

Yuwaya Ngarra-li:

Data Linkage Protocol

Version 2 October 2022



DHARRIWAA
ELDERS GROUP



COMMUNITY-LED
DEVELOPMENT



UNSW
SYDNEY

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Purpose

The purpose of this Data Linkage Protocol is to summarise what data linkage is, explain the reasons for creating a deidentified linked dataset about young people in Walgett, describe how the principles of Yuwaya Ngarra-li will be embedded in this work, identify the steps required to create the linked dataset, and outline the data framework and possible data sources.

What is data linkage?

Data linkage is when two or more separate sets of data are put together which can improve our understanding of an issue (e.g., the relationships between people's education experiences/outcomes and their contact with the criminal justice system).

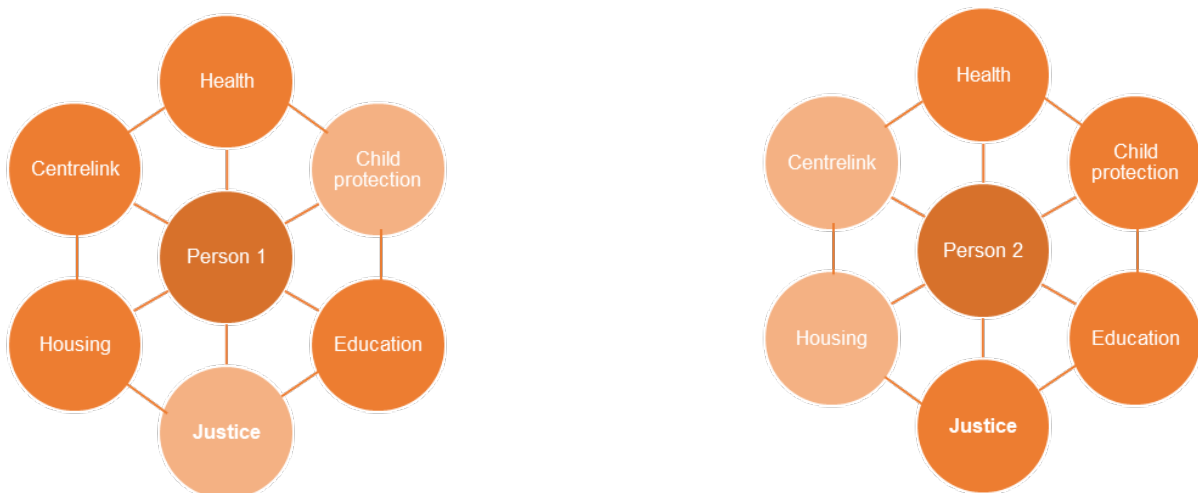
Data from multiple agencies and multiple individuals can be linked to give a better understanding of how different people interact with different services over time and the impact of this.

This information can help with planning and advocacy to ensure people get access to the services and support they need. Linked data can also help to evaluate how changes in services influence changes in other outcomes.

Personal identifying information (like name or address) is only used by data linkage experts (such as the Centre for Health Record Linkage) to link the data from different sources and is kept separate from other information (like details of service use).

Each person who appears in different datasets is assigned a random "project person number" which is the same across the different datasets. The data from different data sources (e.g., government agencies and surveys) are then provided to the researchers without identifying information but with the project person numbers. The researchers can then look at the patterns and pathways for people across the different datasets.

Figure 1: Example of linking data from multiple agencies and individuals



Why link data relating to young people in Walgett?

Understanding and improving outcomes for Aboriginal children and young people in Walgett is a key priority of the Elders who are particularly concerned about poor educational outcomes and the overrepresentation of young people in the justice system.

Discussions between the DEG and Yuwaya Ngarra-li's Research and Evaluation team have highlighted the complex interactions between justice, education, health and wellbeing, housing, and family and community factors.

Linking agency and survey data for young people in Walgett and their immediate family members can help to better understand and respond to issues faced by young people in Walgett and reflects Yuwaya Ngarra-li's holistic approach to planning, implementation and evaluation.

Yuwaya Ngarra-li's data linkage project will help to improve outcomes for young people in the following ways:

- **Community control** – Providing evidence to assist the DEG to drive change for improved outcomes for young people in Walgett
- **Advocacy** – Demonstrating the relationships between education, health, and criminal justice contacts
- **Evaluation** – Informing the planning and tracking the impact of youth diversion work
- **Understanding** - Identifying drivers of change in outcomes for young people

Embedding Yuwaya Ngarra-li principles in the linked data research

The core principles of Yuwaya Ngarra-li underpin the way we undertake research and evaluation generally and will be integrated throughout the data linkage work as explained under each of the five principles below.¹

1. Community-led

Research and evaluation generally	Data linkage project
DEG leadership in developing research protocols and data governance arrangements before commencing research.	Developing data linkage protocol with DEG Secretary Virginia Robinson to guide the research agenda.
Ensuring alignment with Indigenous Data Sovereignty and Indigenous Data Governance principles adopted by the DEG, to ensure data is used for the purpose of generating information and knowledge to address community led priorities.	Consultation with and reporting back to the DEG at all phases of the research to ensure the research is informed by and contributes to community priorities, and protocols are being followed.
Building capacity, with Aboriginal people leading, engaged and employed wherever	Peta MacGillivray, Yuwaya Ngarra-li's Youth Justice Advisor and Executive Committee

¹ Virginia Robinson (April 2020) "Yuwaya Ngarra-li partnership: Core Principles Research Brief", Dharriwaa Elders Group, Walgett; Ruth McCausland (August 2019) "Yuwaya Ngarra-li partnership: Research Protocol", Dharriwaa Elders Group and UNSW

possible, ensuring that young peoples voices, priorities and rights are centred in this work.	Member of Maiaam Nayri Wingara, ² helping to lead the project at UNSW. Building Indigenous quantitative research capacity wherever possible.
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2. Culturally connected

Research and evaluation generally	Data linkage project
Respecting and drawing on the knowledge of the Elders through ongoing collaboration with the DEG throughout the research design, analysis and interpretation of findings.	Regular meetings with the DEG to inform all phases of the research to ensure that it is conducted in a way that is culturally connected and responsive to the needs and expectations of Aboriginal people in Walgett.
Communicating research findings in an appropriate, respectful and accessible way, and reflecting the needs and expectations of the broader Aboriginal community in Walgett.	Consultation with Aboriginal young people via the DEG, to ensure the research reflects their experience, needs and expectations.
	Ensuring that the research findings are presented in a way that is useful, respectful and accessible.

3. Strengths-based

Research and evaluation generally	Data linkage project
Seeking opportunities to complement and develop existing strengths and capacities.	Identifying the enablers of positive pathways and outcomes for Aboriginal young people in Walgett, including education, through consultation via the DEG, and gathering appropriate data to capture these, as well as systemic barriers, including over policing, that prevent young people reaching their potential.
Recognising resilience and focusing on potential, interest, ability, knowledge and capacity, rather than deficits and disadvantage.	
Focusing on individual, social, environmental and system characteristics that enable positive change and identifying barriers.	Assisting the DEG to use the research findings in communications with key institutions to advocate for positive change and required resources.

4. Holistic

Research and evaluation generally	Data linkage project
Integrated, holistic approach to planning, implementation, and evaluation.	Recognising that the solutions do not lie solely in one area and linking data from multiple sources to better understand and demonstrate this, and plan and respond appropriately led by the DEG and other ACCOs.
To overcome siloed thinking by addressing problems in an integrated way to help develop long term systemic solutions.	

5. Human rights-based approach

Research and evaluation generally	Data linkage project
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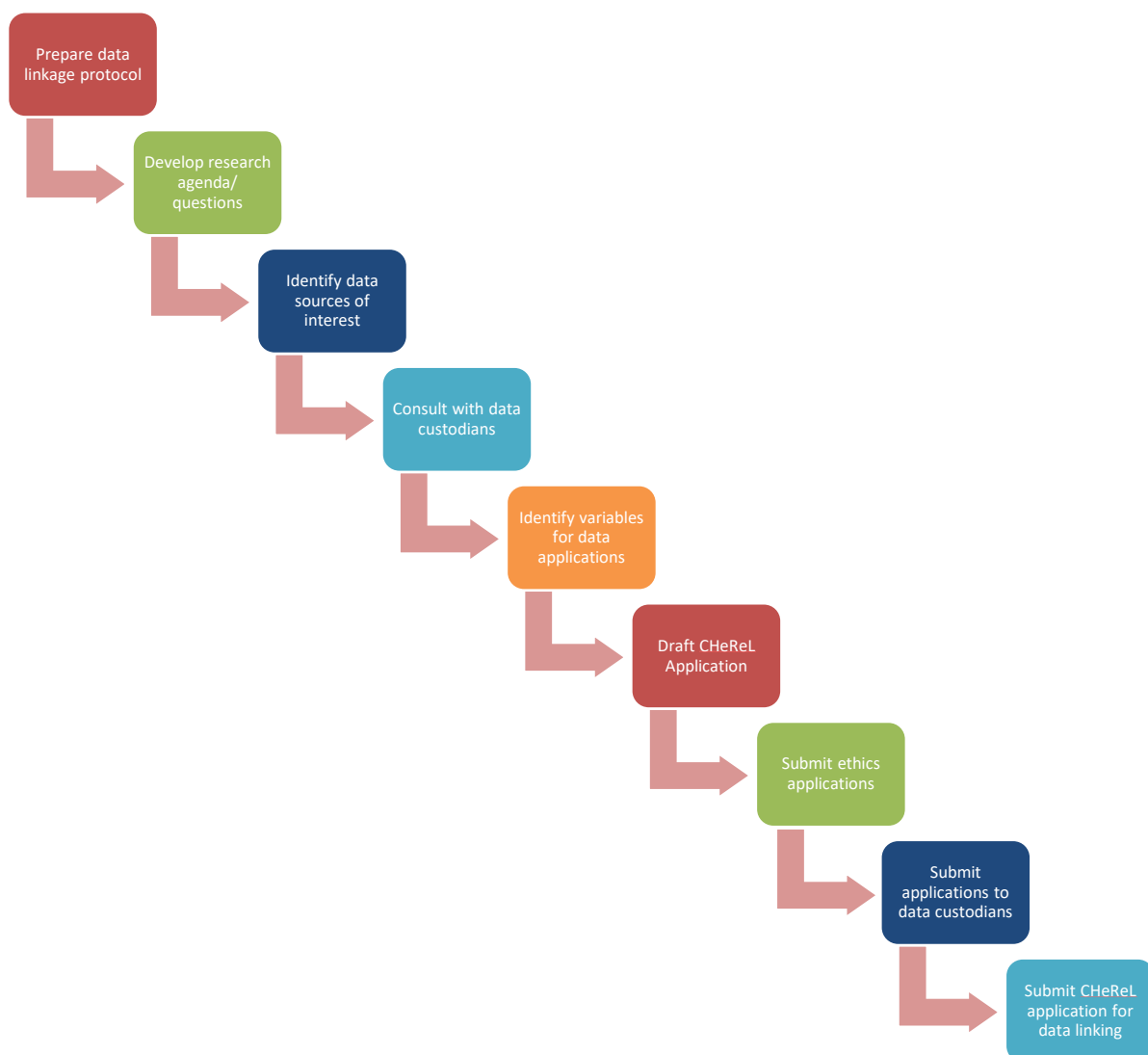
² Maiaam Nayri Wingara Indigenous Data Sovereignty Collective:
<https://www.maiaamnayriwingara.org/about-us>

Conducting research that promotes understanding and respect for the rights of Aboriginal people.	Working in partnership with the DEG to undertake research that will provide evidence to help respond to the systemic issues facing Aboriginal young people in Walgett so that they can more fully enjoy their human rights.
Using research findings to make evidence-based recommendations to help Aboriginal people to more fully enjoy their rights.	
To work in partnership with the DEG to address gaps in health, living standards and imprisonment rates.	Build on and contribute to broader research on data sovereignty, including that which references the Declaration on the Rights of Indigenous Peoples.

Steps for undertaking the data linkage

The Yuwaya Ngarra-li data linkage project will take time and care. This will ensure that the right data are collected so that the project is useful and relevant to the community. The diagram below summarises the steps required, using the Centre for Health Record Linkage (CHeReL) to link the data.

Figure 2: Steps for undertaking data linkage



Yuwaya Ngarra-li data linkage framework

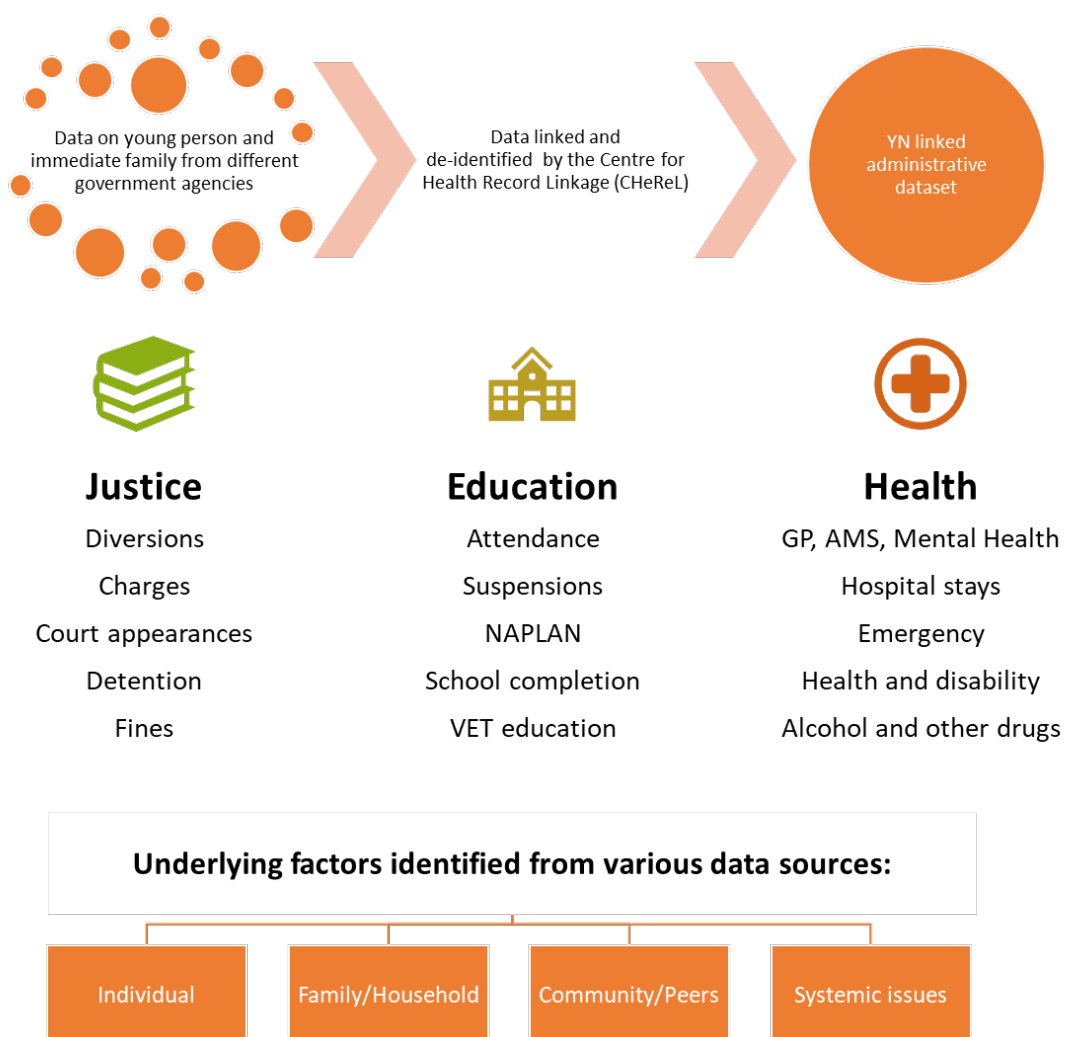
While the final datasets and variables are still to be determined in consultation with the relevant data custodians and subject to ethical approvals, based on discussions over the last year we are planning to link youth justice, education and health data for Aboriginal children and young people in Walgett, together with underlying factors including family circumstances. This will:

- Reflect our holistic approach to planning, implementation and evaluation.
- Provide evidence of the relationships between education, health and criminal justice contacts and other factors (like family, housing, peers, etc.).
- Track the impact of Yuwaya Ngarra-li's work with children and young people.

This is an update to the December 2021 framework (to include family members and additional data sources) and subject to further change as we progress through the steps of developing the research agenda with the DEG and Yuwaya Ngarra-li's UNSW Team.

The diagram below illustrates what the final data linkage may consist of.

Figure 3: Yuwaya Ngarra-li data linkage framework



Data sources

At this stage we are considering linking data for young people in Walgett and their immediate family members from the following sources. This list may change or expand as the project evolves, in which case we will submit the required modifications to ethics committees and the CHeReL.

Data custodian	Data	Application
Bureau of Crime Statistics and Research	- Finalised charges and court appearances - Diversions under the YOA - Custody episodes (adult and juvenile)	ROD data Corrective Services
NSW Health	- Emergency department data collection - Admitted patient data collection - Mental Health Ambulatory Data - Notifiable conditions (including COVID 19 cases) - Non admitted patient data (includes AMS, GP, AOD services) - Registry of births deaths and marriages (births and deaths) - Cause of death	Via the CHeReL application
NSW Dept Education	- Attendance - NAPLAN - Suspensions/expulsions - Disability and support classes - Record of school achievement (ROSA) - HSC - VET in school	Data services custom request form
NSW Education Standards Authority	Post school VET participation and completion	research@nesa.nsw.edu.au
NSW Department of Communities and Justice	- Housing - Homelessness - Out of home care - Child protection	Research Support Request Form
Revenue NSW	Fines/penalty notices	https://www.nsw.gov.au/customer-service/who-we-are/access-to-information/gipa-act-application