



Pathways of Care Longitudinal Study

The artist is a young person who grew up in care.

"The banner shows many pathways through the care system with a carer or caseworker acting as a guide, ultimately leading to independence for every young person. Whether we live with family or strangers, study, work, or just try our best, the paths we choose and are guided through in our youth are what we use to prepare ourselves for the happiest adulthood we can achieve" Billy Black

Health Data Linkage Special Interest Group Meeting
9 November 2017



Acknowledgement

We acknowledge Aboriginal nations as the first people of Australia and pay our respects to their Elders past and present. And we extend our respect to Aboriginal children and young people who are the future Elders.

We remember the Stolen Generations – Aboriginal and Torres Strait Islander children forcibly removed from their families, communities and culture under past government practices.

Ethics approval



Human Research Ethics Committee

University of New South Wales HREC (HC10335 & HC16542).

Aboriginal Ethics Committee

Approval from Aboriginal Health & Medical Research Council (AH&MRC) of NSW Ethics Committee (766/10).

NSW Department of Education

State Education Research Applications Process (SERAP) (2012260).

NSW Population & Health Services Research Ethics Committee

Cancer Institute New South Wales (HREC/14/CIPHS/74).

Aims of the study



To describe children's pathways

- **into care:** eg characteristics, child protection history
- **through care:** eg access to services, placements, development, family contact, casework, friends and school
- **out of care:** eg restoration, adoption, leaving care at 18 years

To understand factors influencing child outcomes

- Safety, physical health, socio-emotional wellbeing, cognitive/learning ability

To inform policy and practice to improve the service system

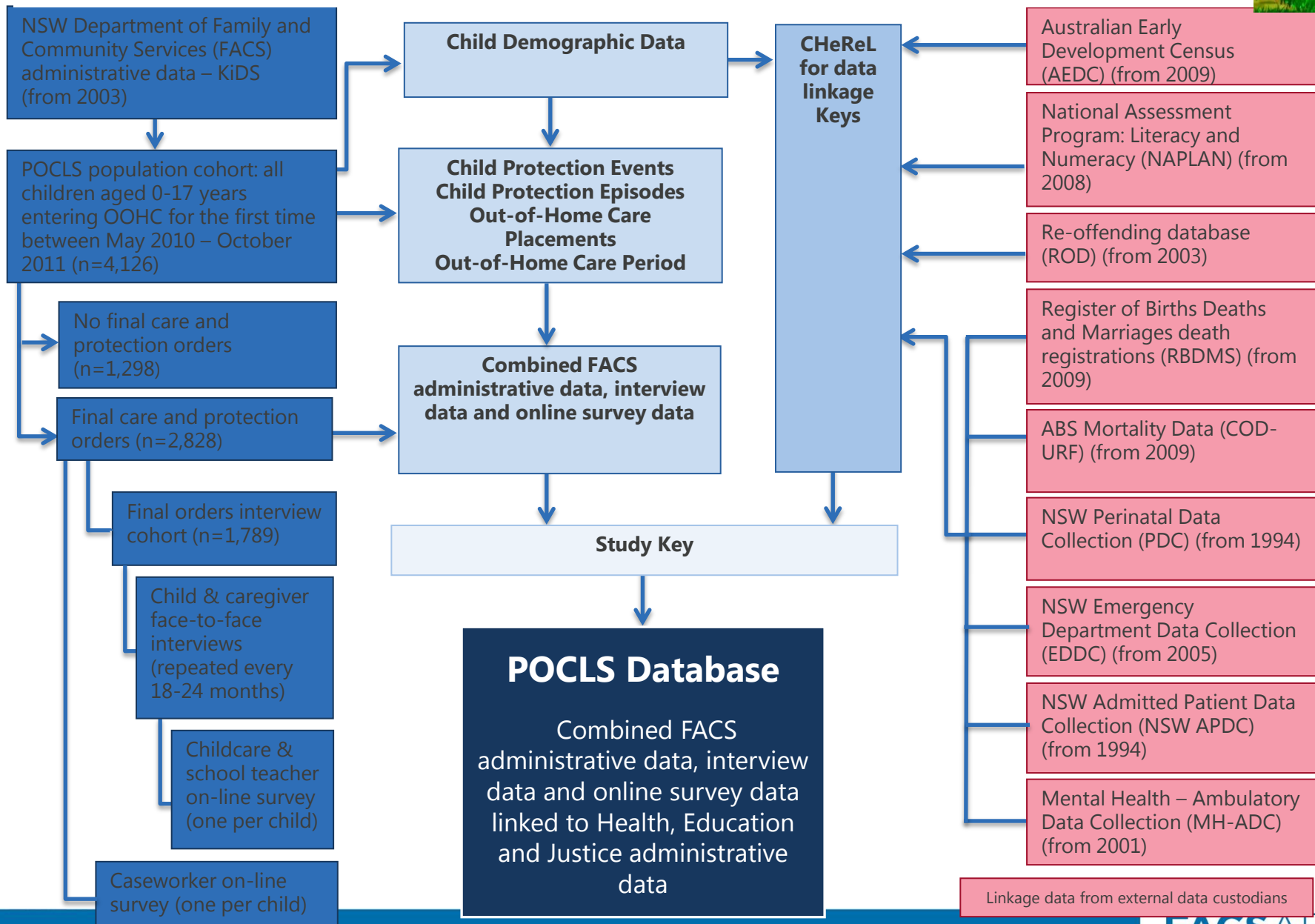
Who is conducting this study?



NSW Department of Family & Community Services with assistance from:

- Professor Judy Cashmore (University of Sydney)
- Professor Paul Delfabbro (University of Adelaide)
- Professor Ilan Katz (University of NSW)
- Dr Fred Wulczyn, Chapin Hall, University of Chicago
- Australian Institute of Family Studies
- Sax Institute
- I-view, experts in social research data collection

POCLS Data Linkage Diagram





Study cohorts

Study population cohort

Entered OOHC on interim orders May 2010-October 2011
(n=4,126)

Final orders cohort

Children's Court order by April 2013 (n=2,828)

Interview cohort

(n=1,789)

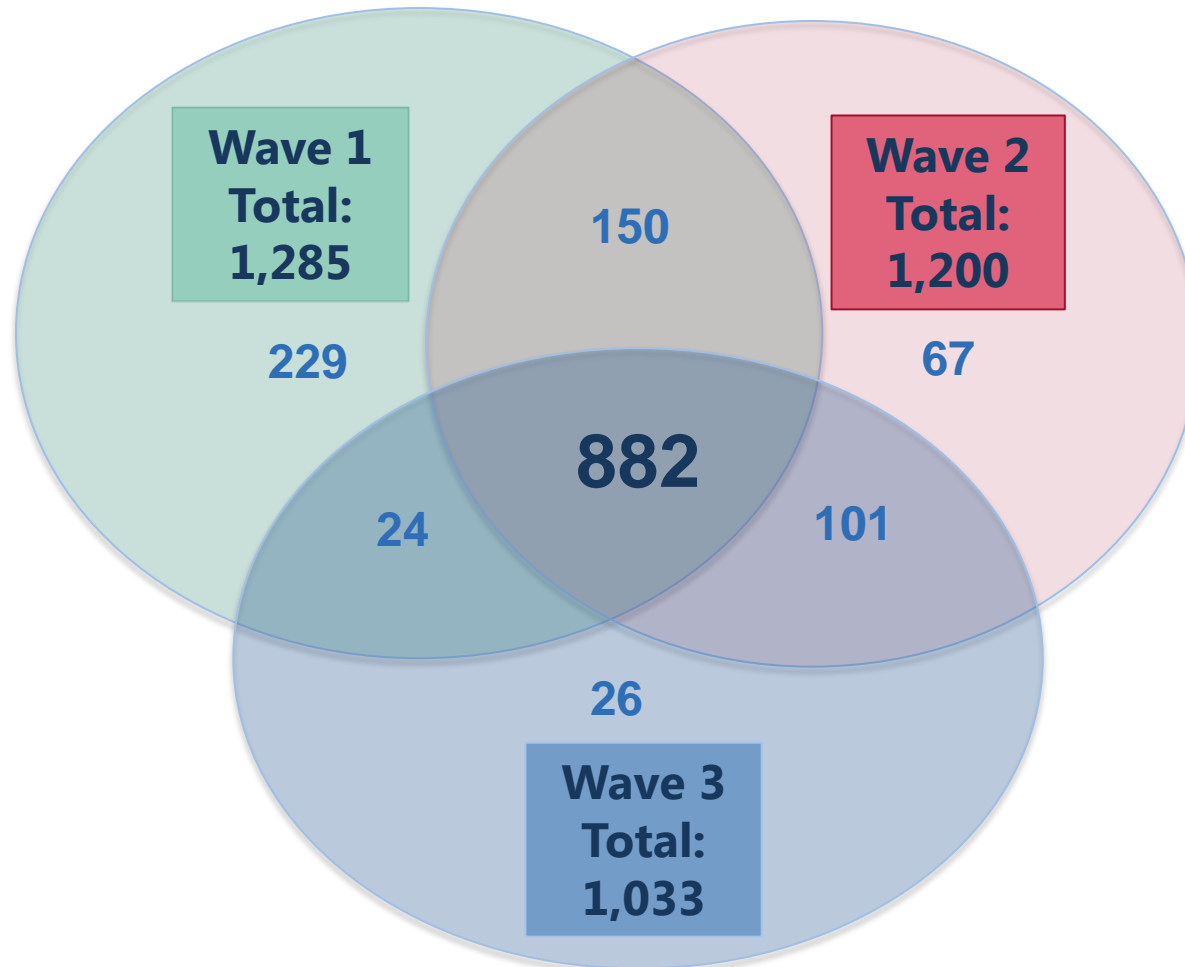
Wave 1 n=1,285

Wave 2 n=1,200

Wave 3 n=1,033

Wave 4&5 ongoing

Participation in the interview cohort: Wave 1-3



Child & caregiver interview cohort

Wave 1 to 3 data collection involved 8,500 hours of in-depth interviewing, plus 5,000 hours travelling over 265,000kms. Total number of children participating in any wave is **1,479**.

Teacher interview cohort on-line survey on their perspective of the child's wellbeing – one survey per child. To date **670** surveys have been completed.

Caseworker final orders cohort on-line survey completed on their perspective of the system. **1,625** surveys completed during Wave 3.

Characteristics of the interview cohort, W1-3



| | No. | % |
|-----------------------------------|-------|------|
| Age at first entry to OOHC | | |
| 0-2 years | 802 | 54.2 |
| 3-5 years | 275 | 18.6 |
| 6-11 years | 310 | 21.0 |
| 12-17 years | 92 | 6.2 |
| Aboriginality * | | |
| Non-Aboriginal | 905 | 61.2 |
| Aboriginal | 574 | 38.8 |
| Gender | | |
| Male | 734 | 49.6 |
| Female | 745 | 50.4 |
| Total | 1,479 | 100 |

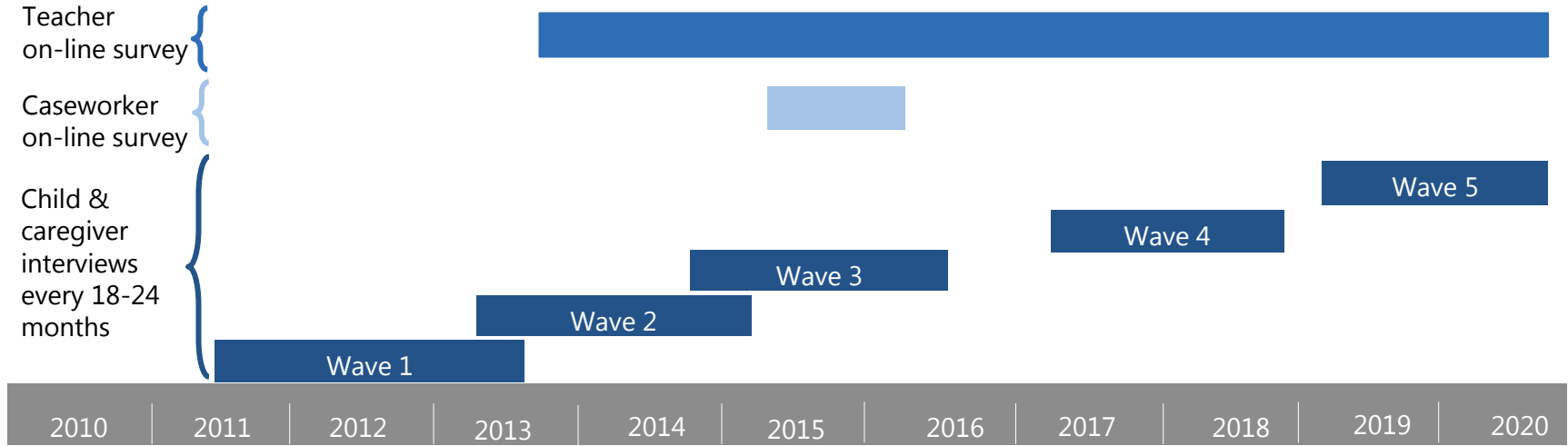
* Based on FACS administrative OR subsequent carer interview at Wave 3.

POCLS data collection timelines



Mode of data collection:

- Teacher on-line survey {
- Caseworker on-line survey {
- Child & caregiver interviews every 18-24 months {



Entry into Care

Received final orders by April 2013

Sample Recruitment

Record Linkage Data

Child Protection, Out-of-Home Care, Education, Health and Offending Data

Linkage data from external agencies

- Health
 - NSW Perinatal data collection
 - NSW Emergency Department data collection
 - NSW Admitted Patient data collection
 - NSW Mental Health Ambulatory data collection
 - NSW Registry of Births, Deaths and Marriages
 - ABS Mortality data
- Education
 - Australian Early Development Census
 - National Assessment Program: Literacy and Numeracy (NAPLAN)
- Justice
 - Re-offending database

Outcome domains and linked data

- 'Safety' domain
 - FACS risk of significant harm (ROSH) reports
 - FACS substantiated reports
 - NSW Emergency Department data collection
 - NSW Admitted Patient data collection
- 'Cognitive' domain
 - AEDC
 - NAPLAN

Outcome domains and linked data

- ‘Socio-emotional’ domain
 - FACS ROSH reports (suicide risk, runaway, drug/alcohol misuse)
 - AEDC (emotional maturity and social competence)
 - Mental Health – Ambulatory data collection
 - Admitted Patient data collection (psychiatric issue, pregnancy/childbirth)
 - Emergency Department data collection (psychiatric issue)
 - Offending
- ‘Physical health’ domain
 - Admitted Patient data collection
 - Emergency Department data collection
 - AEDC (Physical health domain)

Challenges in accessing administrative data

- **Dealing with many people across different agencies** – forms need to be signed by data custodians, chief investigator, those approved to access the data
- **Selecting variables** – link to research question, any changes need to go back to ethics, multiple analysts
- **Lots of forms to fill out** – each data custodian, accredited linkage agency, ethics
- **Data custodian concerns** – re-identification, statistical competence, breaches
- **Time-frames** – takes longer than you anticipate! Try and get it right the first time!
- **Change of personnel**
- **Processing** – data needed to be matched, cleaned, value labels added, some data had errors and had to be re-requested
- **Interpretation** – some are easy to understand while others more difficult especially if no data dictionary

Managing the linked datasets

- Named collaborators in this study will have to seek permission in writing from the relevant data custodian and FACSAR stating the variables required and the research question justifying the request.
- The research questions and analyses must remain within the remit of the rationale for each variable.
- Data custodians requested that all linkage data be stored in only one site - agreed it would be stored at SURE.
- Any changes to the agreed data storage arrangements or data de-identification processes will require an amendment to the existing ethics application and an amendment to the conditions of data release.

Managing the linked datasets

- Requests for linked data can only be made by those named in the individual data custodian request for data applications and the ethics application.
- No unit record data is to be given to anyone, in any instance, who is not named either in this application or an amended application (including research assistants employed by the researcher).
- FACS cannot release any linked data to anyone, including those named in the application, unless directed to by the relevant external custodian.
- Where all permissions have been obtained and the data custodian asks FACS to grant access to a researcher, the access will be provided through SURE.
- 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.

Managing the linked datasets

- The key linking the FACS generated STUDY_ID to the final third party generated POCLS_ID is held by a third party. This third party can hold either identifiers and no linkage data, or information but no identifying data.
- Where linkage data is requested it will be linked to the most confidentialised version dataset. This data set only has month and year of birth for children and carers, it does not contain addresses, postcodes are replaced with an alternative code, ABS categories only are used for language and cultural identity.
- Researchers who wish to publish or present their findings must submit the paper or presentation for review to FACS and the relevant external data custodian at least one month before the presentation or submission deadline.
- All linkage data **MUST** be deleted after five years

Results...

- Powerful dataset that will be able to be used by FACS and researchers to improve children's experiences in care and the experiences of carer's and ultimately improve outcomes for children.
- First study of it's kind in Australia using:
 - First hand accounts from children, young people, carers, caseworkers and teachers
 - Linked to FACS, health, offending and education administrative data

Questions????