Introduction

The Pathways of Care Longitudinal Study (POCLS) is funded and managed by the NSW Department of Family and Community Services (FACS). 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 links data on children’s child protection backgrounds, OOHC placements, health, education and offending held by multiple government agencies; and matches 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 an 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
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 769 of 1,285 (60%) children and young people of all ages; and 648 of 832 (78%) for children aged 5 years or younger.

A total of 553 blue books (66%) were scanned for children up to five years old at Wave 1 with 95 books not scanned due to varying reasons (blue book not available at the time, unable to find, in another location, etc.) and one refusal.

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” of “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.