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15

Technical report

# Pathways of Care Longitudinal Study: Outcomes of Children and Young People in Out-of-Home Care

## Guidelines for Using Record Linkage Data

# Pathways of Care Longitudinal Study: Outcomes of Children and Young People in Out-of-Home Care in NSW

Technical Report No.15

Guidelines for Using Record Linkage Data

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Pathways of Care Longitudinal Study Clearinghouse
All study publications including research reports, technical reports and evidence to action notes can be found on the study webpage www.facs.nsw.gov.au/resources/research/pathways-of-care

Study design by NSW Department of Communities and Justice (Insights, Analysis and Research); Australian Institute of Family Studies; Professor Judy Cashmore, University of Sydney; Professor Paul Delfabbro, University of Adelaide; Professor Ilan Katz, University of NSW; Dr Fred Wulczyn, Chapin Hall Center for Children University of Chicago.

Study data collection by I-view Social Research.

Advisors Expert advice and support has been provided by the CREATE Foundation; Aboriginal Child, Family and Community Care State Secretariat (AbSec); My Forever Family NSW; and program areas.

Acknowledgements We wish to extend our thanks to all the children, young people and caregivers who participated in interviews; childcare teachers, school teachers and caseworkers who participated in on-line surveys; and the data custodians in the relevant NSW and Commonwealth government departments. Ms Sammy Verma grew up in care and played a key role in the production of the study video for children and stakeholders. Ms Billy Black also grew up in care and designed the study artwork. Ms Sammy Verma and Mr Samuel Eyeson-Annan both did the voiceover for the audio computer-assisted self-interview (ACASI) for the child/young person interview.

Ethics approval by The University of NSW Human Research Ethics Committee (approval number HC10335 & HC16542); Aboriginal Health and Medical Research Council of NSW Ethics Committee (approval number 766/10); NSW Department of Education and Communities State Education Research Approval Process (SERAP, approval number 2012250); NSW Population & Health Services Research Ethics Committee (Ref: HREC/14/CIPHS/74 Cancer Institute NSW: 2014/12/570).

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# Preface

The Pathways of Care Longitudinal Study (POCLS) is funded and managed by the New South Wales Department of Communities and Justice (DCJ). It is the first large-scale prospective longitudinal study of children and young people in out-of-home care (OOHC) in Australia. Information on safety, permanency and wellbeing is being collected from various sources. The child developmental domains of interest are physical health, socio-emotional wellbeing and cognitive/learning ability.

The overall aim of this study is to collect detailed information about the life course development of children who enter OOHC for the first time and the factors that influence their development. The POCLS objectives are to:

- Describe the characteristics, child protection history, development and wellbeing of children and young people at the time they enter OOHC for the first time.
- Describe the services, interventions and pathways for children and young people in OOHC, post restoration, post adoption and on leaving care at 18 years.
- Describe children's and young people's experiences while growing up in OOHC, post restoration, post adoption and on leaving care at 18 years.
- Understand the factors that influence the outcomes for children and young people who grow up in OOHC, are restored home, are adopted or leave care at 18 years.
- Inform policy and practice to strengthen the OOHC service system in NSW to improve the outcomes for children and young people in OOHC.

The POCLS is the first study to link data on children's child protection backgrounds, OOHC placements, health, education and offending held by multiple government agencies; and match it to first-hand accounts from children, caregivers, caseworkers and teachers. The POCLS database will allow researchers to track children's trajectories and experiences from birth.

The population cohort is a census of all children and young people who entered OOHC for the first time in NSW over the 18 month period between May 2010 and October 2011 (n=4,126). A subset of those children and young people who went on to receive final Children's Court care and protection orders by April 2013 (2,828) were eligible to participate in the study. For more information about the study please visit the study webpage www.facs.nsw.gov.au/resources/research/pathways-of-care.

The POCLS acknowledges and honours Aboriginal people as our First Peoples of NSW and is committed to working with the DCJ Aboriginal Outcomes team to ensure that Aboriginal children, young people, families and communities are supported and

empowered to improve their life outcomes. The POCLS data asset will be used to improve how services and supports are designed and delivered in partnership with Aboriginal people and communities.

DCJ recognises the importance of Indigenous Data Sovereignty (IDS) and Indigenous Data Governance (IDG) in the design, collection, analysis, dissemination and management of all data related to Aboriginal Australians. The POCLS is subject to ethics approval, including from the Aboriginal Health & Medical Research Council of NSW. DCJ is currently in the process of scoping the development of IDS and IDG principles that will apply to future Aboriginal data creation, development, stewardship, analysis, dissemination and infrastructure. The DCJ will continue to collaborate with Aboriginal Peoples and will apply the DCJ research governance principles once developed.

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# 1 Introduction: record linkage data extension to Pathways of Care Longitudinal Study

Record linkage data from a number of administrative data systems have been obtained as part of the POCLS. These data will provide service use and broad outcome indicators for children and young people in the POCLS population cohort (n=4126), including those who did not proceed to final orders by April 2013 as well as those who remained in OOHC on final orders but did not participate in an in-depth interview.

The datasets included are:

- DCJ child protection and OOHC data (from 2003)
- Bureau of Crime Statistics and Research (BOCSAR) re-offending data base (from 2003)
- NAPLAN scores for Scholastic Years 3, 5, 7 and 9 (from 2008)
- Australian Early Development Census (AEDC) data for children entering school (2009, 2012 and 2015)
- Mortality data
    - Australian Bureau of Statistics (ABS) - cause of death (from 2000)
    - Registry of Births Deaths and Marriages (RBDM) - fact of death (from 2000)
- NSW Health data
    - Perinatal (from 1994)
    - Ambulatory Mental Health (from 2001)
    - Emergency Department visits (from 2005)
    - Admitted Patient (from 2001).

This document sets up the requirements and processes for accessing the record linkage data component of the POCLS. Please also refer to POCLS Technical Report 14: Guidelines for Accessing the Data and Publication.

It is recommended that approved researchers also refer to the POCLS Data Book Number 32: Record Linkage Data Variables available in the Secure Unified Research Environment (SURE), Sax Institute.

Only researchers who are approved by the NSW Population Health Services Research Ethics Committee (NSW PHSREC) [1] are able to access the linkage data in SURE[2]. Researchers not approved cannot access or use the linkage data.

Section 2 describes the linkage data, the conditions of use and the process for gaining access to the data. It is important that these conditions are met as a breach may result in the study losing access to these data. Section 3 includes the templates to be used when applying for access to the linkage data. Appendix 1 includes the original protocol and statistical plan for the linkage data as provided to the NSW PHSREC.

If you are not a named researcher and are interested in using the POCLS linkage data, please contact the POCLS team on Pathways@facs.nsw.gov.au. Information about how to access the POCLS data in general can be found in the document "Data Access, Analysis and Publication Guidelines", available on the POCLS website https://www.facs.nsw.gov.au/resources/research/pathways-of-care.

Other useful documents, also available on the POCLS website, include the Data Dictionary for the linkage data and the POCLS report of simple frequency counts of selected linked data variables.

[1] The original ethics application was approved by the NSW Population and Health Services Research Ethics Committee (NSW PHSREC) on the 31 March 2015 AU RED Reference: HREC/14/CIPHS/74; Cancer Institute NSW reference: 2014/12/570) expires until 31 March 2021. Ethics approval will be renewed for another five years in 2020. An amendment that the data would be stored In SURE was approved on 4 March 2016. The POCLS also has ethics approval from the University of NSW Human Research Ethics Committee (NSWHREC) and the Aboriginal Health and Medical Research Council of NSW Ethics Committee (AH&MRC).

[2] All approved personnel are listed in Appendix 10 of the POCLS Technical Report Number 1: POCLS Objectives and Strategic Research Agenda.

# 2 What do I need to know before I use the POCLS record linkage data?

This section outlines the background and conditions under which the POCLS record linkage data can be requested and used.

## 2.1 Background

Unit record data has been obtained from the NSW Ministry of Health, the state and federal departments of Education, BOCSAR, ABS and RBDM for the 4,126 children in the POCLS sample. The linkages were performed by the NSW Centre for Health Record Linkage (CHeReL) from their Master Linkage Key (MLK) using probabilistic record linkage methods and ChoiceMaker software.

The sample consists of all children who entered OOHC for the first time in an 18 month period between May 2010 and October 2011 and is made up of a group who went on to final orders (likely to be an order until the child's 18th birthday) and a group who remained on interim orders at April 2013[3].

Data includes AEDC information, NAPLAN results, Juvenile Justice and adult offending records, details of hospital admissions and emergency department visits, ambulatory mental health data, mortality records and perinatal information from the respective data custodians.

This provides a minimal outcomes and service use data set for all children in the sample, including those who were not interviewed. It provides developmental data for some children on entry into the school system (AEDC), children's achievement levels throughout their schooling (NAPLAN), general health and mental health status and service use (Ministry of Health data from various data sources), a record of offences (BOCSAR) as well as ongoing child protection and OOHC status (DCJ). Perinatal health data allows some congenital health issues to be taken into account as well as providing some maternal demographic information at the time of the birth of the child.

[3] For more details please see the POCLS Technical Report Number 18: Examining Differences between Care and Protection Legal Order Status: Final and No Final Order Cohorts

## 2.2 Linkage data sources and their rationales

This section briefly describes each data source and the rationale for inclusion in the POCLS. The Data Dictionary for the linkage data, available on the POCLS website, provides details on the variables contained in each of the datasets.

The current linkage data for the POCLS are up to 31 March 2016. At the time of writing this document, the POCLS team is requesting to have the linkage data updated to 30 November 2018 to coincide with completion of the wave 4 survey data collection.

### Education

- NAPLAN participation and results from 2008 to 2014 for those children in Scholastic Years 3, 5, 7, and 9 at the time of the test are included. NAPLAN provides a snapshot of student attainment and reports against a nationally agreed minimum standard of skills and understandings, below which a student is unlikely to be able to progress satisfactorily at school without targeted intervention.

  There are 6 achievement bands applicable to each year level: Year 3 – Bands 1 to 6, Year 5 – Bands 3 to 8, Year 7 – Bands 4 to 9, Year 9 – Bands 5 to 10. For each year level, the lowest band is defined as 'below national minimum standard' and the second lowest band is defined as 'at national minimum standard'. Students can be considered 'educationally at risk' if they are below national minimum standard, 'likely educationally at risk' if they are at national minimum standard, 'educationally on track' if they achieve results in the middle two achievement bands for their year level, and 'educationally well on track' if they achieve results in the top two achievement bands for their year level. Children and young people in OOHC have a higher likelihood of being educationally at risk.

  Please contact data.services@det.nsw.edu.au or 1300 972 196 before commencing analysis of NAPLAN data to ensure the complex measurement issues around NAPLAN are adequately covered.

- AEDC scores from 2009 to 2015 for those children starting school in the years of data collection (2009, 2012 and 2015) are included. The AEDC is administered nationally to children a few months into their first year of school with a 97% response rate. It provides a screening assessment on 5 developmental dimensions: Physical Health and Well-being; Language and Cognitive; Emotional Maturity; Social Competence; and Communication and General Knowledge. Please see the AEDC data guidelines for more information on the AEDC website at - https://www.aedc.gov.au/resources/detail/aedc-data-guidelines-2017.

## Justice

- Re-Offending Database (ROD) data for all those children over ten years of age from 1 January 2003 to 30 June 2015 are included. Children and young people in OOHC are more likely to have contact with the juvenile justice system. It is hypothesised that the severity, type and chronicity of abuse and neglect will be associated with offending and the seriousness of the offence. It will be investigated whether entry into OOHC acts as a catalyst for change in either increasing or decreasing the probability of offending and the seriousness of the offence. Of interest is also the impact of services offered, penalties received and the experience and length of any custodial sentence on the risk of reoffending.

## Health and mortality

- Perinatal Data Collection from 1 January 1994 to 31 October 2011. There may be factors that have a detrimental effect on the developmental outcomes of children, regardless of whether or not they enter OOHC. If there are more babies than expected in OOHC who are, for instance, born to young mothers, this needs to be taken into account when looking at the effects of child maltreatment and OOHC.
- Admitted Patient Data Collection from 1 July 2001 to 30 June 2015. Poor health of children may be associated with an increased likelihood of entering OOHC or it may be that the experience of maltreatment and OOHC have a negative impact on health.
- Mental Health Ambulatory Data Collection from 1 January 2001 to 31 December 2015. Children who have been abused or neglected and have entered OOHC are more likely to suffer poor mental health.
- Emergency Department Data Collection from 1 January 2005 to 31 March 2016. The number of emergency presentations (especially for injury and poisoning) is correlated with child abuse and neglect and sometimes used a proxy measure for maltreatment. Both the number and reason for presentation need to be considered.
- Register of Births, Deaths and Marriages from 1 May 2000 to 31 March 2016 year of registration of death. If some children in the sample have died (especially if restored to their parents and so no longer the responsibility of the Minister) it may be easy to draw the erroneous conclusion that their restoration was a success because they have not been reported to child protection services.
- ABS Mortality Data (Cause of Death Unit Record File) from 1 January 2000 to 31 December 2013 year of registration of death. Children who are ‘known to DCJ’ are over-represented in the child mortality rates.

## Child Protection

- DCJ Key Information Directory System (KiDS) from 1 January 2001 to 30 June 2016. Children and young people enter OOHC to protect them from further abuse and neglect. The number of reports in specific time periods, the nature of

maltreatment and the severity reflects this protection. This may depend on if they are returned to birth parents or remain in OOHC, if they are with kin, foster care or in residential care. Early intervention or intensive family services may assist parents of children who have been restored to their birth families. The impact of age of placement, stability of placement and stability of carer can also be examined in relation to the other linked outcomes.

## 2.3 Conditions of using the data

Specific conditions were negotiated with each of the data custodians and the NSW PHSREC in order to obtain permission to access this linked data. These conditions are important and any breach of them by anyone using the data will revoke the permission to store and analyse any of the data. Any review of submissions for publication will be made with these conditions in mind.

### Implicit condition - public good

It is inherently understood that any use of this data in analysis and publication is governed by values of reciprocity, non-exploitation and service of the public good. The argument of public good in this study has permitted access to data where, in the majority cases, participant consent was waived. It is therefore essential that this value underpins the approach to any analysis and publication. This means that the ramifications for participants of any analysis and publication will need to be carefully considered.

### Conditions for disclosure of information by the NSW Ministry of Health regarding the use of health and mortality data[4]

1. The data are to be used only for 'Pathways of Care: a longitudinal study of children and young people in out-of-home care';

2. The project is carried out in accordance with the approved ethics application and all subsequent amendments;

3. The data are to be kept in a secure physical and electronic environment that is accessible only by persons directly involved in the above project;

4. A confidentiality undertaking will be completed prior to the information being released;

[4] These are the excerpts from the approval letters from the NSW Ministry of Health.

5. The NSW Ministry of Health is to be acknowledged in any publication or report that arises from the use of the data;

6. The data will not be matched with information on individuals from another source other than the datasets specified in the Schedule/s;

7. A copy of any publication or report is to be provided to the NSW Ministry of Health at least two weeks prior to public release, emailed to ermail@doh.health.nsw.gov.au;

8. The data are to be destroyed after 7 years;

9. No information will be released with which it may be possible to identify an individual person;

10. Individuals identified in the data are not to be personally identified in any publication or report;

11. This authority continues until and unless it has been revoked in writing;

12. The Centre for Health Record Linkage is to be acknowledged in any publication, report or presentation that arises from the use of the data;

13. The use of Aboriginal and Torres Strait Islander status is subject to the approval of the Aboriginal Health and Medical Research Council (AH&MRC) and AH&MRC Ethics Committee if one or more of the following apply:

    - Aboriginality is a key determinant
    - Data collection is explicitly directed at Aboriginal peoples
    - Aboriginal peoples, as a group, are to be examined in the results
    - The information may have an impact on one or more Aboriginal communities
    - Aboriginal health funds are a source of funding.

14. When using the Cause of Death Unit Record File (COD URF), a copy of any publication or report is to be provided to the to the Australian Coordinating Registry (ACR) for the COD URF at least two weeks prior to public release, emailed to BDM.CODURF@justice.q1d.gov.au;

15. When using the Cause of Death Unit Record File (COD URF), any publication, report or data output will include:

- the following source: "Source: Cause of Death Unit Record File held by the NSW Ministry of Health Secure Analytics for Population Health Research and Intelligence";
- the following acknowledgement: "The Cause of Death Unit Record File (COD URF) is provided by the Australian Coordinating Registry for the COD URF on behalf of the NSW Registry of Births, Deaths and Marriages, NSW Coroner and the National Coronial Information System."

16. When using the Cause of Death Unit Record File (COD URF), securely destroy the data and notify the ACR within the timeframe specified in the ethics application or earlier as to the destruction (unless approval for extension or indefinite retention has been provided by the ACR/data custodians). Notification should be to the ACR, emailed to BDM.CODURF@justice.q1d.gov.au, and to the NSW Ministry of Health, emailed to cermail@doh.health.nsw.gov.au;
17. When using the Cause of Death Unit Record File (COD URF), acknowledge that these conditions continue to apply after projects end and/or approvals expire and Investigators will comply with any audit processes required to check the compliance of these and any additional conditions of approval;
18. When using the Cause of Death Unit Record File (COD URF), acknowledge that a breach of any of these conditions may result in further data access being restricted or current access being revoked.

## DCJ requirements for accessing the linkage data

1. Data custodians requested that all linkage data be stored in only one site. It was agreed it would be stored at SURE on a secure network. Files would be encrypted, and remote access available through password protected computers.
2. Any changes to the agreed data storage arrangements or data de-identification processes will require an agreement from the NSW PHSREC via an amendment to the existing ethics application and the external data custodians via an amendment to the conditions of data release.
3. Any data analysis which threatens an individual's confidentiality (e.g. through small cell sizes or an entire group all scoring in a similar way) must be destroyed and cannot be reported as this could compromise confidentiality. Any threat to confidentiality should be addressed by data reduction methods for example (e.g., collapsing variables). See the POCLS Technical Report Number 16: Guidelines for Reporting Results with Small Sample Sizes for more details.
4. Researchers who wish to publish or present their findings must submit the paper or presentation for review to DCJ and the relevant external data

custodian at least one month (although the Ministry of Health requires two weeks in advance only – see point 7 above) before the presentation or submission deadline.

5. All linkage data must be deleted after the ethics approval expires. The current ethics approval is valid until 31 March 2021. A request for renewal of ethics approval will be submitted by DCJ in 2020.

6. The research project must remain within the remit of the rationale for the POCLS. If the research project is beyond this remit, a separate amended application needs to be made to both the relevant external data custodian and the NSW PHSREC (specific form available on their website).

7. Only the named researchers can access and work on the linkage data. If a new researcher or research assistant joins the approved project they need to obtain ethics approval first before accessing the data. The NSW PHSREC and data custodians also need to be notified when a named applicant is no longer involved in the project. The lead researcher should notify DCJ about the additional and/or removal of researcher(s) and DCJ will submit a personnel change form to NSW PHSREC for the additional names to be added or existing names removed. Failure to do this by the lead researcher constitutes a breach of the conditions of using the linkage data and will result in access to linkage data being restricted/removed.

8. Researchers are advised to consult/involve relevant data custodians early on if they have any issues with the data and/or interpreting results to avoid spending lots of time analysing and writing up only to find that the data custodian does not approve the publication.

9. The above requirements apply to all linkage data associated with the POCLS. However, there are currently slightly different processes when it comes to accessing specific linkage datasets.

For all linkage data except for NAPLAN (i.e., BOCSAR re-offending, AEDC, ABS - cause of death and RBDM - fact of death, Perinatal, Emergency Department visits and Admitted Patient and Ambulatory Mental Health).

10. The named researchers are required to sign the self-declaration form (see Section 3.1) and submit the completed form to DCJ.

11. Once the signed declaration form is received by DCJ, the POCLS data manager will arrange for relevant data to be copied into the project folder for the named researchers in SURE.

12. The signed declaration form will be forwarded to the relevant data custodians by DCJ for information. Any subsequent update of approved researchers (i.e., additional researchers and/or removal of existing researchers will be communicated to the relevant data custodians by DCJ).

13. The named researchers will receive all variables that are supplied to the POCLS by the relevant data custodians.

### For NAPLAN data

14. Named researchers are required to seek permission in writing from the NSW Department of Education and DCJ stating the variables required and the research question justifying the request (see Section 3.2 for the application template).

    The named researcher completes/signs the Statement and the Letter (in Section 3.2) by specifying the variables requested and research questions and sends the signed documents to DCJ. The list of variables that are supplied by the NSW Department of Education can be found in the Data Dictionary for linkage data.

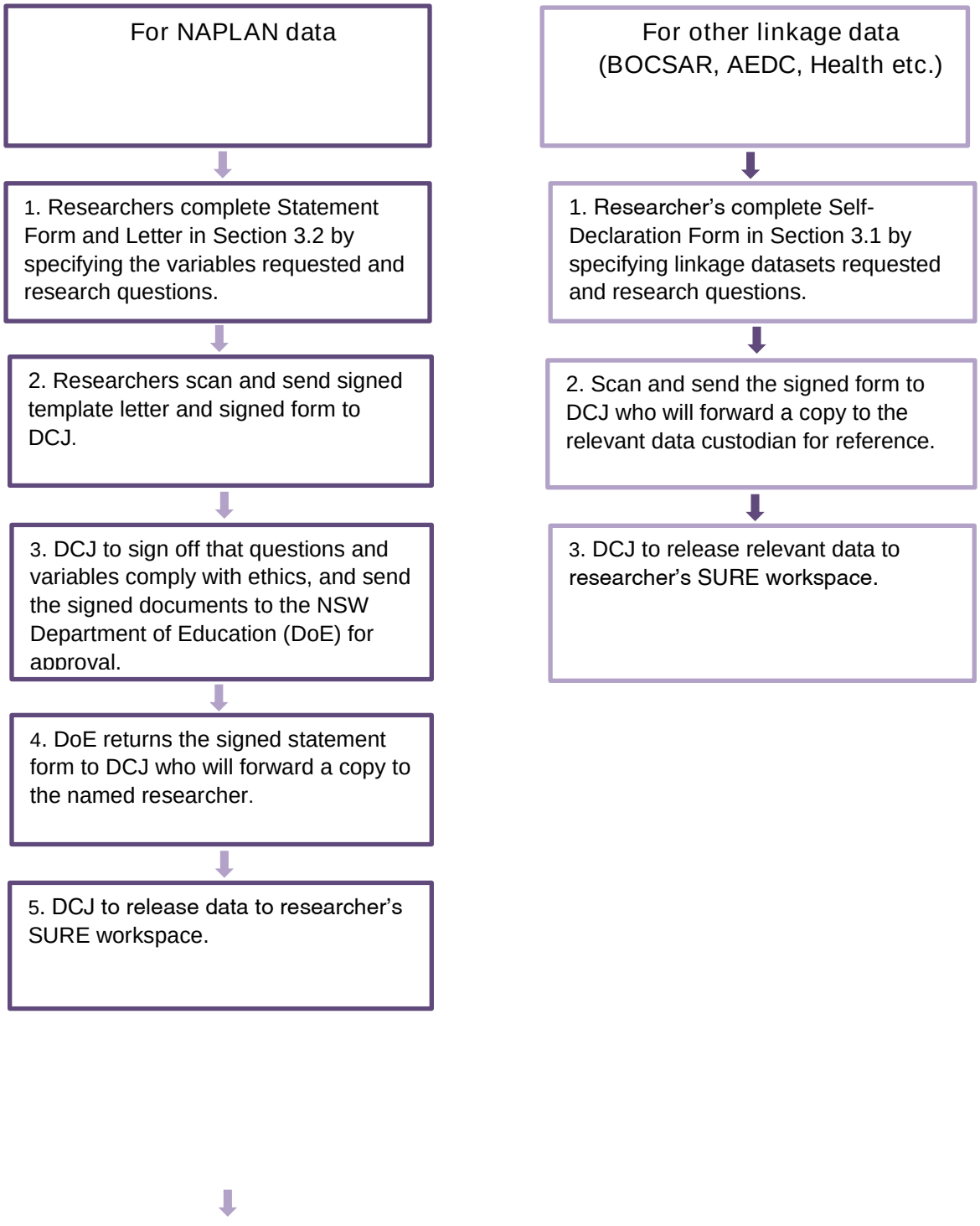
    DCJ will check the questions and variables for compliance with ethics and co-sign the Statement Form and forward the signed documents to the NSW Department of Education for approval.

    The NSW Department of Education returns the signed Statement Form to DCJ who will forward a copy to the named researcher.

    Where permission has been obtained and the NSW Department of Education asks DCJ to grant access to the named researcher, the data will be copied into the project folder for the named researcher in SURE.

    The named researchers will receive only the variables that are listed in the letter.

## Flowchart of process for requesting access to linkage data



# 3 Templates to be used in applying for access to the data

The template in Section 3.1 is completed by named researchers to gain access to all record linkage data except for NAPLAN data. The templates in Section 3.2 are completed by named researchers to gain access to the NAPLAN data.

## 3.1 Self-declaration form

Self-declaration form to be completed and provided to DCJ by the named researcher (on the letterhead of the lead researcher's institution) to gain access to all record linkage data except for NAPLAN data.

Declaration

I/We:

Of: [insert address of CI institution]

in the State of [insert the State where the chief investigator resides], declare as follows:

I/we have approval from the NSW Population and Health Services Research Ethics Committee (HREC/14/CIPHS/74, Cancer Institute NSW: 2014/12/570) to use the linkage data as supplied to the NSW Department of Communities and Justice (DCJ) funded Pathways of Care Longitudinal Study of Children and Young People in Out-of-Home Care (POCLS).

For the analysis I am/we are undertaking under the research agreement with DCJ, I/we would like to use these linkage data set(s): [insert]

to answer the following research question(s):

[insert research questions]

My/our proposed data analysis falls within the scope of the POCLS and I/we understand the conditions for using this data. I/we also understand that approval is required from the relevant data custodians before publishing or presenting the results of the analysis.

Yours sincerely,

[Lead researcher signature]
[Date]

## 3.2 Template letter and statement form

Template letter to the data custodian to be completed by the named researcher on their institution's letterhead to gain access to the NAPLAN data:

Ref:

[Name]
[Address 1]
[Address 2]
[State Postcode]

Dear NSW Department of Education

I have approval from the NSW Population and Health Services Research Ethics Committee (HREC/14/CIPHS/74 Cancer Institute NSW: 2014/12/570) to use the linkage data as supplied to the NSW Department of Communities and Justice (DCJ) funded Pathways of Care Longitudinal Study of Children and Young People in Out-of-Home Care (POCLS)

The NSW PHSREC conditions of use of the linkage data stipulate that the relevant data custodian and DCJ be informed of any proposed data analysis to ensure that this use is within the remit of specific research questions proposed in the original sign-off by both the relevant data custodian and the granted ethics approval.

I would like to use the variables nominated below to answer the following research question/s:

Research question/s:

[insert]

Nominated variables and rationale for use:

[insert]

The research question accords with that specified, and approved by the NSW PHSREC. Please let me know if you have any questions regarding this.

I have attached a signed statement acknowledging I am an eligible user of the data and understand the conditions of use of this data. DCJ has also signed an acknowledgement that the proposed analysis aligns with the research questions approved of by the data custodian and the NSW PHSREC at the time of ethics application.

I would appreciate it if you could countersign the attached statement(s) to acknowledge your approval for use of these variables to answer the nominated

research question, and return by email to the POCLS Project Manager Pathways@facs.nsw.gov.au. If you have any concerns please contact me on [insert email address and/or contact number].

I have attached a copy of the NSW PHSREC ethics approval. I also understand that approval is required from you before publishing or presenting the results of this analysis.

Thank you for supporting the use of linked data for this research. It allows us to compare the broad outcomes for children who have experienced out-of-home care under a variety of circumstances.

Yours sincerely,

[Researcher signature]
[Date]

Attachment:
Signed Statement Form from the researcher and DCJ

## Statement Form

Statement Form to send to the data custodian signed by the researcher and DCJ:

### Researcher Agreement

I have read and understood the Guidelines for Using Record Linkage Data provided to researchers analysing data from the Pathways of Care Longitudinal Study (POCLS). I am aware I cannot make this data available to others (who are not ethics approved by NSW PHSREC) to analyse, including other researchers working with me on this project such as statisticians or research assistants.

PRINT NAME……

Signed……

Date…….

### DCJ Agreement

I……. the Chief Investigator of the POCLS being undertaken by the NSW Department of Communities and Justice (DCJ) agree that the use of the nominated variables to answer the specified research question are within the parameters of standing research ethics committee agreements (University of NSW Research Ethics Committee (HC10335 & HC 16542), Aboriginal Health and Medical Research Committee (No. 766/10) and the NSW Population and Health Services Research Ethics Committee (HREC/14/CIPHS/74 Cancer Institute NSW: 2014/12/570).

PRINT NAME……

Signed……

Date…….

### Data Custodian Agreement

I ……., data custodian of

……..Data Collection agree to the use of the nominated variables by the above named researcher to answer the research question specified.

PRINT NAME……

Signed……

Date…….

# Appendix 1 – Protocol and statistical plan[5]

## Protocol

The main focus of this research is to compare the proportion of children entering care for the first time on each outcome as a function of whether they remained in OOHC on final orders or were returned to their birth parents (interim orders group). It aims to examine how children are faring as a function both of their child protection histories and the system response.

In order to do this linked data has been requested from NSW Health, BOCSAR, Commonwealth and NSW Education Departments and DCJ. By targeting three adjoining 18 month periods which correspond to the three waves of in-depth interview data collection, the linked data parallel the time frame of the in-depth data, while ensuring that all available linked data are counted but that double counts are avoided. The data collection periods are 1 Jan 2012-30 Jun 2013 (Wave 1); 1 July 2013-31 Dec 2014 (Wave 2) and 1 Jan 2015 – 30 June 2016 (Wave 3)[6].

AEDC is not collected for every calendar year and results will be matched with the corresponding data collection year where available. NAPLAN data is not collected for every scholastic year and results will be matched with the corresponding data collection year where available. Collection years are 2012 and 2015 for the AEDC data (Wave 1 and Wave 3). NAPLAN is conducted every year and covers all students in Years 3, 5, 7, and 9 (see Table 1 for detail correspondence with POCLS data collection waves). Retrospective data are also sought as they increase the number of data points, strengthening the longitudinal database for more children. Retrospective data also allow comparisons of children who entered OOHC at older age with those who entered OOHC before starting school. This would include the AEDC from 2009 and the NAPLAN scores from 2008-2011.

The corresponding interview data are based on in-depth interviews and standardised psychological measures but are only collected for children who were in OOHC on final orders and therefore less likely to be returned home (n=1,285). Comparisons within this group will concentrate on factors influencing developmental outcomes such as carer characteristics, placement characteristics, child characteristics and support services within the group who mostly remained in OOHC long-term. Wave 1

[5] As provided to ethics

[6] With this pattern continuing for subsequent waves subject to funding

and Wave 2 of this study's data collection are complete and the third wave has commenced.

Figure 1 provides an overview of the relationship between the interview data and linked data.

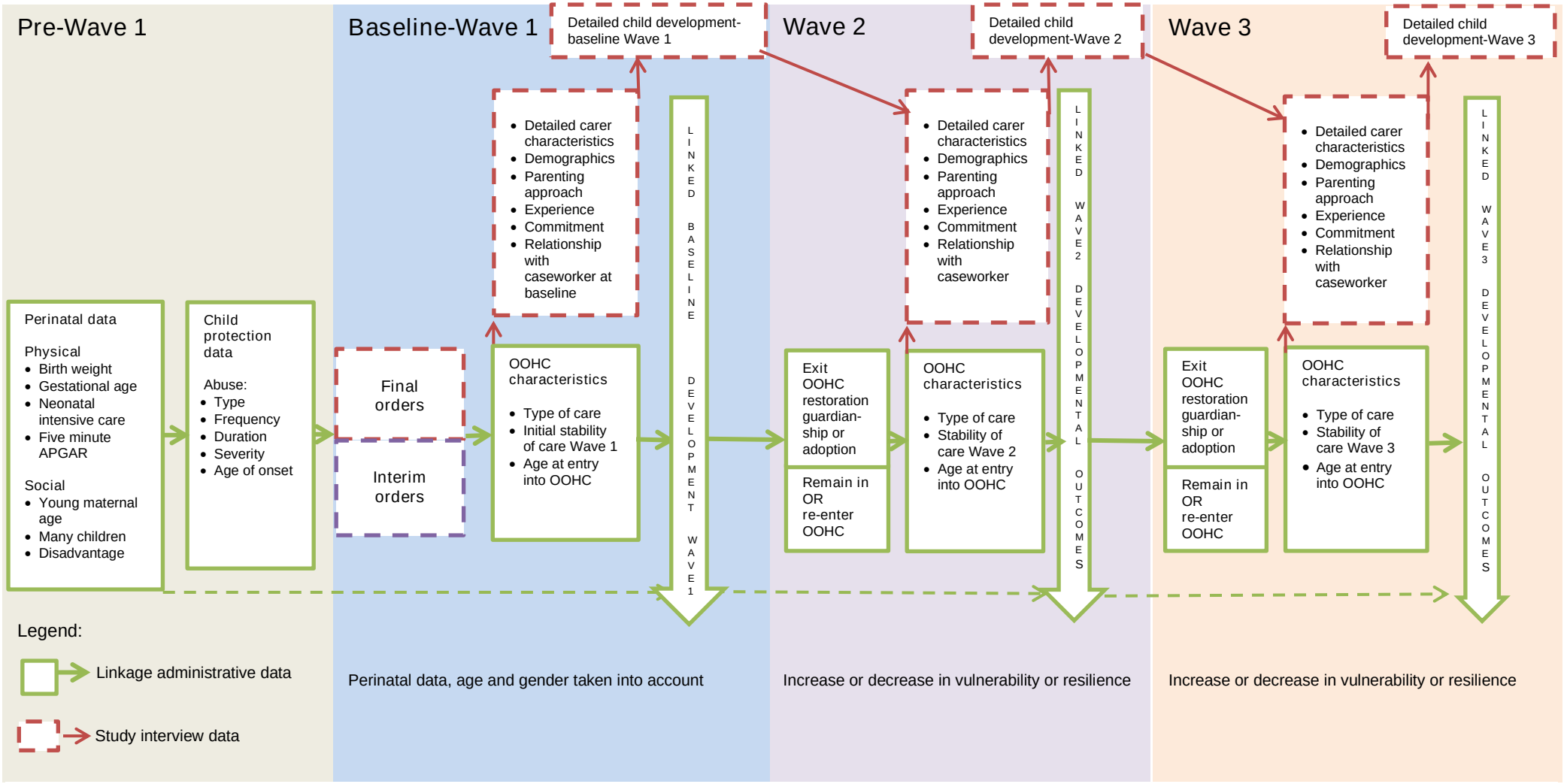



Figure 1: Overview of the relationship between the Pathways of Care Longitudinal Study primary interview data and administrative linked data

# Statistical plan

## Longitudinal analysis

A generalised linear mixed model will be used to analyse the data in general, however, other models may better suits specific data and research questions and the models will be varied accordingly. A mixed model is necessary to allow for the correlated outcomes for subjects over time and also for correlations between the outcomes for members of the same family. The outcome variables will be categorical (nominal to two or more categories, or ordinal categorical), and counts, as well as interval data, which is why the generalised form of the mixed model will be used. Tests of moderation (interaction) and mediation can be accommodated in this model framework. Maximum likelihood methods will be used to handle missing data as necessary. The longitudinal nature of the study over at least three time periods means it is in a good position to test for mediation.

## Outcomes

The primary aim of a statutory child protection agency is to prevent child abuse and neglect. However, definitions of abuse and neglect have more recently expanded beyond child protection to include children's physical health, cognitive ability and socio-emotional well-being. Child outcomes as measured by the linked administrative data can be considered to fall into these main domains which mirror the domains of interest for the interviewed sample, that is, cognitive, socio-emotional and physical health. Overall whether children fare poorly on four, three, two or one domain at each data point will categorise their overall level of vulnerability. How they are faring on each individual domain, as well as specific categorised outcomes, is of interest.

### 'Safety' domain

Data collected for this study will provide a record at each 18 month interval of data collection of:

DCJ (all children aged 0-17 years)

- counts of risk of significant harm reports
- counts of substantiated abuse and/or neglect reports.

NSW Health data (Emergency Department Data Collection and Admissions Data Collection) corresponding to data collection waves

- counts of Emergency Department visits and/or hospital admissions for 'Injuries and Poisonings'

Analysis will compare the counts for those children who remained in OOHC with the counts for those who returned home on these indicators. In some cases the results may be expressed as proportions, for example, the proportion of children who had at least one substantiated risk of significant harm report. How children are faring on this outcome will also be examined as a function of the type and stability of care while controlling for age and gender.

### 'Cognitive/Education' domain

Cognitive ability will be measured for all children of kindergarten age by the AEDC ('Language and cognitive skills' and 'Communication skills and general knowledge') and by NAPLAN results (particularly reading and numeracy) in Scholastic Years 3, 5, 7 and 9.

AEDC

Following the AEDC guidelines:

- 'on track' if a score is >25$^{th}$ percentile rank on a relevant AEDC scale
- 'developmentally at risk' for that domain if a score is ≥11$^{th}$ ≤ 25$^{th}$ percentile rank
- 'developmentally vulnerable' if a score is ≤10$^{th}$ percentile rank.

Analysis will examine the proportion of children on track', 'at developmental risk' or 'vulnerable' who remain in OOHC compared with those who were returned home. These can also be compared with the proportions in the general population.

NAPLAN in Scholastic Years 3, 5, 7 and 9.

Please contact data.services@det.nsw.edu.au or 1300 972 196 before commencing analysis of NAPLAN data for assistance in creating a detailed analysis plan to ensure analysis adequately covers the complex measurement issues around NAPLAN.

NAPLAN is conducted annually for students in Scholastic Years 3, 5, 7 and 9. As the longitudinal study continues, most children in the study will have three or four data points. The length of time in care is also of interest with regard to these outcomes.

NAPLAN participation is an important variable as patterns of participation may vary systematically between groups, and hence impact NAPLAN results. For example, children with significant disabilities may be exempted from testing - these students do not get a NAPLAN score but are considered by the commonwealth to be below the national minimum standard. NAPLAN results are presented as bands and scores

The national minimum standard is a nationally agreed minimum standard of skills and understandings, below which a student is unlikely to be able to progress satisfactorily at school without targeted intervention. Student are classified:

- below national minimum standard – 'educationally at risk' and need focused intervention and additional support to help them achieve the skills they require to progress in schooling
- at national minimum standard – 'likely educationally at risk' and are often considered to also be at risk of having difficulty making sufficient progress at school and are likely to need additional learning support
- middle two bands – 'educationally on track'
- top two bands – 'educationally well on track' and have met the level of attainment set as proficient in the NSW Premier's education target

NAPLAN results vary by the socio-educational background of the child making comparisons to state average for the socio-educationally vulnerable OOHC children inappropriate. The preferred option is to compare NAPLAN results only between groups of children in the study.

If external comparisons absolutely must be done, stratifying NAPLAN results by socio-educational disadvantage is required. NAPLAN data includes the level of socio-educational disadvantage (in deciles) for the school the child was at when the test was conducted. This socio-educational disadvantage level is derived by the aggregation of the socio-educational characteristics of the parents of the students at the school at the time of the NAPLAN test.

The results for children in OOHC may be compared to NSW government school students from schools with the same socio-educationally disadvantage decile. Look-up tables of NSW government school students' results in terms of NAPLAN percentages in bands and average scores, stratified by socio-educationally disadvantage deciles are provided if external comparisons are deemed essential.

The AEDC data collection years coincide with Wave 1 and Wave 3 of the data collection (2012 and 2015). The 2009 (retrospective data) and 2012 data collection provide the first baseline data obtainable relating to developmental indicators on around 380 five year old children and can be used as in indicator of baseline vulnerability for later NAPLAN results (Reading and Numeracy). For those who complete the AEDC in 2015 this provides outcome data for children who entered care soon after they were born.

### 'Socio-emotional' domain

Aside from the existing AEDC cut-offs, categorisations of socio-emotional health will depend on the structure and distribution of the data.

AEDC

This will be reflected on Emotional Maturity and Social Competence domains of this indicator for a small group of five-year old children (around 1,400 in total) in 2009, 2012 and 2015.

Following the AEDC guidelines:

- 'on track' if a score is >25$^{th}$ percentile rank on a relevant AEDC scale
- 'developmentally at risk' if a score is ≥11$^{th}$ ≤ 25$^{th}$ percentile rank
- 'developmentally vulnerable' if a score is ≤10$^{th}$ percentile rank.

NSW Health

Psychiatric health will be measured for all children aged 0-17 years by using the diagnostic categories (defines if there is an issue or not) and numbers/days of treatment (severity).

Mental Health – Ambulatory Collection (MH-A)

- A Mental Health diagnosis or not during each data collection period (yes or no)
- Counts of treatments during each period.

Admitted Patient Data Collection (AP-Psy)

- Admitted to hospital for a psychiatric issue in the 18 month period (yes or no)
- Number of days admitted for a psychiatric issue
- Pregnancy or child birth (yes or no)

Emergency department data collection (EDDC)

- Counts of emergency department visits for a psychiatric issue

BOCSAR (ROD)

For children over the age of ten years anti-social behaviour will be defined through

- Counts of the number of proven offences during each data collection period
- Type of offence (property, person, or drug related)

- Severity of each offence
- Severity of penalty for each offence

Of interest is the proportion of those in OOHC compared with those who were restored who had a mental health issue, or displayed antisocial behaviour (especially crimes against person considered severe). It is also of interest how these proportions compare with general published statistics for the general population.

DCJ (KiDS)

- Counts of risk of significant reports which reflect that a child is distressed or not faring well during a data collection period (rather than being related to a specific type of maltreatment or parental risk factor). These include, for instance, suicide risk, running away, drug misuse, alcohol misuse and child inappropriate sexual behaviour).

### 'Physical Health' domain

Admitted patient data collection

Diagnostic category

- Counts of admissions for chronic illness that are not congenital or chromosomal abnormalities and not counted elsewhere (e.g. injuries and poisonings and pregnancy)
- Counts of admissions for acute illness
- Counts of admissions for congenital abnormalities (not an outcome)

Emergency Department data collection

Diagnostic category

- Counts of visits for chronic illnesses not considered elsewhere
- Counts of visits for acute illnesses not considered elsewhere

AEDC physical health domain

Following the AEDC guidelines if a child:

- on track' if a score >25$^{th}$ percentile rank on physical health and well-being,
- 'developmentally at risk' if they ≥11$^{th}$ ≤ 25$^{th}$ percentile
- 'developmentally vulnerable' if ≤10$^{th}$ percentile.

In general the AEDC has the advantage of reflecting all developmental domains and providing an early indicator of vulnerability. General vulnerability will also be defined in accordance with AEDC protocols, that is vulnerable in two of more domains. Children who are not vulnerable in any domains (scoring at the 25$^{th}$ percentile rank or above) will be regarded as faring well. A limitation of the AEDC is that this Index is only available for a subgroup of children.

For those entering OOHC at birth there are around 1000 for whom the AEDC will provide subdomain data as well as global developmental vulnerability (vulnerable in two or more domains).

## Obtaining an overall picture of each child's vulnerability

Children's outcomes, ranging from very vulnerable to very resilient will be examined for each outcome individually. An overall vulnerability index will also be constructed which clusters children into groups considering outcomes across multiple domains.

The pathways of these children through OOHC will be examined to see what contributes to vulnerability in terms of child protection history and OOHC experience while taking perinatal and prior levels of vulnerability into account over successive data points (as well as prior to entering OOHC where retrospective data is available).

By categorising vulnerability or resilience at baseline and at subsequent data points we can see if children have become more or less vulnerable and how this relates to their circumstances (whether they are returned home or are still in OOHC), their child protection history and their OOHC experience.

## Predictor variables

### Perinatal Data Collection

Risk factors for abuse and neglect as well as poor developmental outcomes have been selected from this data set[7].

Physical

- Birth weight (vulnerable <2,499gm, low 1,500 to 2,499gm, very low 1,000 to 1,499gm, <999gm extremely low)

[7] The AH &MRC (Aboriginal Health and Medical Research Ethics Committee) would not permit the maternal data base to be attached limiting the information able to be collected with regard to perinatal factors (eg cigarettes smoked and level of antenatal care).

- Gestational age (vulnerable= 32≥≤36 weeks, very premature =28-31 weeks, extremely premature= <28 )
- Neonatal intensive care (yes or no)
- Five minute APGAR (<7)

Social

- Young maternal age (≤19 years)
- Large number of children - five or more (proxy = number of previous pregnancies)
- Disadvantage (maternal postcode at time of birth – SEIFA Index)

Further categorisations of perinatal vulnerability will depend on the structure and distribution of the data.

### Characteristics of the child

- Gender of the child (male, female)
- Cultural background of the child (Indigenous, CALD, other)
- Age
- Level of development at entry into care for interviewed sample - only available for a subsample of the total group (n=1285). For details of the scales, their psychometric properties and use in previous research, please see the attached POCLS Measures Manual. These measures will be used to detail the interviewed children's cognitive, social-emotional and physical development at repeated waves:
    - Cognitive ability (age dependent testing for verbal and non-verbal ability)
        - CSBS ITS and McArthur-Bates for children aged under 3 years
        - PPVT for children and young people aged 3-17 years – verbal ability
        - WISC matrices for children and young people aged 6-16 years - non-verbal reasoning
    - Social-emotional wellbeing
        - Child Behaviour Checklist (CBCL, 3-17 years)
        - Abbreviated Temperament Scales for Infants Toddlers (Australian norms – 9m -17yrs)

        - BITSEA (12-35 months)
        - Ages and stages (9 months to 5 years)
        - School problems scale
        - Self-report delinquency scale
        - Felt security – Kvebaek Family Sculpture Technique
    - Physical health
        - Ages and stages
        - Information regarding health conditions and services received.

Comparisons cannot be made between those on final and interim orders on the more detailed measures because they are only collected for the final orders cohort. This also applies to comparisons between those on final orders who were interviewed and those on final orders who were not interviewed.

### DCJ administrative data – abuse and neglect and characteristics of OOHC

Variables related to both maltreatment and OOHC placement characteristics.

Child protection data (risk factors for negative developmental outcomes)

- Type of reported issue (defined by the predominant type of maltreatment, that is ≥50% reports relating to a specific type of reported issue i.e. physical, emotional, sexual, neglect plus a category where the child has been reported for multiple types of maltreatment)
- Frequency (defined by the number of reports)
- Duration (defined by elapsed time between first report date and removal date)
- Severity (defined by number of reports requiring an urgent ≤24 hour child protection response)
- Age onset (defined by the date of first report)

Categories of vulnerability will depend on the nature and distribution of this data. The relationship between child protection history and outcomes is a focus of the study.

OOHC placement data (risk factors for negative developmental outcomes)

- Age of entry into OOHC

- Stability of care defined by the number of carers experienced over each data collection wave period (this will reflect both the number of times a child has re-entered care after returning home, as well as the number of placements while in care. It excludes respite care)
- Predominant type of care-kin, foster or residential (≥ 50% of the placement in this type of care)

### Legal orders - Final or Interim Orders

Those entering OOHC for the first time on legal orders between May 2010 and October 2011 in NSW are all children in the study.

## Overview of inter-relationships between data sources and domains

As detailed in the previous section each developmental domain relies on a number of data sources. Figure 2 provides an overview indicating which domains (ellipses) are informed by which data source (boxes). Vulnerability levels in each domain in turn inform overall vulnerability for a child at any given data wave. The relative importance of perinatal factors, child protection history and care characteristics can be examined while taking factors such as age and gender into account.

Legend of data bases in Figure 2 below:

- DCJ – KiDS DCJ administrative data base
- JJ – Re-Offending Database
- MH-A – Mental Health – Ambulatory Data Collection
- AP-psy – Admitted Patient Data Collection (psychiatric health)
- EDDC– Emergency Department Data Collection
- AEDC– Australian Early Development Census
- NAPLAN – National Assessment Program – Literacy and Numeracy
- AP-phy – Admitted Patient Data Collection (physical health)
- ED- phy – Emergency Department Data Collection (physical health)
- AP- P&I – Admitted Patient Data Collection (Poisonings and Injuries)
- ED-P&I – Emergency Department Data Collection (Poisonings and Injuries)

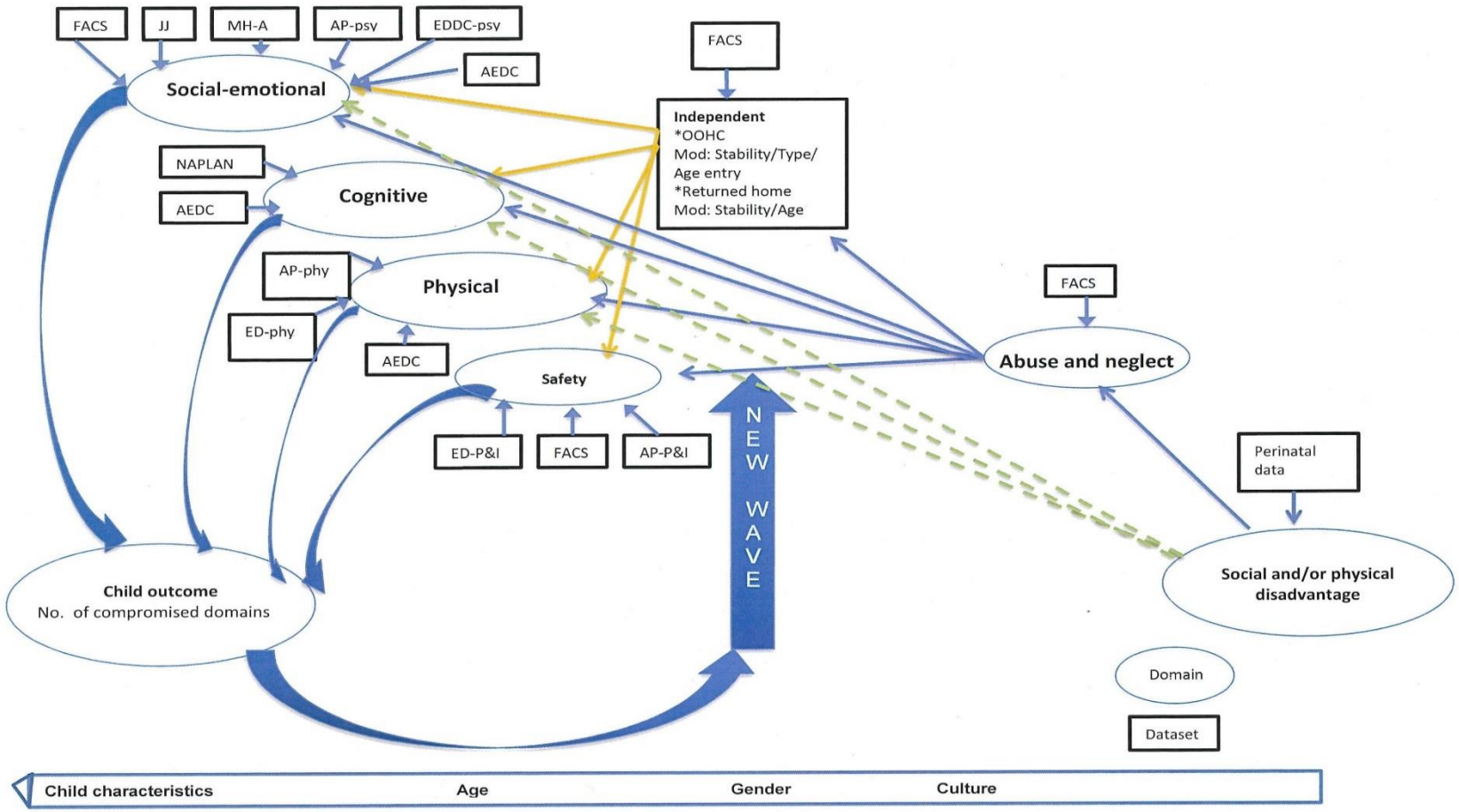



Figure 2: Overview of data sources for each developmental domain in relation to analysis

**Table 1: Administrative data measuring children's safety, permanency and wellbeing outcomes in the POCLS through** record linkage (n=4,126).

| Domains | Data source | Description of the administrative data | Study age range |
|---|---|---|---|
| OUTCOMES | | | |
| Child Safety | | | |
| | Key Information Directory System [1] | • Counts of risk of significant harm reports within a specified time frame | 0-17 years |
| | Key Information Directory System [1] | • Counts of substantiated abuse and/or neglect reports within a specified time frame | 0-17 years |
| | Emergency Department Data Collection [2] | • Counts of injury or poisoning within a specified time frame | 0-17 years |
| | Admitted Patient Data Collection [2] | • Counts of injury or poisoning within a specified time frame | 0-17 years |
| Child Permanency | | | |
| | Key Information Directory System [1] | • Number of OOHC placements within specified time frame | 0-17 years |
| | Key Information Directory System [1] | • Number of carers experienced within a specified time frame | 0-17 years |
| | Key Information Directory System [1] | • Number of re-entries into OOHC (spells) | 0-17 years |
| | Key Information Directory System [1] | • Length of time in an OOHC placement | 0-17 years |
| Child Wellbeing | | | |
| Physical health | Admitted Patient Data Collection [2] | Diagnostic category:<br>• Counts of admissions for chronic illness that are not congenital or chromosomal abnormalities and not counted elsewhere (e.g. injuries, poisonings and pregnancy)<br>• Counts of admissions for acute illness | 0-17 years |
| | Australian Early Development Checklist [5] | Physical health and Wellbeing domain of this indicator in 2009, 2012 and 2015. Following the AEDC guidelines:<br>• 'on track' if a score is >25$^{th}$ percentile rank on a relevant AEDC scale<br>• 'developmentally at risk' if a score is ≥11$^{th}$ ≤ 25$^{th}$ percentile rank<br>• 'developmentally vulnerable' if a score is ≤10$^{th}$ percentile rank. | First year of school |
| Socio-emotional | Key Information Directory System [1] | Counts of risk of significant harm reports which reflect that a child is distressed or not faring well during a data collection period (rather than being related to a specific type | 0-17 years |

| | | | |
|---|---|---|---|
| | | of maltreatment or parental risk factor) e.g., suicide risk, running away, drug misuse, alcohol misuse, child inappropriate sexual behaviour and child a danger to themselves or others. | |
| | Australian Early Development Checklist [5] | Emotional Maturity and Social Competence domains of this indicator in 2009, 2012 and 2015. Following the AEDC guidelines:<br>• 'on track' if a score is >25$^{th}$ percentile rank on a relevant AEDC scale<br>• 'developmentally at risk' if a score is ≥11$^{th}$ ≤ 25$^{th}$ percentile rank<br>• 'developmentally vulnerable' if a score is ≤10$^{th}$ percentile rank. | First year of school |
| | Mental Health – Ambulatory Collection (MH-A) [2] | Psychiatric health will be measured using the diagnostic categories (defines if there is an issue or not) and numbers/days of treatment (severity):<br>• A mental health diagnosis (or not) during each data collection period (yes or no)<br>• Counts of treatments during each period | 0-17 years |
| | Admitted Patient Data Collection (AP-Psy) [2] | • Admitted to hospital for a psychiatric issue in the specified timeframe<br>• Number of days admitted for a psychiatric issue<br>• Pregnancy or child birth (yes or no) | 0-17 years |
| | Emergency Department Data Collection (EDDC) [2] | • Counts of Emergency Department visits for a psychiatric issue | 0-17 years |
| | Re-offending Data [4] | Anti-social behaviour will be defined through:<br>• Counts of the number of proven offences during each data collection period<br>• Type of offence (property, person, or drug related)<br>• Severity of each offence<br>• Severity of penalty for each offence | 10-17 years |
| Cognitive/ Education | Australian Early Development Checklist [5] | Language and Cognitive Skills, Communication Skills and General Knowledge of this indicator in 2009, 2012 and 2015. Following the AEDC guidelines:<br>• 'on track' if a score is >25$^{th}$ percentile rank on a relevant AEDC scale<br>• 'developmentally at risk' if a score is ≥11$^{th}$ ≤ 25$^{th}$ percentile rank<br>• 'developmentally vulnerable' if a score is ≤10$^{th}$ percentile rank. | First year of school |
| | National Assessment Program: Literacy and Numeracy [3] | A child's NAPLAN band results can be categorised as:<br>• Below national minimum standard (bottom band) - 'educationally at risk' and need additional learning support<br>• At national minimum standard (second bottom band) - 'likely educationally at risk' and are likely to need additional learning support | Scholastic years 3, 5, 7 and 9 |

| | | | |
|---|---|---|---|
| | | • Middle two bands - 'educationally on track'<br>• Top two bands - 'educationally well on track' | |
| RISK FACTORS FOR POOR DEVELOPMENTAL OUTCOMES TO BE TAKEN INTO ACCOUNT | | | |
| Physical health | Perinatal Data Collection [2] | • Birth weight (vulnerable <2,499gm, low 1,500 to 2,499gm, very low 1,000 to 1,499gm, <999gm extremely low)<br>• Gestational age (vulnerable= 32≥≤36 weeks, very premature =28-31 weeks, extremely premature= <28 )<br>• Neonatal intensive care (yes or no)<br>• Five minute APGAR (<7)<br>• Congenital illness | 0-17 years |
| Social factors | Perinatal Data Collection [2] | • Young maternal age (≤19 years)<br>• Large number of children - five or more (proxy = number of previous pregnancies)<br>• Disadvantage (maternal postcode at time of birth – SEIFA Index). | 0-17 years |

1 NSW Department of Communities and Justice (DCJ) Key Information Directory System (KiDS)
2 NSW Ministry of Health administrative data
3 NSW Department of Education (DEC) National Assessment Program: Literacy and Numeracy (NAPLAN) results .
4 Bureau of Crime Statistics and Research (BOCSAR) re-offending data (ROD)
5 Commonwealth Department of Education Australian Early Development Checklist (AEDC) conducted in 2009, 2012 and 2015 measures five areas of early child development (teacher completed) including physical health and wellbeing, social competence, emotional maturity, language and cognitive skills, communication skills and general knowledge.

Record linkage will be performed by an authorised linking agency - the Centre for Health Record Linkage (CHeReL).

NSW GOVERNMENT