This manuscript has not been submitted for publication. It compares stillbirth reporting from four different population data sources, and develops an algorithm for maximum identification of definite and probable stillbirths in linked population data while avoiding false positive and duplicate reports. By placing the results on this repository we are hoping to inform future use of population data for research on stillbirths in NSW.

Identification of stillbirths in NSW linked population health datasets

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Introduction

The unexpected death of an unborn child can be devastating for a woman and her family. Over the past two decades the stillbirth rate in Australia has remained largely unchanged at ~6/1000 or ~1 in 170 births.[2-4] During this period neonatal mortality (death of a live born infant in the first 28 days of life) has declined and this decline has been attributed to advances in neonatal care and obstetric interventions.[2-4] In Australia and other high-income countries, the majority of stillbirths occurred before the onset of labour (antepartum stillbirths) with few deaths occurring during labour (intrapartum stillbirths).[5] The lack of ability to prevent antepartum stillbirths is a major contributor to the intransigent stillbirth rates.[6] Furthermore, antepartum and intrapartum stillbirth rates have been suggested as strong and direct indicators of the quality of antenatal and obstetric care.[7]

In the past when asphyxia was a common cause of both intrapartum stillbirth and early neonatal death, stillbirth and neonatal deaths were often combined in a single category of 'perinatal deaths', but this is no longer considered appropriate for high income countries because the aetiologic determinants have diverged.[8] There are now fewer neonatal deaths caused by asphyxia and more attributed to conditions existent before labour, such as congenital anomalies.[8]

Attempts to prevent stillbirths need to be supported by specific, high quality population-level information.[5,7] Difficulties arise around the use of different birthweight and gestational age limits for reporting of stillbirths, and varying inclusion of pregnancy terminations and stillbirths affected by congenital malformations, which can result in registration artifacts in national and international comparisons.[5,7,9,10] Furthermore uncertainty may arise around when a stillbirth occurred (before or during labour) and the classification of death (stillbirth or early neonatal death). Accurate reporting of stillbirth characteristics facilitates comparative research using consistent criteria.[5,7,10,11]

Population-based studies are necessary to describe the total burden of stillbirth in the population, determine the frequency of known risk factors (especially potentially modifiable factors), assess access to antenatal care and medical facilities, determine subgroups at increased risk and assess the utilisation of effective prevention strategies.[12] In the past, some population-based studies have relied on hospital discharge data where stillbirths are under-ascertained.[13,14] Although perinatal data collections accurately identify stillbirths, these data may lack information on the cause and timing (before or during labour) of stillbirths.[15,16] Linking of population level data has the potential to overcome some of the disadvantages associated with single data sources, improve ascertainment and provide comprehensive information enabling stillbirth research at a population level (see Box).[1] However, studies assessing the quality of perinatal record linkage have consistently identified lower linkage rates among pregnancies that end in a stillbirth compared to those resulting in a live birth.[17,18]

To best utilise NSW linked data for stillbirth research, a comparison of stillbirth reporting in the Perinatal Data Collection with other population datasets was needed. Therefore, the aims of this study were to compare stillbirth reporting from four different population data sources, and develop an algorithm for maximum identification of definite and probable stillbirths in linked population data while avoiding false positive and duplicate reports.

What we know about population perinatal data[1]:

- Stillbirths are well recorded in birth data but not uniformly in hospital data (which relies on maternal admissions, since a baby that is stillborn does not usually have an admission record)
- Although the birth data in NSW have excellent ascertainment of stillbirths, it lacks information on the timing (antepartum or intrapartum) and cause of fetal death
- Reporting of maternal medical conditions in birth data is limited in the number of conditions, and by the accuracy and reliability of reporting
- Longitudinal linkage of maternal records increases the ascertainment and accuracy of maternal medical information and reproductive histories
- In general, if conditions or outcomes are reported in more than one linked data source, identifying a condition/outcome from either source increases ascertainment without increasing the false positive rate
- Overall, excellent linkage proportions are obtained for birth and maternal

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Methods

Study population

The study population included all births, liveborn and stillborn, in NSW from 2001 to 2005. A stillbirth was considered to be a fetal death in utero in the second half of pregnancy.[19]

Data sources and record linkage

Data were obtained from four linked population health datasets, one with information on all births, one including all mothers who gave birth in hospital and two that only have information on stillbirths and neonatal deaths.

The **NSW Perinatal Data Collection (PDC)** is a population-based statutory surveillance system that contains information on *all births* (live and stillborn) in NSW with gestational age ≥20

weeks or (if gestational age is unknown) birth weights ≥400g.[20] The PDC includes maternal demographic characteristics and information on maternal health, pregnancy, labour, delivery and infant outcomes. Information on birth outcomes (including live or stillborn status, and Apgar score at one and 5 minutes) are reported by the attending midwife or doctor. Of the four data sources, the PDC has the most comprehensive perinatal information (including both numerator and denominator information) and is readily available (typically 6-8 months after the end of a calendar year).

The **Admitted Patients Data Collection (APDC)** contains demographic and hospitalisation-related data for *every inpatient admission* to public and private hospitals and day procedure centres in NSW.[17] Diagnoses and procedures are abstracted from each medical record by clinical coders and classified according to the International Classification of Diseases Version 10 – Australian Modification (ICD-10AM) and the Australian Classification of Health Interventions (ACHI).[21] Importantly, stillbirths are recorded on the mother's hospital delivery admission record and do not usually generate an infant hospital admission record.[17] Furthermore there is a single maternal record for multifetal pregnancies which is problematic for correct linkage to infant records when the infant outcomes differ (e.g. Z37.3 Twins, one liveborn and one stillborn).[17]

For the period 2000 to 2005 the **NSW Perinatal Death Review (PDR) Database** contains information on *stillbirths and neonatal deaths* in NSW of at least 22 weeks gestation or 500 grams birth weight.[20] (Note that in 2006 this changed to births of at least 20 weeks gestation or 400 grams birth weight.) The information is obtained from confidential reviews carried by the NSW Maternal and Perinatal Committee, which is a quality assurance committee appointed by the Minister for Health to review perinatal morbidity and mortality in NSW. Deaths are classified according to the Perinatal Society of Australia and New Zealand Perinatal Mortality Classification.[22]

The **Australian Bureau of Statistics (ABS) Perinatal Death** data includes information on registered *stillbirths and neonatal deaths* registered in NSW. The registration of deaths is the responsibility of the individual state and territory Registrars of Births, Deaths and Marriages (RBDM). As part of the registration process, information about the cause of death is supplied by the medical practitioner certifying the death or by a coroner.[23] Other information about the deceased is supplied by a relative or other person acquainted with the deceased, or by an official of the institution where the death occurred. Importantly, in NSW stillbirths are registered only as a birth, whereas neonatal deaths are registered first as a birth and then as a death.[4] After registration the Registrar General passes the information from the birth and death certificates to the Australian Bureau of Statistics (ABS) where the cause of death is coded according to the International Classification of Diseases.[23] The ABS Perinatal Death dataset is constructed by selecting stillbirths from the NSW RBDM birth registrations and neonatal deaths from the RBDM death registrations.

Records from the four data sets were probabilistically linked by the Centre for Health Record Linkage (CHeReL) using a best practice approach in privacy preserving record linkage.[17] Best practice involves ensuring separation of personal identifiers and health information.[24] The CHeReL only receives personal identifiers from the data custodians to generate a linkage key and the linkage key is returned to the data custodians. Researchers only receive the health information and linkage key from the data custodians.

Potentially if a woman gave birth in hospital and her infant(s) was stillborn, all 4 datasets (PDC-PDR-APDC-ABS) would link to the delivery (referred to as 4-way linkage). However this does not always occur (and cannot for homebirths where the mother does not have a hospital record, or for perinatal deaths of gestations <22 weeks in the study time period). We refer to the other linkage combinations as 3-way and 2-way linkage, while records that do not link to any other data source are referred to as unlinked records. When birth records from different datasets are linked, the birth outcomes (stillbirth or live birth) recorded on different datasets may not agree in some cases. *Discordance* may arise due to a discrepancy on the classification of death (stillbirth versus neonatal death), missing information on a record, errors in reporting or data entry, or incorrect record linkage. In addition, in some instances records which should link do not and these *missed links* result in duplicate records.

Identification of stillbirths

Initially any record potentially indicative of stillbirth in any of the 4 individual datasets was flagged. In the PDC this included baby discharge status of stillbirth, Apgar scores of zero at both 1 and 5 minutes,[25] or where the reason for labour induction was reported as fetal death. PDR and ABS records were flagged as stillbirth if the death record indicated stillbirth. The first 20 diagnostic codes of the mother's record in the APDC dataset were searched for any of the ICD-10-AM codes that indicate the status of the infant(s) (liveborn or stillborn) at birth (including Z37 Outcome of delivery, O31.2 Continuing pregnancy after intrauterine death, O36.4 Maternal care for intrauterine death). However, the outcome of delivery codes are only reported in ~96% of mothers' records and are more likely to go unreported when the pregnancy or birth is complicated.[14,17]

Finally, some stillbirths are associated with pregnancy terminations. Research into stillbirth generally is concerned with spontaneous stillbirth and terminations are excluded from such studies.[25,26] Terminations were identified using the PDR and/or maternal APDC record.

Assessment of unlinked records
Unlinked records may include records that should have linked and did not (missed links). If the number of missed links is large and all such records are included in analyses this has the potential to incorrectly inflate the number of stillbirths.[27] On the other hand, excluding records for which a link could not be identified (missing records rather than missed links) has been shown to underestimate cancer mortality rates.[28] We used the Poisson distribution to estimate the

probability of two independent singleton births occurring by chance on the same day, at the same hospital and/or with the same birthweight, based on the hospital with the largest number of stillbirths.

We then used all available information to compare unlinked stillbirth records from each dataset with each other and with the 2- and 3-way linked records to quantify potential missed links. This was conducted independently by two researchers. Date of birth/death, birthweight, and birth hospital were key matching characteristics for stillbirths. When all three characteristics matched for two unlinked records these were extremely likely to refer to the same stillbirth. If two of the three key variables were available and the same, a match on other non-missing fields (plurality, gestational age and sex) was required in order to categorise a record pair as a probable missed link. Disagreements about potential duplicates were resolved by consensus. Note that the maternal APDC records do not have the baby's date of birth, birthweight, gestational age or sex information that was necessary for comparison. To represent how the datasets would conventionally be analysed, record pairs that were identified as probable missed links were left unlinked in this analysis.

Managing linked records that are discordant on stillbirth status
Linked records were classified as *discordant* where one dataset indicated stillbirth and another livebirth (including neonatal deaths). Consequently, a method needed to be developed to assign stillbirth or livebirth status to linked records that were discordant. This involved iterative review (including 2-way, 3-way and 4-way linked records) to identify patterns and use any additional information (eg Apgar scores, neonatal transfers, multiple gestation) to set up rules for accepting records as a stillbirth or not. The iterative review resulted in an algorithm with a hierarchical approach to the datasets in the event of discordant stillbirth reporting.

Analysis

Associations between maternal/pregnancy characteristics and linked and unlinked records, and discordant and concordant records, were assessed by calculating odds ratios (OR) and 95% CI's.

Crude stillbirth rates were calculated on a yearly basis using the separate datasets and the stillbirth algorithm. The stillbirth 'rate' (or approximation) was calculated as the number of identified stillbirth records, divided by the number of PDC birth records per year. A two-sided Cochran-Armitage test was used to test for any trend in annual rates.

Results
From 2001 to 2005, there were 434,468 PDC records, 424,960 maternal APDC delivery admission records, 3,150 PDR records and 3,262 ABS records. Of the PDC records, 2,672 were reported to be stillbirths and an additional 70 were reported as neonatal deaths but with zero (or missing) Apgar scores. There were 2,120 stillbirths in the PDR, 1,866 in the ABS data and of the maternal APDC delivery admission records 2521 indicated a stillbirth (Table 1). Few records

were missing infant outcome status, although in 3.5% of the ABS records the type of perinatal death (stillbirth or neonatal death) was not specified. Information on the timing of stillbirth (before or during labour) was only available in PDR and ABS but this information was not reported in 20% and 30% of records, respectively.

Using the entire dataset (including all linked and unlinked records), there were 3,102 potential stillbirths including 1,311 from 4-way linkage, 1,154 from 3-way, 397 from 2-way and 240 unlinked records. Only 7 PDC stillbirth records (0.3%) did not link to any record from another dataset.

Review of unlinked records
The hospital with the highest number of singleton stillbirths over 2001-2005 had 198 stillbirths, equating to 40 per year or 0.108 per day. The probability of two independent singleton stillbirths occurring within a three day period at this hospital (the recorded date of birth [DOB] plus or minus one day) is 0.038 (one out of 26). The probability of two stillbirths delivered at the same hospital with matching birthweight is even lower. For example, the probability of two singleton stillbirths with the same 400 g birthweight on the same day is less than one in 100,000. Even if the time window is expanded to a month, the probability of matching birthweights is only 3 per 1000. Based on these probabilities, our cautious assumption was that a PDR or ABS record that matches a PDC record on all but one of hospital, birthweight, DOB, gestational age, plurality and infant sex represents a single unlinked stillbirth, rather than two separate stillbirths.

Compared to the stillbirths with fully linked records, the unlinked ABS and PDR stillbirths were more likely to have birthweights <500 g [37% vs 19%, OR=2.59 (95% CI 1.86-3.59) vs ≥1000 g] but did not have significantly different proportions with birthweights of 500-999 g [22% vs 24%, OR=1.25 (95% CI 0.86-1.80) vs ≥1000 g]. Multifetal gestations are recorded in the PDR and the rate in unlinked PDR stillbirths was similar to that among stillbirths with fully linked records (13% versus 11.4%, P=0.64).

Of 240 unlinked stillbirth records (85 PDR, 148 ABS, 7 PDC), 68 of these PDR (2.2% of all PDR) and 85 of these ABS (2.6% of all ABS) records could be categorised as probable missed links (duplicate records). However, only 2 (13.3%) of the 15 records with 2-way PDR-ABS linkages appeared to be probable missed links to a PDC record. Of note, 4 record pairs which matched on hospital, gestation, sex, birthweight and plurality appeared to have the LMP date (DOB minus gestational age) entered into the DOB field on the PDR. Based on this review, we determined that unlinked PDR and ABS records were more likely to be missed linkages rather than unreported stillbirths. On this basis, we excluded these from further analysis to avoid overestimation of stillbirth rates.

Identification of linked records with discordance on stillbirth status
We next examined the 2869 records where the PDC, or linked dataset(s), indicated that the birth outcome was a stillbirth or where the Apgar scores were zero or missing. Sets of linked records

where there was discordance (one dataset indicating a stillbirth and another a livebirth) on the reporting of stillbirths were identified. There were 218 (7.6%) records indicating a stillbirth in one or more datasets that linked to another dataset where the birth outcome was not specified. These were not categorised as discordant records. Of these, 101 (3.5%) were ABS records on which the type of perinatal death was not specified and 117 (4.1%) were maternal APDC records where infant birth status was not coded, or not specific (i.e. twin pregnancy admission with one twin stillborn and the other liveborn).

Of the 2869 potential stillbirths, 235 (8.2%) were discordant on stillbirth/livebirth status in at least one dataset, ranging from 3.0% discordance among PDC-APDC-PDR 3-way linkages to 24% among PDC-APDC 2-way linkages (Table 2). The discordance rates remained largely unchanged when the analysis was limited to births ≥22 weeks or 500 g. Most stillbirths were antepartum (before labour) (68.9% of PDR records which linked to a PDC record), with only 11.0% reported as intrapartum (during labour) on the PDR and the remainder reported as uncertain or indeterminate. The discordance between datasets on stillbirth/live birth status was lowest (1.6%) for the PDR antepartum deaths whereas the discordance was highest (8.0%) for the intrapartum deaths. The discordance was intermediate (4.8%) for stillbirths where timing of fetal death (before or during labour) was indeterminate.

Development of the algorithm

Review of the 235 linked records categorised as discordant resulted in the development of an algorithm for assigning stillbirth status to these records (Table 3). The primary feature of the algorithm is that the PDC and PDR reporting of stillbirth/livebirth status were accepted over ABS and APDC reports, given that the former data sets rely on information collected by the birth attendant, and have more accurate and complete labour and delivery information than the other sources. Furthermore, the PDC is the major source of other perinatal information (eg maternal and pregnancy characteristics, birth interventions, place of birth) and provides the denominator for all analyses.

There was some discordance around the classification of death (stillbirth versus very early neonatal death). For example, there were 32 PDC records which reported a neonatal death with missing or zero Apgar scores and where the PDR indicated a stillbirth. For 12 PDR records (0.4% of PDR records), we considered that the linkage might be incorrect because the PDC indicated a livebirth with non-zero Apgars, but linked to a PDR record that reported a stillbirth. Incorrect linkages were more frequent with the ABS and APDC records, as a combined 108 of APDC and/or ABS records indicating a stillbirth linked to a PDC livebirth with non-zero Apgar scores. Application of the stillbirth classification algorithm to the 235 discordant records ultimately resulted in 94 (40%) records being classified as stillbirths, 121 (51%) were deemed probable live births and 20 (9%) were PDC records of neonatal death with Apgar scores of zero which were ultimately categorised as concordant with PDR/ABS/APDC neonatal death records. The maternal and pregnancy characteristics of the concordant and discordant stillbirths are presented in Table 4. The stillbirths with discordant records were more likely to be to be those

born before 25 weeks gestation [OR=1.96 (95% CI 1.29-2.99)] compared to stillbirths with concordant records. Associations with plural gestations [OR=1.66 (95% CI 0.94-2.93)] and birthweight <1500 g (OR=1.42 (95% CI 0.90-2.23)] did not reach the level of statistical significance.

Adding the 94 discordant records to the concordant 2634 resulted in a total of 2728 stillbirths. Compared with the algorithm, the PDC on its own had a sensitivity of 97.9% (2672/2728 stillbirths). All stillbirths reported in the PDC also recorded Apgar scores of zero, so there was no basis to recategorise any PDC stillbirths as neonatal deaths. On this basis, the specificity of the PDC for stillbirth is 100% compared with the algorithm. Inclusion of the PDR and APDC records made possible the identification of an additional 56 stillbirths; the further inclusion of ABS perinatal mortality data did not add to the total of stillbirths that could be identified by linkage between the PDC-APDC-PDR but did exclude one potential (discordant) stillbirth record. Linkage of the PDC to other datasets also increased the availability of information about stillbirths. Of the final 2728 stillbirths, 2462 (90.2%) with PDR or ABS linkage had a cause of death available (2033 based on PDR expert review), of whom 724 (29.4%) were coded as unexplained fetal deaths. Similarly, 2415 stillbirths had information recorded on the timing of the stillbirth although for 422 (17.5%) the time of demise was reported as uncertain. The PDR included timing information for 2033 deliveries, the ABS data further contributed timing information on 382 deliveries not covered by the PDR.

Application of the algorithm: trends in stillbirths 2001-2005
Based on the 2728 stillbirths identified by the algorithm, in NSW from 2001-2005, the overall stillbirth rate was 6.3/1,000 births of ≥20 weeks or ≥400g. Excluding 377 (13.8%) records identified as terminations of pregnancy, the rate was 5.4/1,000 births. Of those identified as terminations of pregnancy, 54% were at 20-21 weeks, and 97% were ≤26 weeks gestation.

Figure 1 shows stillbirth rates as identified by individual datasets (solid lines) and by the stillbirth algorithm. The individual ABS and PDR datasets identified substantially fewer stillbirths than either the PDC or the APDC. There was no evidence of an annual trend in the stillbirth rate as identified by the algorithm either overall (P trend=0.96) or excluding terminations (trend P=0.34).

Discussion
The key findings of this review of linkage of stillbirth records in NSW are:
- Single unlinked PDR or ABS records should not be included in stillbirth analyses as they are more likely to be unlinked duplicates of a PDC record than new records, and would result in over-estimation of stillbirth rates.
- Infants with discordant livebirth/stillbirth status in linked records cannot be simply accepted as stillbirths.

- o Discordant linkages included PDR and ABS stillbirths records linked to PDC records of infants with viable Apgar scores who were transferred or discharged home, almost certainly incorrect linkages.
- o Discordance also arose around the classification of death where the PDC indicated a neonatal death with Apgar scores of zero at one and five minutes but a linked PDR and/or ABS record classified the death as a stillbirth
- Linkage slightly improved the ascertainment of stillbirths (by 2%), consistent with previous findings of high stillbirth ascertainment in PDC.[16] Part of the additional ascertainment was PDC neonatal deaths reclassified as stillbirths, and part was inclusion of PDR linked stillbirths. The inclusion of ABS perinatal mortality data did not increase ascertainment beyond that available from PDC-PDR-APDC linkage.
- Linkage resulted in 90% of stillbirth records (74% from the PDR and an additional 16% from ABS) potentially having information on cause and timing of death. However of these, 24% of records reported the time of stillbirth as uncertain.
- In the absence of record linkage to evaluate discordance, PDC records classified as neonatal deaths but with Apgar scores of 0/0 can be accepted as stillbirths.
- Unlinked records and linked records with discordance on stillbirth status were more likely to be at or below the edge of viability (<25 weeks and birthweight <500 g) and/or where the death occurred intrapartum or was of uncertain timing.
- Multifetal pregnancies were not over-represented in unlinked records (consistent with separate linkage processes for twins and higher order multiples)[17,18] but there was a tendency to over-representation in the discordant records. This finding supports future separation of analyses for stillbirths among singleton and multifetal pregnancies.[17]

Although stillbirths constitute the majority of perinatal deaths, they have a lower visibility than neonatal deaths.[5,7] This arises because of the way stillbirths are counted. Currently in NSW, stillbirths are registered with the Registry of Births, Deaths and Marriages (RBDM) as a birth, but not a death, so they are not recorded in mortality statistics.[29] Along similar lines, stillbirths are recorded as a maternal outcome in hospital data, there is no infant hospital admission.[17] Stillbirths are under-ascertained in maternal hospital records and birth outcome is less likely to be coded when the mother's hospitalisation is complicated and/or prolonged.[14,17,18]

Registered (ABS) or reported (PDR) stillbirths that cannot be linked to a birth record may be reflective of linkage obstacles, rather than representing stillbirths that were not reported in the birth records. The smaller "footprint" of records for stillbirths compared to livebirths[17,29] means that the available linkages are reduced and they may also be more subject to failure than for neonatal deaths. Furthermore, parental, family, sociocultural and other factors may influence a decision about recording a livebirth as opposed to a stillbirth.[11,27,30,31] In a few cases, deaths were categorised as neonatal deaths in the PDC and as stillbirths in the PDR or ABS, but with PDC Apgar scores of zero and no record of an attempt at resuscitation. Our algorithm

reclassified 41 of 61 (67%) of such PDC linked neonatal deaths as stillbirths. For these few instances, the PDR/ABS stillbirth categorisation was deemed to better represent the timing of the deaths, at least for purposes of research into antecedent conditions of perinatal death. Decision-making around both resuscitation and registration may vary within and across institutions and countries but are rarely made explicit.[30,31]

The PDC is a reliable data source for enumerating stillbirths,[16] and linkage to hospital discharge records and death registrations added relatively little to ascertainment. However, if a causal or predictive study of stillbirth is contemplated, both the maternal antepartum and intrapartum conditions and the cause or timing of fetal death can provide vital information.[7,8,32] The PDC has no information on the cause and timing of stillbirth, and limited information on antenatal and intrapartum conditions,[20] so linkage with the APDC and PDR becomes essential for detailed analyses. Linkage of the PDC to the PDR and APDC is timely with annual updates.[21] However, the last available year of ABS Perinatal Mortality for NSW was 2005.[21] The unavailability of ABS data for later years should not affect the stillbirth ascertainment rate but may reduce the number of records that have a cause and timing of stillbirth. On the other hand, the proportion of stillbirths that are reviewed by the NSW Maternal and Perinatal Committee and had a PDR record has increased from 93% in 2001 to 97% in 2009 although those where the timing of death was recorded as uncertain did not change (~20%).[20]

The Centre for Health Record Linkage routinely assesses the quality of the linkage it undertakes.[21] For this project, their assessment was 0.3% false positive (incorrect) links and <0.5% false negative (missed) links for the linkage of all births for mother and babies. Examining only stillbirth records we cautiously estimate the rate of incorrect and missed PDR to PDC links among stillbirth records at 0.4% and 2.2% respectively, but with higher rates for ABS and maternal APDC linkages. Although the application of our stillbirth algorithm aims to overcome these errors, stillbirth studies may benefit from specialist linkages as is currently undertaken for twins and higher order multiple pregnancies.

Strengths of the study include the consistent application of the Perinatal Society of Australia and New Zealand Perinatal Mortality Classification - a single, well-recognised classification for coding of the cause of death.[7,11] Exclusion of unlinked (and probable duplicate) records and an algorithm for managing discordant records reduces the impact of both missed links and incorrect links. False positive links or use of duplicate (missed link) stillbirths could potentially inflate the number and rate of stillbirths,[27] especially if they occurred disproportionately in high-risk population subgroups such as rural and remote communities, and older[26,33,34] mothers. From 2001 to 2005 the PDR review criteria were more restrictive than the PDC, although from 2006 the inclusion criteria conform to those used for the PDC (all births ≥20 weeks or ≥400 g). This change is likely to increase the number of records with full linkage and the proportion of linked records with information on the cause and timing of the fetal death.

In conclusion this work demonstrates that the use of linked perinatal data in NSW for stillbirth research (PDC-PDR-APDC) can largely overcome the five broad areas cited as obstacles to the study of reproductive loss,[11] namely incomplete ascertainment; incorrect or inconsistent classification of the timing of death; incorrect assignment of the cause(s) of death; systematic bias due to missing information among high risk populations; and changes over time in schemes used to code the cause of death. High quality population-level stillbirth research is achievable in NSW. Examining the impact of trends in maternal and pregnancy risk factors on trends in stillbirth rates is a first priority.

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Table 1: Infant outcome status by dataset (all records)

Variable		PDC N=434,468 n (%)	APDC 424,960 n (%)	PDR N=3,150* n (%)	ABS N=3,262 n (%)
Discharge status	Livebirth	†431,653 (99.4)	418,983 (98.6)	1030 (32.7)	1281 (39.3)
	Stillbirth	2,672 (0.6)	2,521 (0.6)	2120 (67.3)	1866 (57.2)
	PND unspecified				115 (3.5)
	Missing/unknown	78 (0.0)	3,456 (0.8)		
Time of stillbirth	Before labour	NA	NA	1471 (69.4)	1026 (55.0)
	During labour	NA	NA	234 (11.0)	272 (14.6)
	Uncertain	NA	NA	415 (19.6)	568 (30.4)

* ≥22 weeks gestation or ≥500 grams birthweight
† includes neonatal deaths with Apgar scores of zero
PND = perinatal death

Table 2: Number of potential stillbirths by linkage type and rate of *discordance* on stillbirth status among 2869 linked records where at least one record indicated a stillbirth.

Linkage type	Datasets*	Any Stillbirth† N	Discordant on stillbirth status‡ N (row %)
4-way	PDC-APDC-PDR-ABS	1311	42 (3.2)
3-way	PDC-APDC-PDR	630	19 (3.0)
	PDC-APDC-ABS	455	83 (18.2)
	PDC-PDR-ABS	69	8 (11.6)
2-way	PDC-APDC	326	78 (23.9)
	PDC-PDR	22	1 (4.5)
	PDC-ABS	34	2 (5.9)
	PDR-ABS	15	2 (13.3)
1-way	PDC	7	─
Total		2869	235 (8.2)

* There were no stillbirths with only APDC-PDR-ABS, APDC-PDR, or APDC-ABS because the only way a maternal APDC record can link is through the PDC
† At least one dataset indicates a stillbirth (or Apgar scores of zero); excludes 148 unlinked ABS and 85 unlinked PDR records
‡ Two or more datasets discordant on stillbirth/live birth status

Table 3: Algorithm for classifying 2864 records where at least one data source reports a stillbirth.

Hierarchies referred to in each step	Description	Classification	
		Stillbirth N	**Live birth N**
No discordant stillbirth reports	a. 4-way linkage	1269	
	b. 3-way linkage	1044	
	c. 2-way linkage	314	
	d. unlinked PDC	7	
		2634	
PDC and PDR agree on stillbirth status*	PDC and PDR indicate a stillbirth but APDC or ABS indicate live birth.	14	
PDC and PDR disagree on stillbirth status	PDC indicates neonatal death but with Apgar scores of 0 or missing and PDR indicates a stillbirth	32	
	PDC indicates day zero neonatal death (nonzero Apgars) and PDR indicates stillbirth, in addition APDC and/or ABS indicate a stillbirth	1	
	PDC indicates day zero neonatal death (nonzero Apgars) and PDR indicates stillbirth, but both APDC and ABS indicate a live birth		5†
	PDC indicates stillbirth and Apgar scores are zero, PDR indicates neonatal death	11	
	PDC indicates neonatal transfer or discharge home, but PDR indicates stillbirth		7†
No PDR record.	PDC indicates neonatal death but with an Apgar score missing or zero, APDC or ABS indicate stillbirth	9	
	PDC indicates a stillbirth, APDC and /or ABS records are either stillbirth, neonatal death or missing	26	
	PDC indicates neonatal death with Apgar scores of zero, APDC and/or ABS indicate livebirth (concordant livebirths)		20‡
	PDC indicates neonatal death (with nonzero Apgar) but APDC or ABS record indicates stillbirth		26†
	PDC indicates a neonatal transfer or discharge home, but APDC or ABS indicate stillbirth		82†
No PDC record.	PDR indicates neonatal death, but ABS indicates stillbirth.		1
	PDR indicates stillbirth but ABS indicates neonatal death	1	
Sub-total of classification of linked records with discordant stillbirth status		94	141
Total		2728	141

* There were no instances where the PDC and PDR indicate a neonatal death but APDC or ABS indicate stillbirth.

† Probable incorrect linkages of PDC to PDR, or PDC to APDC and/or ABS

‡ These 20 records proved not to be discordant. *A priori* PDC records with zero Apgar scores were included as potential stillbirths as it could not be known what APDC, PDR or ABS birth outcome record they would match to.

Table 4: Pregnancy characteristics of stillbirths with concordant and discordant reporting in linked records

Pregnancy Characteristics	Concordant stillbirths	Discordant stillbirth records	
		Classified as stillbirths	Classified as live births
	n (%) N=2634	n (%) N=94	n (%) N=121†
Maternal age *mean (s.d.)*	30.2 (6.1)	31.3 (6.6)	29.7 (5.6)
Nulliparous	1224 (46.7)	48 (51.6)	52 (43.3)
Australian-born	1868 (71.3)	71 (76.3)	93 (77.5)
Singleton	2349 (89.2)	78 (83.0)	93 (76.9)
Multiple	272 (10.3)	15 (16.0)	27 (22.3)
Missing	13 (0.5)	1 (1.1)	1 (0.8)
Gestational age (weeks)			
<22	515 (19.6)	24 (25.5)	22 (18.2)
22-24	529 (20.1)	28 (29.8)	7 (5.8)
25-36	976 (37.1)	17 (18.1)	17 (14.0)
≥37	600 (22.8)	23 (24.5)	74 (61.2)
Missing	14 (0.5)	2 (2.1)	1 (0.8)
Birth weight (grams)			
<500	785 (29.8)	34 (36.2)	26 (21.5)
500-1499	744 (28.3)	30 (31.9)	7 (5.8)
1500-2499	391 (14.8)	5 (5.3)	12 (9.9)
2500-3999	522 (19.8)	21 (22.3)	59 (48.8)
≥4000	48 (1.8)	2 (2.1)	16 (13.2)
Missing	144 (5.5)	2 (2.1)	1 (0.8)
Place of birth			
Perinatal Centre	1053 (40.0)	29 (30.2)	30 (24.8)
Public hospital	1175 (44.6)	46 (47.9)	70 (55.6)
Private hospital	353 (13.4)	17 (17.7)	18 (14.9)
Outside of hospital	53 (2.0)	4 (4.2)	3 (2.5)
Linkage			
4-way	1269 (48.2)	36 (38.3)	6 (5.0)
3-way	1044 (39.6)	44 (46.8)	51 (42.1)
2-way	314 (11.9)	14 (14.9)	64 (52.9)
unlinked PDC	7 (0.3)		

† excludes 20 concordant livebirths/neonatal deaths from Table 3

Figure 1: Stillbirth rates by year for each dataset.