

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

Pathways of Care Longitudinal Study Data Collection
My Personal Health Record (Blue Book) Scans



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Data Brief No. 1

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Prepared by

Marina Paxman - NSW Department of Communities and Justice
Andy Cubie, I-view
Dian Smart, Australian Institute of Family Studies.

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.

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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 over an 18 month period for the first time in NSW 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.

The DCJ recognises the importance of Indigenous Data Sovereignty and Governance (IDS and 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. The 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 POCLS will continue to collaborate with Aboriginal Peoples and will apply the DCJ research governance principles once developed.

My Personal Health Record – Blue Book

NSW Health My Personal Health Record (the Blue Book) holds information about a child's health and development. It records valuable information about a child's health, illnesses, injuries, immunisation, growth and development. For more information go to

www.health.nsw.gov.au/kidsfamilies/MCFhealth/Pages/child-blue-book.aspx

The Blue Book is an important source of baseline information about children's health on entry to OOHC and the use of this data in the POCLS would complement the other sources of data collected for the study (this includes interviews with carers and children/young people, on-line surveys with teachers and caseworkers; and record linkage). It is also likely that much of the blue book information will be replicated in the Perinatal Data Collection.

The Blue Book scans are a valuable research asset that has the potential to answer several policy and practice questions.

Method

The child's Blue Book was scanned during the POCLS Wave 1 data collection with carers if (a) the carer had the child's Blue Book and (b) provided consent to do so. I-view interviewers scanned all pages that had entries at the carer's home. I-view redacted the scans and stamped them with the POCLS ID. The scanned copies are stored in the Secure Unified Research Environment (SURE) at the Sax Institute with the other POCLS data files.

A total of 1,285 children and their carers participated in Wave 1. I-view reported that carers had the child's Blue Book for 771 of 1,285 (60%) children and young people of all ages; and 655 of 832 (79%) for children aged 5 years or younger.

A total of 545 Blue Books (83%) were successfully scanned for children up to five years old at Wave 1.

Researchers would benefit from liaising with NSW Health to understand how useful the Blue Book information is and how best to use it to inform improvements to OOHC health service delivery and consistency in health data records for children and young people in care.

Review of 10 Blue Book scans

I-view provided 10 de-identified blue book scans to researchers at the Australian Institute of Family Studies (AIFS) who were contracted to provide

data management support to the POCLS. The purpose of the review was to determine how useful the data would be for POCLS.

Issues identified with use of Blue Book information

- The information in the ten examples reviewed is very variable and includes:
 - Record of illnesses and injuries
 - Family medical history (mother, father and other children)
 - Progress notes (weight, height, illnesses, immunisations)
 - Health checks
 - Growth charts, weight, length and head circumference for age percentiles
 - But not each case has the same pages copied (presumably because they are blank) so there will be a lot of missing data
 - Progress notes are completed to varying levels, and focus on different aspects of child's progress.
- Differing levels of completion – some have four pages completed and others have 14 pages. This may be indicative of completion levels generally
- Legibility is an issue – some handwritten notes, particularly in immunisation and progress notes, often cannot be read
- No dates are recorded on feeding records and daily health check in some Blue Books
- Scan quality is an issue – some scans are too dark and can't be read.
- Personal details included in the blue book are also collected in the other POCLS data collections and record linkage data e.g., the number of children in family and details of ethnicity.
- Child health check at 1-4 weeks and 6-8 weeks section could be useful and coded as “normal”, “review” or “refer”.
- Before health check section could be useful if available in sufficient numbers
- Health protective factors could be useful if available in sufficient numbers
- Percentile charts and the tick box sections such as the health check could be useful
- Percentile length and weight measurements may be of use.
- Reviewing what information and how often information is entered into the Blue Book would be of interest.

Limitations

For example, weight, length and head circumference for age percentiles as recorded on charts in blue books would be valuable for tracking developmental progress, used in conjunction with the self-reporting height and weight modules in the carer's questionnaire. However, there are limitations to this information in the blue books. Only 3 of the 10 scanned blue books supplied have these charts. If this were representative of the 553 Blue Books scanned of children aged 5 years or younger at Wave 1 there would be approximately 166 Blue Books with this information, approximately 20% of final Wave 1 sample of children aged 5 years or younger (n=832).

The interviewers have scanned only pages with information on them, but we don't know how consistently this was done. For example, would a mark on a growth chart be systematically scanned? Or was it only writing that was scanned? Variability in completion levels.

Overall, it depends on the research question being addressed.

Access to the Blue Book scans

The scans of Blue Books belonging to 553 children aged 5 years and younger who entered OOHC for the first time on final care and protection orders are available to approved researchers.

