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South Australian Productivity Commission  
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Dear Dr Butlin

### **Submission to Inquiry into Health and Medical Research**

On behalf of the SA NT Datalink Steering Committee I would like to thank the Commission for the opportunity to make this submission to the Inquiry into Health and Medical Research in South Australia.

SA NT Datalink is the only data linkage research infrastructure supporting population based data linkage in South Australia and the Northern Territory and works closely with other jurisdictional data linkage units, including the Commonwealth.

In this submission, SA NT Datalink has drawn on its 10 years experience at state, national and international levels to understand the current situation of data linkage research and data analytics, as well as the challenges to supporting the future development of this increasingly important area of [big] data for health and medical research.

SA NT Datalink sees the need for greater investment in and well-defined strategic directions for this infrastructure in order to make its capacity more competitive and attractive to national and international health and medical research and to better support South Australian based research undertaken by the universities and research institutes.

The submission from SA NT Datalink is focused on the area of access to data and the governance and regulatory environments that from a researcher perspective and from SA NT Datalink's experience, often provide significant challenges to access and provision of timely information, and from a consumer perspective, needing assurances of privacy and accountability in the use of their data.

Mr Andrew Stanley, Director, SA NT Datalink is very happy to address any questions that the Commissioners may have arising from this submission.

Yours sincerely



**Professor Susan Hillier**  
Chair  
SA NT DataLink

**SA Productivity Commission**

**Inquiry into Health and Medical Research in South Australia**



**Submission from SA NT Datalink**

**May 2020**

## Contents

Key points .....	1
Background to SA NT DataLink .....	1
Is the current regulatory environment at the national level conducive to data generation and sharing? .....	3
Is the current regulatory environment at the state level, including the operation of the Public Sector (Data Sharing) Act 2016, conducive to data generation and sharing? .....	4
Is there overlap between national and state legislation? .....	5
What types of data are important to share in HMR? .....	5
What barriers are there to sharing data for HMR? [and] What data related bottlenecks constrain HMR and what can be done to remove them? .....	6
Professional concerns .....	6
Governance and approvals .....	7
Resourcing and capacity limitations of SA NT Datalink .....	7
Competitive and other issues .....	8
Table 1: Organisations participating in SA NT DataLink supported projects .....	9
Table 2: Data Integration Unit - Datasets held or awaiting provision .....	10
Table 3: Inventory of linked data .....	11

## Information request 5.2: access to data

### Key points

- SA NT Datalink provides access to over 70 health, registry, education and human services datasets and 70 million individual records for linked data research and analysis. This research data infrastructure established in 2009 is now essential data linkage research infrastructure for South Australia and the Northern Territory.
- There have been ongoing issues relating to timely approval and access to integrated and linked data for the research sector for many years, at both state and national levels.
- The time required for approval processes by data custodians and Human Research Ethics Committees (HRECs) has been a significant impediment for timely access to data for linked data projects, particularly where data may be required from multiple jurisdictions. This indicates opportunities for process improvement and streamlining of the governance.
- There are activities progressing to improve the timeliness of HREC approvals. Work is progressing through Health Translation SA arising from the Birch Report for pre-consultation by the SA Health HREC with SA NT DataLink on data linkage applications, and recent support by most jurisdictional HRECs for the National Mutual Acceptance will reduce the HREC approvals required for multi-jurisdictional data projects.
- Some data custodians for a mix of legal, attitudinal and resource reasons remain reluctant to make their data available for worthwhile public good projects through the SA NT Datalink privacy protecting linkage system. Of note is the lack of private sector health data available for linkage, ie general practice and private hospital data, in effect making approximately one third of health data unavailable in SA.
- The SA Health authorised data repository managed by SA NT Datalink has the potential to hold a much wider range of data, including clinical registries and practitioner databases, and importantly make these available for wider research on approval of their respective data custodians.
- The financial contribution to SA NT DataLink from a range of Joint Venture member organisations is leaving it vulnerable to reductions in funding should one or more of its Joint Venture partners choose not to continue contributing.
- State government agencies contribute approximately 20% of funding to SA NT Datalink compared with most other jurisdictional linkage units receiving between 60%-100% of State government funding.
- Faced with a real risk of reduction in funding for 2021 and beyond, SA NT Datalink is re-considering its capacity to respond in a timely manner to the current demand for integrated data services, with possible less ability to expand these to build on the opportunities it sees to better support a wide range of health and medical research.

### Background to SA NT DataLink

SA NT DataLink was established in 2009 (along with other jurisdictional linkage units) as part of the Population Health Research Network (PHRN), part funded by the Australian Government through the National Collaborative Research Infrastructure Strategy (NCRIS) to support the development of population based data linkage research infrastructure across Australia.

SA NT DataLink operates as an unincorporated joint venture initially supported by the then Minister for Health and Minister for Education. Since then, it has expanded its joint venture partners and operated successfully with their support for over 10 years. The current members of the Joint Venture are:

- University of South Australia
- The University of Adelaide
- Flinders University
- Menzies School of Health Research (joined 2018)
- NT Government
- SA Health
- SA Department for Education
- Cancer Council SA
- South Australian Health and Medical Research Institute (SAHMRI)
- Health Consumer Alliance (SA)

Since its establishment, SA NT DataLink has completed 150 health and human services projects and is currently supporting a further 50 projects, including at a national level and significant programmes of work supporting the SA and NT Governments. A list of the completed projects can be found on the [SA NT DataLink website](#) (Projects/Completed projects). The projects have involved some 216 researchers from across 45 universities, research organisations and government agencies from across Australia (refer Attachment 1, Table 1).

As a result of the ongoing investments made by the university, research and government sectors, and through the partnership with the Health Consumers Alliance of SA, SA NT DataLink is now recognised an essential data infrastructure for South Australia (SA) and the Northern Territory (NT) able to support population and clinical based data linkage research for these sectors and for government policy, planning and evaluation.

In 2018, SA NT DataLink established its Data Integration Unit (DIU) managing custodian controlled de-identified content data (CCDR) within a government approved secure repository. The CCDR hold de-identified patient level service and clinical data (refer Attachment 1, Table 2). The CCDR is hosted in the Secure Unified Research Environment (SURE) facility managed by the SAX Institute in NSW.

The CCDR has enabled more efficient access to approved SA Health and BDM data and reduced the resource demands on these agencies when supporting SA NT DataLink projects, achieving a key establishment aim, that is the timelier access to sensitive patient level data for researchers.

To support this work, SA NT DataLink has over the past 10 years continually increased the data available for research and analysis. Starting in 2009 with 3 datasets, it now holds 70 data sources covering health, clinical registries and a range of human services including Education, Public Housing, Child Protection, Youth Justice, Corrections and Justice data for SA and NT. The data collections encompass some 70 million records for 2.5m people covering past and current resident and is regularly updated with SA Crown Law prepared data agreements with data custodians (Attachment Two, Table 3).

SA NT DataLink is unique in Australia in that it has the most diverse range of linked longitudinal datasets available for research and analysis of any data linkage unit in Australia. For example, in 2020 it was provided with SA Department of Corrections data with agreements in progress for the SA Ambulance Service and SA Pathology data to be routinely provided to SA NT DataLink for linkage and to be held as de-identified content records within the Custodian Controlled Data Repository (CCDR).

In 2019, SA NT DataLink received final accreditation by the Commonwealth Government as one of very few Integrating Authorities in Australia. This accreditation enables SA NT DataLink to be provided with high risk Commonwealth data for linkage with existing state based datasets and therefore increase its capacity to support health and medical research by facilitating access to Commonwealth data for approved projects.

SA NT DataLink also supports Government agencies by providing feedback about the quality of data it receives from data custodians. It checks the quality of the identifying information provided against longitudinal and enduring Master Linkage File and provides advice back to data custodians about records that may require their further review. It also supports specific requests from an agency. For example, SA

NT DataLink has supported:

- SA Health's mental health services as part of the process of merging and quality assuring multiple databases required for consolidating and providing more effective data access and internal use.
- SA Cancer Registry in improving the accuracy of information identifying Aboriginal and Torres Strait Islander people.
- The South Australian Registrar, Births, Deaths and Marriages in identifying potentially missing Births registrations or duplication registrations.
- The Northern Territory Registrar, Births, Deaths and Marriages in identifying potentially missing Births registrations or duplication registrations.
- BreastScreen SA in the geocoding of address information.
- The Electoral Commission of SA in identifying potential duplicate enrolments.
- The confirmation and provision of high-quality patient identifiers by the Department of Health and Wellbeing for the National Integrated Health Service Information (NIHSI) through AIHW.

### **Is the current regulatory environment at the national level conducive to data generation and sharing?**

There have been several inquiries into this question by the Australian Productivity Commission and the Commonwealth Government to which SA NT Datalink has made submissions. These Inquiries have all articulated similar barriers to data sharing and made recommendations in relation to these. SA NT Datalink submission include:

- Australian Productivity Commission
  - Data Availability and Use (2016)
  - Education and Evidence (2016)
- Senate Select Committee into Health (2015)
- NCRIS: National Research Infrastructure Roadmap (2015)
- The Australian Government's proposed *Data Sharing and Release* legislation.

All of the inquiries (and SA NT Datalink submissions) recognised the lack of a coherent and consistent policy, regulatory and governance requirements supporting access and integration of data for research, as well as institutionalised attitudes that are resistant to the sharing of data, usually characterised as data custodians being risk averse and, as they perceive, in the context of little or no protection for them should a data breach occur.

The result is that researchers often experience significant access and cost barriers to undertaking population or cohort level data linkage particularly where multi-jurisdictional or national research is to be undertaken.

From SA NT Datalink's experience over the past 10 years, while there have been improvements, the regulatory environments at the national and state level generally remain frustrating for researchers, not only to gain approval but subsequently the long period of time to be provided with the linked data by data custodians. Often however, this is due to the resource constraints and the need for data custodians to prioritise their work program to meet their Government's priorities.

For access to Commonwealth datasets through AIHW, although the processes are in principle straight forward, often, given the above issues combined with their policy requirements and only quarterly ethics meetings, these can result in research projects experiencing very long delays (particularly if amendments are required). The cost of AIHW services and linkage can also be prohibitive. Compared to SA NT DataLink, there are significant costs for researchers using the AIHW data linkage services. For example, what is considered as a simple linkage of a small cohort (n~2000) identified by SA Pathology to MBS, PBS and National Death Index (NDI) was costed at \$21,500. SA NT Datalink's cost of linking the same cohort to eight SA datasets was costed at \$8,200.

Proposed Commonwealth *Data Sharing and Release* legislation to make sharing of data easier provides an opportunity for reform, and whilst the act is still to be drafted, its scope is restricted to Commonwealth agencies only and it is believed, will not make data sharing a firm requirement for Commonwealth data custodians.

The release of data for research from the recently amended *My Health Record Act 2012* is not as yet established, although the [Framework to guide the secondary use of My Health Record system data](#) (the Framework) has been developed and published. However, it is not expected to come into effect *until the establishment of robust processes and governance arrangements* that will ensure the privacy of health care recipients. Based on this requirement, it was anticipated the availability of data would not be before 2020. To date the framework has not been implemented.

### **Is the current regulatory environment at the state level, including the operation of the Public Sector (Data Sharing) Act 2016, conducive to data generation and sharing?**

The approval of the Privacy Committee of South Australia was a necessary requirement for the establishment of SA NT Datalink and for the provision of data to it. The Privacy Committee and the exemptions to the SA Government Privacy Principles is a unique SA requirement because there is no privacy legislation in this State. The lack of this legislation also made accreditation of SA NT Datalink as a Commonwealth Data Integrating Authority a much longer and protracted process (>5 years) than for other jurisdictions that have privacy legislation.

The *Public Sector (Data Sharing) Act 2016*, (the Act) was established to overcome the barriers to data sharing between government agencies. It was a response to the many regulatory and attitudinal barriers that existed which limited the sharing of data between agencies and therefore be more available for facilitating SA Government planning, policy, interventions and evaluation.

The legislative framework for the Act established the Office of Data Analytics (ODA). The ODA operations and priorities are clearly in the government operational business arena and not that of health and medical research. It could be difficult for the ODA to directly undertake such research under the Act, since there is no clear remit for itself to undertake health and medical data linkage research and no specific requirement for ethics approval for the work it undertakes (approvals are guided by a set of principles – the Five Safes). The ODA can and has worked with researchers who themselves undertake ethically approved research.

SA NT Datalink has built its resources and data provision processes not because of any regulatory requirements, but because of the trust that it has demonstrated over time with data custodians as they became familiar with SA NT Datalink's data privacy and security policies that protect and securely manage risk and their data. The extensive number of data agreements SA NT DataLink has with data custodians, while a recognition of the benefits that data custodians see in making their data available for research, also places a significant burden on SA NT Datalink in the development and management of the many agreements.

Nevertheless, the agreements signify the trust that data custodians have in SA NT Datalink to manage the risk and privacy concerns related to the provision of their data. This trust has developed such that some health data custodians are providing their de-identified data to SA NT Datalink for it to be stored and managed in an approved secure data repository and enabling it to be provided by SA NT DataLink for approved projects in more a timely manner.

The use of data repositories as a means of improving researcher access for data linkage projects is becoming more common across Australia and follows international trends. Partnering with data custodians has been a major step forward in enabling the timelier provision of data for projects and reducing a significant resource burden for data provision, while ensuring data custodians maintain their governance, control and approval responsibilities.

At this point in time, the *Data Sharing Act* has not been significantly relevant to SA NT Datalink in the generation of data it holds for research. More generally, as SA NT Datalink understands it, the framework of the Act and/or the ODA is not resourced, compared with SA NT DataLink, for the data and governance expertise required to support ethically approved research specifically in health and medical areas, at State and national multi-jurisdiction levels.

The use of health and medical data for research is regulated by the *Privacy Act 1988* (Cth) at the national level and by state legislation, such as the *Health Care Act 2008* (SA) and the *Mental Health Act 2009* (SA). In addition, at the national level, health and medical research must be undertaken in accordance the NHMRC guidelines to which s95 of the *Privacy Act* refers. The guidelines made by the NHMRC must be followed through the ethical approval for the research, otherwise the researcher may be in breach of s95 of the *Privacy Act*.

Prior to the establishment of the *Data Sharing Act*, the sharing of data was supported by each agency's legislation and the Privacy Committee of South Australia to which the proposed data sharing was to be referred to ensure it did not breach the SA Government's Privacy Principles. It is SA NT Datalink's understanding that with the establishment of that Act, referral to the Privacy Committee is no longer necessary and the role of the Privacy Committee regarding the Privacy Principles and privacy protection is now unclear as is the existence any oversight independent of Government of privacy relating to data sharing and use of data by SA Government agencies.

As stated previously, SA has no privacy legislation and will be the only jurisdiction in Australia that does not once Western Australian has passed its privacy legislation which it is currently developing.

The lack of privacy legislation has been a barrier to both data custodians and consumers having the confidence to make their data available to SA NT Datalink and to researchers. While there is governance from an ethics perspective, there is no legislative mechanism that provides transparency in the use of data and that, particularly consumers feel, protects their rights or provides significant sanctions should data be misused.

The lack of state based privacy legislation, an essential component for SA NT DataLink being finally accredited as a Commonwealth Data Integrating Authority for the purpose of linking State and Commonwealth data, the Australian Government made amendments to the Cth *Privacy Act* and prescribed SA NT DataLink and the SA Health staffed Data Linkage Unit to be an agency operating under that Act.

### **Is there overlap between national and state legislation?**

SA NT Datalink is not aware of any direct overlap of jurisdictional legislation in relation to data sharing and data linkage. There is enabling legislation for example under the SA *Health Care Act 2008* that supports the provision of SA Health data to AIHW on approval of the Chief Executive SA Health, and has been used to supported the development of the NHISI by AIHW through SA NT Datalink.

There is no legislation at the Commonwealth or State level that directly supports health and medical research and protects the provision of data for research. Currently research is enabled under S95 of the *Privacy Act 1998* (Cth) and exemptions to the Information Privacy Principles requires health and medical research to follow the NHMRC guidelines and have research approved by a NHMRC accredited Human Research Ethics Committee (HREC). At the State level, the capacity for an agency to support research is enabled under the legislation for that agency and most often as a minor mention in the functions of the Minister, and/or CE, or Board.

### **What types of data are important to share in HMR?**

As stated below, SA NT Datalink seeks data where it is requested by a researcher. However, areas of increasing research importance are in the use of data from genomics, clinical trials and post marketing surveillance of drugs and medical devices linked to other health and human services data.

The linkage of the data is particularly important to understand impacts at a population level and/or particular cohorts over time and where other factors including geography, environment, socio-economic status, education, employment, occupation and life pathways may be important variables to understanding the translation of clinical research to health outcomes.

A crucial gap in the knowledge of SA's health system concerns information from the private health sector (for example, from this sector's hospital inpatient, day surgery and emergency department, pathology, radiography and mental health, GP and specialist services).

Given for example, that this sector provides about one third of the hospital based care in SA and also other related service, the lack of information from this sector imposes a severe limitation on health and medical research seeking to understand clinical outcomes and service delivery in this State.

The inability to integrate and provide researchers access to at least the private hospital data is a key issue impacting on the completeness of research in statewide health outcomes. SA NT Datalink has for many years been trying to convince the private hospital sector to make its data routinely available for data linkage research, to date with little success. Usually concerns raised by this sector are about identification of individual hospitals and practitioners, confidentiality, the commercial sensitivity of information, and/or limited resources and the cost burden of proving the information. Whilst acknowledging these as valid concerns, South Australia and SA NT Datalink in particular, can address these as other jurisdictions have done successfully over the many years where they have regularly collected and provided this data for research.

It should be noted that in February of this year the Government announced an intention to draft legislation requiring private health providers to make data available that will address the information gap between the private and public health sectors. It is intended that *private health facilities will not be asked to provide any more data than public hospitals do, and linked patient data will be covered by the same stringent privacy and confidentiality regime that currently protects patient data in the public health sector.*

SA NT Datalink considers this to be a key policy statement and the legislation once passed and information provided by the private hospital sector, will address a long standing significant gap. However, SA NT Datalink is unaware of the scope of the legislation and if other private sector health services will be included. SA NT Datalink is very willing to consult with the Government and provide any information needed to address the issues and inform the proposed legislation from a health and medical research and data linkage perspective.

Aboriginal and Torres Strait Islander research is of vital importance to Aboriginal people and SA NT Datalink recognises the sovereignty and control of Aboriginal people over their information and research. Working in partnership with Aboriginal researchers and the building of trust with their communities and health services is essential if research is to inform knowledge gaps and advise on and evaluate service delivery pathways that align with Aboriginal and Torres Strait Islander needs, as well as create frameworks for government service delivery and accountability. SA NT Datalink with its resources, has supported projects in this area, but sees a need for more partnerships, not only with existing researchers but to build the research expertise and analytical skills of Aboriginal people to make full use of SA NT Datalink's capabilities.

**What barriers are there to sharing data for HMR? [and] What data related bottlenecks constrain HMR and what can be done to remove them? Please provide relevant supporting examples or case studies, where available.**

#### Professional concerns

Generally, SA Health has been very supportive of the health and medical research and willing to share its data for this purpose with researchers and SA NT Datalink. However, as said previously, this willingness has been the result of SA NT Datalink working with the data custodians and building a positive relationship with them and their agency. Data custodians take their responsibility for ensuring the proper and ethical use of their data very seriously and whilst SA Health now supports the provision of data, other agencies and organisations may still have security and privacy concerns about the provision of their data to SA NT Datalink and its subsequent use, or are limited by their resources to commit to the provision of the data.

Even where there is in-principle support for providing data to SA NT Datalink, not being able to give this sufficient priority and/or professional caution at an officer level may also be factors in the reluctance of owners of clinical registries or practitioner databases to make their data available through SA NT Datalink for other researchers to access (always authorised by the data owners and ethical approvals).

Note that SA NT Datalink focuses resources on seeking access to datasets for linkage where there is a research project or likely project requiring the data. It does not consider it reasonable to approach data owners unless it can justify requesting the data based on an identified research need or emerging priority.

### Governance and approvals

One of the often-stated concerns of researchers is the time taken to be provided with data custodian and ethics committee approvals and the subsequent provision of the approved data for analysis. This can and has in some cases taken well over a year. While in some cases it is observed that the researcher is the source of the delay, nevertheless the end result is when looking at the time elapsed between the lodgement of an application to the provision of the data is unacceptably long. This can be especially so for national or multi-jurisdictional projects where multiple approvals by each contributing data custodian and more than one Human Research Ethics Committee (HREC) is required.

To address the requirements for ethics approvals from each jurisdiction, the HRECs in each jurisdiction (with the exception of NT, WA and AIHW) have only this year become party to the NHMRC approved National Mutual Acceptance (NMA) agreement for data linkage projects. As a result, a project approved in one participating jurisdiction will be accepted in all other participating jurisdictions. The NMA should therefore reduce significantly one of the repetitive governance burdens for researchers undertaking data linkage projects. However, Site Specific Assessments will still be required by each jurisdiction. (Note that the NHMRC must accredit each HREC as being able to assess data linkage research projects).

The PHRN established a nationwide PHRN Online Application System (OAS) that researchers are required to use for all national projects. This was to replace a system where each jurisdiction had its own application for the same national or multi-jurisdictional project. The OAS, along with regular meetings of Client Services staff from each linkage unit to discuss national projects, works with the researcher to facilitate application development and approval processes.

The establishment by SA NT DataLink of its Data Integration Unit and the data repository in the past 18 months, has been successful in providing researchers with timelier data access once approved by data custodians. Data custodian approval of every data item in the repository is essential as is their approval for the release of any data item.

Under these arrangements, SA NT DataLink is seeking to add to the data collections held within the repository by offering its services to owners of registries and other data collections to store their data and increase the timely access for research health and medical research purposes.

### Resourcing and capacity limitations of SA NT Datalink

SA NT Datalink is now essential research infrastructure for data linkage in SA and NT. However, from its perspective SA NT Datalink's capacity to commit to better support of health and medical research is limited because of its resource constraints and in particular funding uncertainties.

SA NT Datalink was established in 2009 under a partnership arrangement as an unincorporated joint venture (JV) with the partners providing the funding as well as data to SA NT DataLink. At that time, the SA Government did not consider funding through an ongoing budget allocation and the JV partners each consider the benefits of being able to progress their research priorities through SA NT DataLink rather than being only focussed on government priorities. This latter was considered to be a significant risk associated with a high reliance on SA (or NT) Government funding.

These funding arrangements along with NCRIS funding have worked reasonably well for ten years, although with only annual funding commitments in some cases, and the need to periodically renew the JV Agreement, SA NT DataLink has not been in a strong position to undertake significant longer term planning with a degree of certainty. The increasing funding pressures on the JV partners has seen some partners significantly reduce their financial contributions to the SA NT DataLink system.

The funding pressures for 2021 and beyond are expected to be even greater on the JV partners resulting from the financial impact of COVID-19 on universities and governments. SA NT DataLink is particularly vulnerable since the JV Agreement expires on 31 December 2020 and is currently being considered by the partners for a further 5 years in the context of the financial pressures being faced.

At this point SA NT DataLink is seeking a reliable commitment from its current JV funding partners as to their willingness to continue under an extended Joint Venture Agreement and continue funding at least at their current levels. SA NT DataLink is therefore struggling to reassure staff as to its ongoing financial status and therefore their future employment. Skilled staff may be considering other employment options and the loss of their expertise would have a significant adverse impact on SA NT DataLink's capacity to provide its high-quality services in a timely manner.

Any reduction in SA NT DataLink's resources would necessarily impact on its capacity to support data linkage research in a timely and effective manner in SA and nationally. One firm funding commitment is from the Australian Government through the Population Health Research Network National Collaborative Research Infrastructure Strategy (PHRN NCRIS), which has committed funding to SA NT DataLink to June 2023, providing approximately 25% of SA NT DataLink of total annual funding, based on 2018/19.

#### Competitive and other issues

Related to the resourcing issues for SA NT DataLink, it is important to note that all other data linkage units, including AIHW are either fully funded or mostly funded by their respective governments (except Tasmania). This means that they do not face the same annual funding uncertainty or the periodic review from funding partners. They are therefore far better placed to undertake long term planning and are not required to recover costs from research projects to the same degree as SA NT DataLink. In fact, currently the Queensland and Victorian linkage units do not charge for their data and data linkage services, which gives researchers in Queensland and Victoria a significant advantage over SA researchers.

As an aside, another factor is the population sizes of these jurisdictions. Compared to NSW which provides the potential for much larger cohort analysis compared to SA. SA though, through SA NT DataLink has the advantage of being to offer a much wider range of data sources for linked data research.

SA NT Datalink's research data infrastructure and available data has enabled researchers to attract significant amounts of grant funding into SA, and the potential to expand the breadth of data (eg Private Health – GP and Hospitals) represents an opportunity for the state to be on a more competitive footing in these areas in grant applications

It is difficult for SA NT DataLink to confirm the value of grant funding researchers and institutions have received based on the data made available to SA NT DataLink. However, from the limited information available, it is estimated to be in the order of \$20 million but in all probability, is more than this. Along with the funding is the benefit to the State from the employment of research staff and/or the expertise in data analytics developed as a result of utilising SA NT DataLink services.

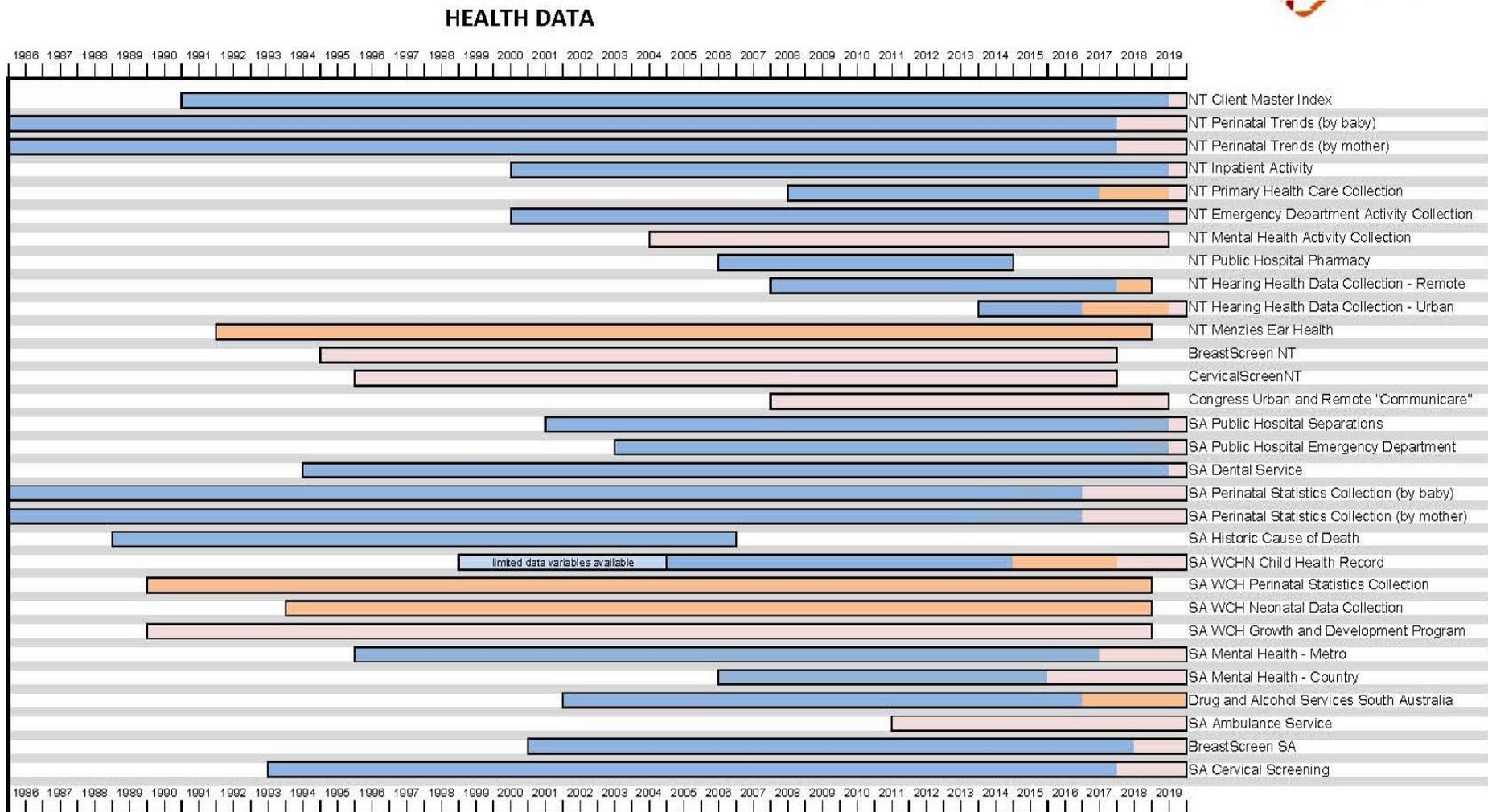
**Table 1: Organisations participating in SA NT DataLink supported projects**

<b>SA Government and other organisations</b>	<b>University sector</b>
SA Health	University of South Australia
– Women’s and Children’s Health Network	Flinders University
– Central Adelaide Area Local Health Network	The University of Adelaide
– Southern Area Local Health Network	James Cook University
Health Performance Council	Monash University
Department for Education	Swinburne University of Technology
Department for Child Protection	The University of Western Australia
Department of the Premier and Cabinet	University of Melbourne
Heart Foundation (SA)	University of Newcastle
Cancer Council (SA)	University of NSW
Australian New Zealand Dialysis and Transplant Registry (ANZDATA)	University of Queensland
Australian Orthopaedic Association National Joint Replacement Registry (AOANJRR)	Griffith University
Australian New Zealand Society of Cardiac and Thoracic Surgeons	University of Sydney
	Curtin University
<b>Other government sectors</b>	The University of Technology, Sydney
Australian Institute of Health and Welfare	Charles Darwin University - Menzies School of Health Research
NT Department of Health	University of Tasmania - Menzies Institute for Health Research
NSW Ministry of Health	
Queensland Health	<b>Other research organisations</b>
WA Department of Health	South Australian Health and Medical Research Institute (SAHMRI)
St Vincent's Hospital, Vic	QIMR Berghofer Medical Research Institute
Royal Prince Alfred Hospital, Sydney	The George Institute
Central Australia Aboriginal Congress Aboriginal Corporation	Murdoch Children's Research Institute
	Telethon Kids Institute (WA)

**Table 2: Data Integration Unit - Datasets held or awaiting provision**

<b>Dataset</b>	<b>Status</b>
SA Birth Registry	Storage completed
SA Death Registry	Storage completed
National (Codified) Cause of Death Unit Record File for South Australia	Storage completed
National (Codified) Cause of Death Unit Record File for South Australia - Coronial Cases	Storage completed
National (Codified) Cause of Death Unit Record File for Northern Territory	Storage completed
National (Codified) Cause of Death Unit Record File for Northern Territory - Coronial Cases	Storage completed
Historical Codified Cause of Death Unit Record File for South Australia (Pre-2006 data)	Storage completed
WCHN Perinatal Statistics Collection	Storage completed
WCHN Neonatal Data Collection	Storage completed
SA Emergency Department Presentations	Storage completed
SA Inpatient Hospital Separations	Storage completed
Australian Early Development Census 2009 - 2018 (for internal SA NT DataLink quality assurance use only)	Storage completed
SA Cancer Registry	Awaiting provision
SA Ambulance Service dataset	Awaiting provision
WCHN Child Health Information - Electronic Client Health Information Management System (eCHIMS)	Awaiting provision
WCHN eCRIB	Awaiting provision
WCHN Growth and Development Program	Awaiting provision
WCHN Service Summary Data	Awaiting provision
SA Perinatal Statistics Collection	Awaiting provision

Table 3: Inventory of linked data As at 2 March 2020



SA NT DataLink is an accredited Commonwealth Data Integrating Authority, and able to facilitate the linkage and provision of Australian Government data sources, including the Medicare Benefits Schedule (MBS), the Pharmaceutical Benefits Scheme (PBS), the National Death Index, National Aged Care Data Clearinghouse data and Centrelink records.

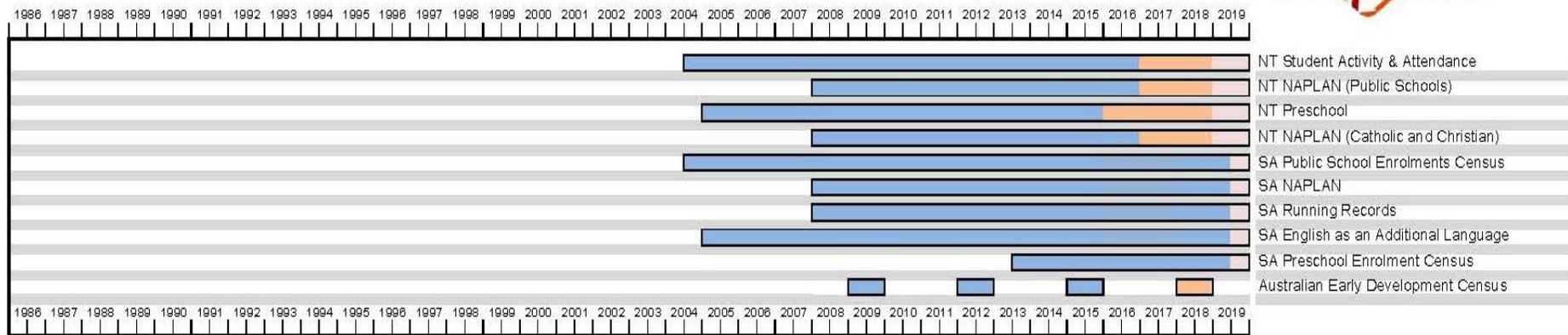
SA NT DataLink can support linked statistical data projects needing longitudinal, case controlled and cohort specific analysis.

All projects using SA NT DataLink provided data are subject to data custodian approval.

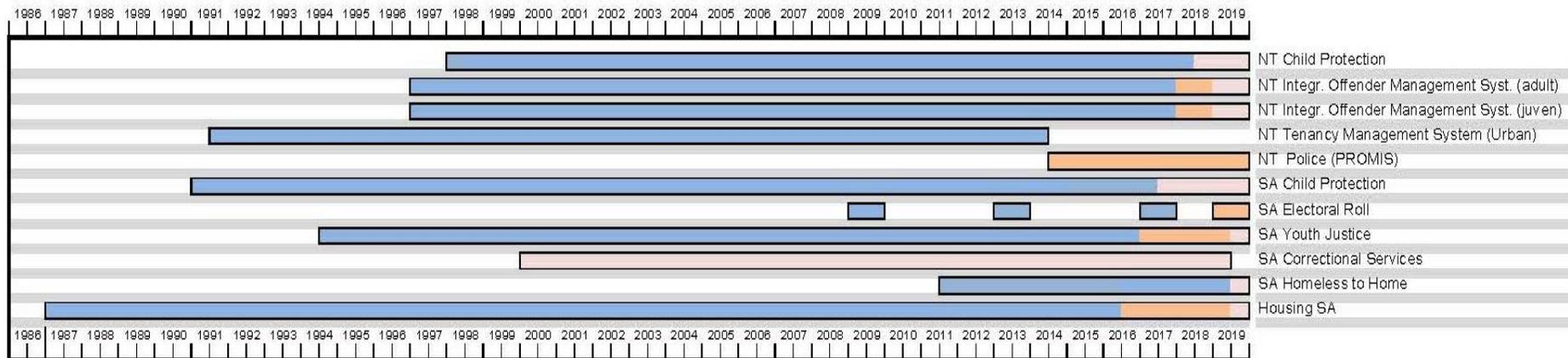
**LEGEND**

- To be provided by data custodian
- Linked
- Received, lined up for linkage

### EDUCATION DATA

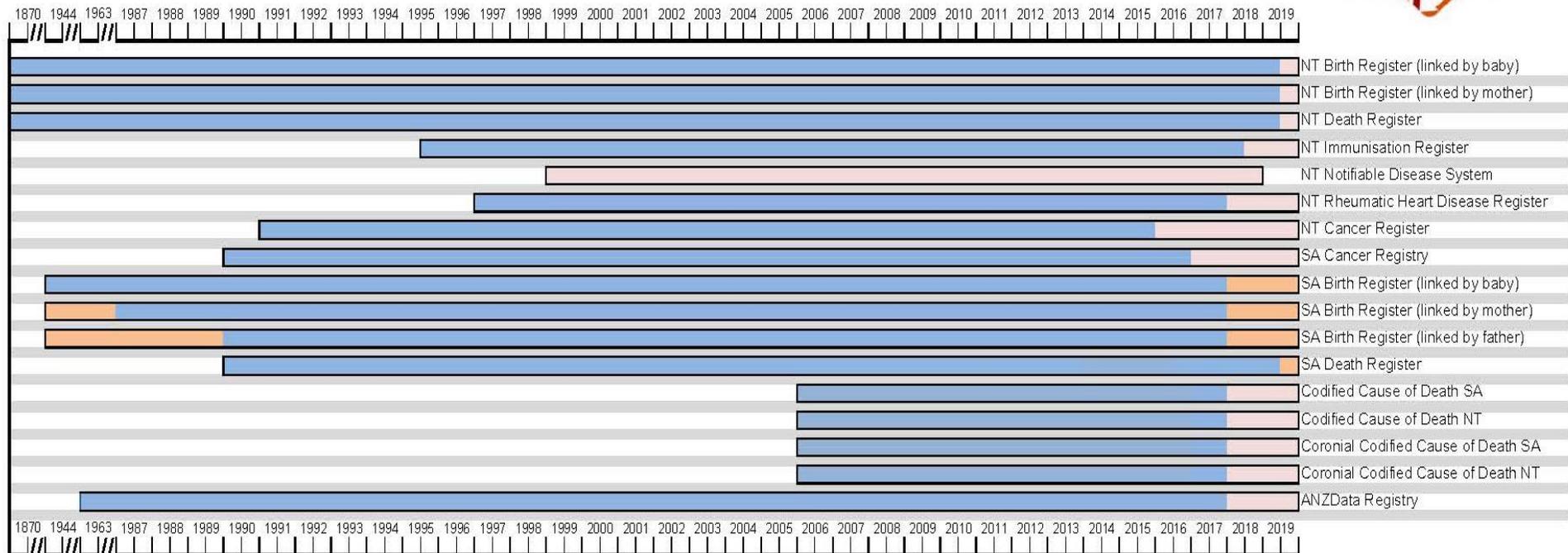


### SOCIAL DATA



**LEGEND**  
 To be provided by data custodian  
 Linked  
 Received, lined up for linkage

REGISTRIES



**LEGEND**  
 To be provided by Data Custodian  
 Linked  
 Received, lined up for linkage

The following datasets were received and linked for specific projects and are not routinely linked into the SA NT DataLink linkage system:

- SA Pathology (IMVS), ClinPath, Gramps Pathology
- Adelaide Pathology Partners
- SA Breast Surgery Quality Audit