medical discoveries. He also led the development of two new state-of-the-art medical research facilities, Perkins North in Nedlands (QEII Medical Centre) and Perkins South in Murdoch (Fiona Stanley Hospital).

**Mr Giles Nunis** – Mr Nunis was appointed the inaugural Chief Executive and Government Chief Information Officer (GCIO) on 30 September 2015. Prior to that, Mr Nunis was the Deputy Director General at the WA Department of State Development. He was responsible for negotiating commercial State Agreements with major resource companies and managing the Government's international trade offices. During this time Mr Nunis was also seconded to the Department of Health and played a major role in restructuring of the Department's Fiona Stanley Hospital ICT Program which was successfully delivered on time for the opening of the hospital. Prior to joining the WA Government, Mr Nunis was the National Managing Director of a multi-national ICT and Management Consulting firm, based in Melbourne, with its head office in Zurich, Switzerland.

**Professor Fiona Stanley AC** – Professor Stanley is a Professor of Child Health at UWA, and Patron and Founding Director of the Telethon Kids Institute. Professor Stanley is medically trained with a strong interest in maternal and child health epidemiology and public health. Professor Stanley has spent much of her career investigating the causes of major childhood illnesses, such as birth defects. One of her major contributions was to establish the Telethon Institute for Child Health Research (now known as the Telethon Kids Institute), an independent multidisciplinary research institute focussing on the causes and prevention of major problems affecting children and youth. Professor Stanley is a passionate advocate for the needs of children and their families, promoting the importance of population data to provide significant health, social and economic benefits to the community. For her research on behalf of Australia's children and Aboriginal social justice, she was named Australian of the Year in 2003 and was made a UNICEF Australia Ambassador for Early Childhood Development in 2006.

The Office of Science in the Department of the Premier and Cabinet and the Office of the Government Chief Information Officer will support the advisory group in undertaking the review.

## Questions and contact

Information about the review will also be made available on the Department of the Premier and Cabinet website, including opportunities to provide information and submissions:

[www.dpc.wa.gov.au/Consultation](http://www.dpc.wa.gov.au/Consultation)

For additional queries, contact:

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