**ACT Perinatal Data Collection**

ACT Government Health Directorate

## Background

The ACT Perinatal Data Collection (formerly known as the Midwives Data Collection) is a population-based surveillance system covering all births in ACT public hospitals (Canberra and Calvary), as well as homebirths. The data collection has operated since 1991 but only data from 1997 is considered of sufficient quality for analysis.

The ACT PDC encompasses all live births, and stillbirths of at least 20 weeks gestation or at least 400 grams birth weight. For every birth in ACT the attending midwife or medical practitioner completes a form (or its electronic equivalent) giving demographic, medical and obstetric information on the mother, and information on the labour, delivery and condition of the infant. The information is sent to the ACT Government Health Directorate where it is checked and compiled into one state-wide dataset. A record is forwarded for each baby, even in the case of a multiple birth. The ACT PDC has undergone multiple minor revisions over the years, major changes occurred in 2002 and 2008.

The ACT PDC includes notifications of births which occur in ACT; it does not receive notifications of interstate births where the mother is resident in ACT. The collection is based on the date of birth of the baby.

## Tips for using the ACT PDC in linkage studies

* The ACT PDC record contains information on mothers and babies. As the CHeReL links records for the same person (rather than across generations), two sets of personal identifiers from the ACT PDC records are provided to the CHeReL—one for mothers and one for babies. These are known as the ACT PDC mother and ACT PDC baby datasets. When using the ACT PDC in linkage studies, please consider whether mothers or babies or both are of interest. If both mothers and babies are of interest, the CHeReL will create an ACT PDC mother linkage key and an ACT PDC baby linkage key. The data custodian will add both mother and baby project person numbers (PPNs) to the ACT PDC dataset for provision to the project investigators.

## Data custodian

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## Perinatal Data Collection – Variable information

| Variable | Description/Notes | Codes |
| --- | --- | --- |
| Mother’s date of birth | Full date of birth will only be supplied if sufficient justification is supplied that age is insufficient. Date of birth may otherwise be supplied as MMYYYY. |  |
| Mother’s age | Age in years |  |
| Mother’s country of birth | The country in which the mother was born | Codes are the Australian Bureau of Statistics 4 digit country of birth names  <http://www.abs.gov.au/ausstats/abs@.nsf/mf/1269.0> |
| Mother’s Indigenous status | Mother’s Indigenous status. Used from 1999 onwards. | 1 = Aboriginal but not Torres Strait Islander origin  2 = Torres Strait Islander but not Aboriginal origin  3 = Both Aboriginal and Torres Strait Islander origin  4 = Neither Aboriginal nor Torres Strait Islander origin  9 = Unknown or not stated |
| Mother’s marital status | Mother’s marital status. | 1 = Never married  2 = Widowed  3 = Divorced  4 = Separated  5 = Married (registered and de facto)  9 = Not stated/inadequately described |
| Hospital of birth | Hospital of birth registration for live births and stillbirths. Babies born before arrival at hospital will be listed against the hospital at which their birth was registered. | 82 = Canberra Hospital  83 = Calvary Public Hospital – Bruce  85 = Calvary John James Hospital  86 = Calvary Private Hospital – Bruce  8888 = Not applicable (home birth)  9999 = Not stated/unknown |
| Mother’s postcode | Mother’s postcode of residence | ACT – 2600-2620; 2900-2915. Postcodes 2600, 2611, 2618, 2619, 2620 are shared with NSW.  NSW – 2000-2599; 2618-2899  VIC – 3000-3999  QLD – 4000-4999  SA – 5000-5999  WA – 6000-6999  TAS – 7000-7999  NT – 0800-0899  O/S – null or 9999 |
| Mother’s SLA of residence | Statistical Local Area of residence | Codes are according to the Australian Standard Geographical Classification (ASGC) issued by the Australian Bureau of Statistics <http://www.abs.gov.au/ausstats/abs@.nsf/mf/1216.0> |
| Accommodation status | Patient accommodation status | 1 = Public  2 = Private  8 = Other  9 = Not stated |
| Baby’s date of birth | Full date of birth will only be supplied if sufficient justification is supplied. Date of birth may otherwise be supplied as MMYYYY. |  |
| Date of LMP | Date of last menstrual period. Full date will only be supplied if sufficient justification is supplied that gestational age is insufficient. |  |
| Previous pregnancy? | Primigravida or Multigravida | 0 = Primigravida  1 = Multigravida  9 = Not stated |
| Number of previous pregnancies | Number of previous pregnancies | 99 = Not stated |
| Was last birth by caesarean section? | Available from 2006 onwards | 1 = Yes  2 = No  9 = Not stated |
| Total number of previous caesarean section | Available from 2006 onwards | 99 = Not stated |
| Amniocentesis (<20 weeks) |  | 0 = No  1 = Yes  9 = Not stated |
| Amniocentesis (≥20 weeks) |  | 0 = No  1 = Yes  9 = Not stated |
| CVS | Chorionic villus sampling. | 0 = No  1 = Yes  9 = Not stated |
| Cervical suture |  | 0 = No  1 = Yes  9 = Not stated |
| Antenatal care providers | Who provided antenatal care?  Main antenatal care provider from 1997–2007, all antenatal care providers from 2008. | 0 = No antenatal care  10 = Obstetrician (including Fetal Medicine Unit)  11 = General Practitioner  12 = Midwife led Clinic  13 = Independent Midwife  14 = Hospital Antenatal Clinic  15 = Primary Midwife model  16 = Aboriginal Health Service  17 = Shared care (GP & Hospital ANC as per guidelines)  99 = Not stated |
| Duration of pregnancy (weeks) at first antenatal visit | Duration of pregnancy at first antenatal visit. Quality improves over time; however the later years are still close to 20% not stated and most often this represents the duration of pregnancy at first hospital antenatal clinic appointment. | 98 = No antenatal care  99 = Not stated |
| Smoking during pregnancy | Did the mother smoked at all during pregnancy? | 1 = Yes  2 = No  9 = Not stated |
| Cigarettes per day 2nd half pregnancy | How many cigarettes each day on average were smoked in the second half of pregnancy | 98 = less than 1 99 = Not stated |
| Alcohol use during pregnancy | Did the mother drink alcohol at all during pregnancy? | 1 = Yes  2 = No  9 = Not stated |
| Standard drinks per week during pregnancy | How many standard drinks each week on average were drunk during pregnancy | 98 = less than 1 99 = Not stated |
| Maternal diabetes mellitus | Maternal diabetes mellitus—pre-existing diabetes | 0 = No/not stated  1 = Yes |
| Gestational diabetes | Gestational diabetes | 0 = No/not stated  1 = Yes |
| Chronic hypertension | Chronic maternal hypertension | 0 = No/not stated  1 = Yes |
| Pregnancy-induced hypertension | Pregnancy-induced hypertension or pre-eclampsia. Available from 1999 | 0 = No/not stated  1 = Yes |
| APH |  | 0 = None  1 = Placenta praevia  2 = Abrupto placenta  4 = Placenta praevia and Abrupto placenta  3 = Other APH |
| Prelabour rupture of membranes (>24 hours) |  | 0 = No/not stated  1 = Yes |
| Threatened premature labour | Available from 1999 | 0 = No/not stated  1 = Yes |
| Major puerperal infection |  | 0 = No/not stated  1 = Yes |
| Third or fourth degree tear |  | 0 = No/not stated  1 = Yes |
| Retained placenta |  | 0 = No/not stated  1 = Yes |
| Post-partum haemorrhage (>600mls) |  | 0 = No/not stated  1 = Yes |
| Labour onset | Onset of labour | 1 = Spontaneous  2 = Induced  3 = No labour  9 = Not stated |
| Type of Induction | Birth event—labour induction type, more than one method is collected  Available from 1999 | 0 = None  1 = Oxytocin  2 = Prostaglandins  3 = Artificial rupture of membranes (ARM)  4 = Combined ARM and Oxytocin  8 = Other  9 = Not stated |
| Type of Augmentation | Birth event—labour augmentation type, more than one method is collected  Available from 1999 | 0 = None  1 = Oxytocin  2 = Prostaglandins  3 = Artificial rupture of membranes (ARM)  8 = Other  9 = Not stated |
| Analgesia for labour | Analgesia administered to the woman to relieve pain for labour and unassisted birth, more than one method is collected | 1 = None  2 = Nitrous oxide  3 = intra-muscular injection  4 = Epidural or caudal  5 = Spinal  6 = Systemic opioids  7 = Combined spinal-epidural  88 = Other  99 = Not stated/inadequately described |
| Anaesthesia for delivery | Anaesthesia administered for operative/assisted delivery of the baby, more than one method is collected | 1 = None  2 = Local anaesthetic to perineum  3 = Pudendal block  4 = Epidural or caudal  5 = Spinal  6 = General anaesthetic  7 = Combined spinal-epidural  88 = Other  99 = Not stated/inadequately described |
| Presentation | The presenting part of the foetus at birth. | 1 = Vertex  2 = Breech  3 = Face  4 = Brow  8 = Other  9 = Not stated |
| Type of Delivery | Available for 1997–2005 | 1 = Spontaneous vaginal  2 = Forceps (assisted vaginal birth)  3 = Vaginal Breech  4 = Caesarean Section  5 = Vacuum extraction  8 = Other  9 = Not Stated |
| Method of Birth | Available from 2006 onwards | 1 = Vaginal - non-instrumental  2 = Vaginal - forceps  4 = Caesarean section  5 = Vaginal - vacuum extraction  9 = Not stated |
| Perineal status | Available from 1998. Calculated from 2012. | 1 = Intact  2 = 1st degree tear/graze  3 = 2nd degree tear  4 = 3rd degree tear  5 = Episiotomy  6 = Combined tear and episiotomy  7 = 4th degree tear  8 = Other  9 = Not stated |
| Perineal status | Multiple response available from 2009, six variables | peri\_stat\_int (1=Yes or 0=No or 9=variables not stated)  peri\_stat\_1st (1=Yes or 0=No/not stated)  peri\_stat\_2nd (1=Yes or 0=No/not stated)  peri\_stat\_3rd (1=Yes or 0=No/not stated)  peri\_stat\_4th (1=Yes or 0=No/not stated)  Episiotomy (1=Yes or 0=No/not stated) |
| Perineal status | Multiple responses field partially available from 2011. Responses are separated by ‘^’ | 1 = Intact  2 = 1st degree tear/graze  3 = 2nd degree tear  4 = 3rd degree tear  5 = Episiotomy  7 = 4th degree tear  88 = Other  99 = Not stated |
| Episiotomy | Available from 1998 | 0 = No  1 = Yes |
| Surgical repair of vagina or perineum | Available from 1999 | 1 = Yes  2 = No  9 = Not stated |
| Baby’s sex | Baby sex | 1 = Male  2 = Female  3 = Indeterminate  9 = Unknown |
| Plurality of birth | The number of foetuses or babies from the pregnancy. On this basis pregnancy may be classified as single or multiple. | 1 = Singleton  2 = Twins  3 = Triplets  etc  9 = Not stated |
| Birth order | The order of birth | 1 = First  2 = Second  3 = Third  etc  9 = Not stated |
| Gestational age | Gestational age measured in weeks, based on the best clinical estimate | 99 = Not stated |
| Birth weight | The newborn infant’s first weight in grams, usually taken within one hour of birth | 9999 = Not stated |
| Birth length | The newborn infant’s length at birth in centimetres | 99 = Not stated |
| Birth head circumference | The newborn infant’s head circumference at birth in centimetres | 99 = Not stated |
| APGAR score (1 min) | A numerical scoring system routinely administered one and five minutes after birth to evaluate the condition of the baby. The score ranges from 0 to 10 | 99 = Not stated |
| APGAR score (5 min) | As above | As above |
| Admitted to Special Care Nursery or Neonatal Intensive Care Unit | Available from 1999 | 0 = No  1 = Yes  9 = Not stated |
| Number of days in SCN/NICU | Number of days in SCN/NICU in hospital of birth. Available from 1999 | 0 = Not admitted to SCN/NICU  888 = Admitted, number of days unknown  999 = Not stated |
| Resuscitation of baby | Available for 1998-2008 | 1 = None  2 = Suction  3 = Oxygen therapy  4 = IPPR by bag and mask  5 = Intubation and IPPR  6 = External cardiac massage and ventilation  7 = Other  9 = Not stated |
|  | Available for 2009 onwards, more than one method is collected. | 1 = None  2 = Suction  3 = Oxygen therapy  4 = IPPR(V) by bag and mask  5 = Intubation and IPPR(V)  6 = External cardiac massage and ventilation  9 = Not stated |
| Baby’s date of discharge or transfer | Full date will only be supplied if sufficient justification is supplied that age is insufficient. |  |
| Baby’s discharge status | Baby’s discharge status | 1 = Discharged home  2 = Transferred  3 = Transferred and died  4 = Stillborn or died  8 = Other  9 = Not stated |
| Baby’s date of death | Full date will only be supplied if sufficient justification is supplied that age is insufficient. |  |
| Baby Outcome | Fetal-infant outcome. Note that whilst termination of pregnancy less than 20 weeks is included in the code set there are no records in the ACT data. | 0 = Stillbirth  1 = Livebirth, survived  2 = Livebirth, neonatal death  3 = Livebirth, post-neonatal death  4 = Termination of pregnancy <20wks  9 = Not stated |
| Baby’s place of birth | Place of birth. Not that whilst free-standing Birth Centre is included in the code set there are no free-standing Birth Centres in the ACT. | 1 = Hospital  2 = Birth Centre attached to hospital  3 = Birth Centre free-standing  4 = Planned home birth  8 = Other including born before arrival  9 = Not stated |
| Mother’s discharge status | Mother’s discharge status | 1 = Discharged home  2 = Transferred  3 = Died  8 = Other  9 = Not stated |
| Antenatal stay | Duration of mother’s antenatal stay in days |  |
| Postnatal stay | Duration of mother’s postnatal stay in days |  |
| Baby’s stay | Duration of baby’s stay in hospital as a newborn. If the baby stays more than 10 days then it is usually statistically discharged and readmitted as an acute care patient. |  |