**Pathways of Care study**

NSW Department of Family and Community Services (FACS) is undertaking *Pathways of Care Longitudinal Study* (POCLS), a large-scale prospective longitudinal study of children and young people aged 0–17 years entering out-of-home care (OOHC) on Children’s Court orders for the first time.

The study will involve interviews with carers, children and young people themselves and will also include record linkage from the existing FACS administrative database and external data custodians. Additional information for the study will also be obtained in surveys of caseworkers, childcare workers and teachers.

This Note describes the processes undertaken for ethical review, approval and monitoring of the study and the Ethics Committees involved.

**Human Research Ethics Committee Approval**

The National Health and Medical Research Council (NHRMC, 1997) *National Statement on Ethical Conduct in Human Research* states that all research in Australia needs to be reviewed, approved and monitored by a Human Research Ethics Committee (HREC). In situations where an organisation wishing to conduct research does not have a HREC, the NHMRC states that the researchers should approach a HREC and seek to establish an arrangement whereby the HREC agrees to act on behalf of the researchers.

As FACS does not have a HREC, the ethics review process had to be undertaken by an external HREC. Therefore an agreement was reached with the University of New South Wales Human Research Ethics Committee (UNSW HREC) to review, approve and monitor POCLS. The UNSW HREC granted approval for POCLS (Approval Number 10335).

**Aboriginal Ethics Committee Approval**

Although Aboriginal children aged 0–17 years make up around 5% of the NSW population (Australian Bureau of Statistics, 2011), 35% of children and young people in OOHC are Aboriginal (NSW Department of Community Services, 2014). For this reason an additional ethics application was required to an Aboriginal Ethics Committee. As Community Services does not have an Aboriginal Ethics Committee and the study included health aspects, the Aboriginal Health and Medical Research Council (AH&MRC) of NSW Ethics Committee was approached to consider the application. The AH&MRC of NSW Ethics Committee granted approval for POCLS (Approval Number 766/10).

**Education Ethics Committee Approval**

Approval for the childcare worker and teacher survey was obtained from the NSW Department of Education and Communities State Education Research Approval Process (SERAP, Approval Number 2012250) and the Catholic Education Office (CEO) Sydney (and relevant Diocese).

**Approval from other ethics committees**

Approval for record linkage will be submitted to the NSW Population and Health Service Research Ethics Committee. To ensure privacy requirements are met, record linkage will be performed by an authorised linking agency—the Centre for Health Record Linkage (CHeReL).
FACS aims to link four external data sources to the POCLS database, in addition to FACS administrative data on child protection and OOHC:

- The Australian Early Development Census (AEDC) Checklist conducted in 2009 and 2012 measures five areas of early childhood development in the first year of school (teacher-completed checklist), including physical health and wellbeing, social competence, emotional maturity, language and cognitive skills, communication skills and general knowledge (Commonwealth Department of Education).
- Education records for all Australian students in Years 3, 5, 7 and 9 collected via the National Assessment Program: Literacy and Numeracy (NAPLAN) tests. Proficiency levels, reported as a band, in reading, writing, language conventions (spelling, grammar and punctuation) and numeracy at the unit-record level (NSW Department of Education and Communities).
- Health records, including those regarding gestational age, birth weight, APGAR scores and neonatal intensive care, mental health diagnosis, hospital admissions and emergency department visits, mother’s age and mother’s postcode at child’s birth date, antenatal care, smoking during pregnancy and birth order (NSW Ministry of Health).
- Youth offending data, including the number of offences, most serious offence, and penalty severity (Bureau of Crime Statistics and Research).

References

