





ORIGINAL ARTICLE

Significant kidney disease in pregnancy: Feasibility and outcomes of a national population-based study using the Australasian Maternity Outcomes Surveillance System

Shilpanjali Jesudason^{1,2}  , Nadom Safi³ , Zhuoyang Li⁴, Mark Brown⁵, William Hague² , Angela Makris^{6,7}, Stephen McDonald^{1,8}, Michael J. Peek⁹ and Elizabeth Sullivan⁴

¹Pregnancy and Kidney Research Australia, Central Northern Adelaide Renal and Transplantation Service, Royal Adelaide Hospital and Faculty of Health and Medical Sciences, The University of Adelaide, Adelaide, South Australia, Australia

²Robinson Research Institute, The University of Adelaide, Adelaide, South Australia, Australia

³School of Medicine and Public Health, Central Coast Clinical School, The University of Newcastle, Gosford, New South Wales, Australia

⁴College of Health, Medicine and Wellbeing, University of Newcastle, Newcastle, New South Wales, Australia

⁵Department Renal Medicine and Medicine, St. George Hospital and University of New South Wales, Sydney, New South Wales, Australia

⁶Department of Renal Medicine, Liverpool Hospital, Sydney, New South Wales, Australia

⁷Faculty of Medicine, University of New South Wales, Sydney, New South Wales, Australia

⁸ANZDATA Registry, South Australia Health and Medical Research Institute, Adelaide, South Australia, Australia

⁹Nepean Clinical School, College of Medicine and Health, The University of Sydney, Sydney, New South Wales, Australia

Correspondence: Prof Shilpanjali Jesudason, Central Northern Adelaide Renal and Transplantation Service, Royal Adelaide Hospital, Adelaide, SA, Australia. Email: shilpa.jesudason@sa.gov.au

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Background: Current understanding of clinical practice and care for maternal kidney disease in pregnancy in Australia is hampered by limitations in available renal-specific datasets.

Aims: To capture the epidemiology, management, and outcomes of women with significant kidney disease in pregnancy and demonstrate feasibility of a national cohort study approach.

Materials and Methods: An Australian prospective study (2017–2018) using a new kidney disease-specific survey within the Australasian Maternity Outcomes Surveillance System (AMOSS). Women who gave birth with acute kidney injury (AKI), advanced chronic kidney disease (CKD), dialysis dependence or a kidney transplant were included. Demographic data, renal and obstetric management, and perinatal outcomes were collected.

Results: Among 58 case notifications from 12 hospitals in five states, we included 23 cases with kidney transplant ($n = 12$), pre-existing CKD ($n = 8$), newly diagnosed CKD ($n = 2$) and dialysis ($n = 1$). No cases of AKI were reported. Reporting rates were better in states with study investigators and, overall, cases were likely under-reported. Nearly 35% of women had a non-delivery-related antenatal admission. Nephrology involvement was 78.3% during pregnancy and 91% post-partum. Adverse events were increased, including pre-eclampsia (21.7%), and preterm birth (60.9%). Women had high rates of aspirin (82.6%) and antihypertensive (73.9%) use, indwelling catheter for labour/delivery (65.2%), caesarean delivery (60.9%), and blood transfusion (21.7%).

Conclusions: This first-ever Australian prospective study of significant kidney diseases in pregnancy provided novel insights into renal-specific clinical patterns and practices. However, under-reporting was likely. Future studies need to overcome the challenges of case identification and data collection burden.

KEYWORDS

acute kidney injury, chronic kidney disease, kidney failure, obstetric, pregnancy

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INTRODUCTION

Chronic kidney disease (CKD) affects one in ten adult Australians, with one in three adults at risk.¹ Pregnancy is a significant period of kidney ‘stress’, which unmasks or worsens underlying CKD. Advanced CKD may be identified preconception, be diagnosed in pregnancy, progress during pregnancy, or necessitate commencement of dialysis.^{2,3} In Australian women receiving chronic maintenance dialysis or kidney transplants to treat CKD, live birth rates have improved, although increased adverse pregnancy outcomes persist.^{4–6} Acute kidney injury (AKI) is a major event, often requiring dialysis support or earlier birth.^{7,8} Both maternal AKI and CKD increase adverse pregnancy outcomes, particularly pre-eclampsia and preterm birth.^{3,9} Women with kidney disease face complex decisions about undertaking pregnancy.^{9,10} Understanding factors determining clinical outcomes and defining existing models of care for these women is critical for decision-making and enhancing pregnancy care.^{11,12} Strategies to improve outcomes, in Australia and globally, are a research priority.¹³

Current Australian data on kidney disease in pregnancy are hampered by data deficits. Kidney function is not routinely measured in pregnancy, despite potential value¹⁴ and rising maternal comorbidity with CKD risk factors: hypertension, diabetes and obesity.^{1,15} Diagnostic coding in perinatal datasets suggests that kidney disorders affect 0.3% of pregnancies,¹⁶ likely underestimated as laboratory data on kidney function are not captured. Approximately 17% (*n* = 1700) of women with a kidney transplant or receiving dialysis are aged 15–45 years, with 20–30 pregnancies/year reported to the national registry.⁵ Under-reporting may reach 25%, and clinical data capture is minimal.

While registries and perinatal data sets can be informative, particularly when linked,^{4,5,17} they have limitations. CKD and AKI in pregnancy may be better studied via purpose-built, kidney-specific, multi-centre cohort studies to capture detailed clinical predictors for risk profiling and understanding pregnancy outcomes.¹⁸ However, there may be barriers to implementing such studies; bespoke data systems need development and testing.

We therefore conducted a prospective national study via the Australasian Maternity Outcomes Surveillance System (AMOSS) to identify cases of significant maternal kidney disease in pregnancy in Australia, exploring incidence, management and pregnancy outcomes in this high-risk cohort. We aimed to advance current Australian obstetric nephrology data infrastructure, implementing a new survey instrument focused on kidney conditions.

MATERIALS AND METHODS

This study is reported using the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.¹⁹ The study protocol was previously published.²⁰

Study design

A national, prospective study was conducted from August 2017 to August 2018 using AMOSS, which ran from 2009 to 2021 to provide a mechanism to systematically study rare disorders in pregnancy.²¹ AMOSS studies have included eclampsia,²² rheumatic heart disease^{23,24} and gestational breast cancer,²⁵ with AMOSS data collectors in Australia and New Zealand maternity hospitals with >50 births/year. For this study, AMOSS covered 260 Australian hospitals: data were reported from 12 hospitals. From past studies, we estimated capturing at least 80 cases.²⁰

Ethics requirements

Ethics approval was obtained for all sites by AMOSS as previously described.^{20,26} Individual patient consent was not required.

Case definition

Inclusion criteria are shown in Table 1; development of these criteria are described in the protocol.²⁰ Cases were identified among women giving birth at >20 weeks gestation or >400 g birthweight (if gestational age unknown) in AMOSS hospitals from August 2017 to August 2018. Serum creatinine was used to define kidney function in pregnancy.

Case identification

Cases were prospectively identified by AMOSS data collectors or reported by clinicians. Data collectors in participating sites received written information about the study, a video explaining the study on the AMOSS website, flyers for maternity clinics and monthly reminders to report the presence/absence of a case. The study was advertised to nephrologists in the national nephrology society newsletter. Investigator SJ presented the study at multiple nephrology

TABLE 1 Study inclusion criteria²⁰

- All women in Australia who gave birth:
- a between 1 August 2017 and 31 July 2018; AND

b at least 20 weeks gestation and/or at least 400 g birth weight; AND

c who present with at least one of the following criteria:

1. having a working kidney transplant (all women regardless of kidney transplant function)

2. receiving any long-term dialysis before conception and continuing any dialysis during pregnancy

3. starting any dialysis during pregnancy (any dialysis – either once-off, temporary or permanent dialysis)

4. Having known preconception estimated glomerular filtration rate <45 mL/min/1.73 m² (known to have a serum creatinine >130–150 μmol/L before conception, regardless of the serum creatinine reading during pregnancy)

5. Having newly identified renal function impairment with any serum creatinine reading of >150 μmol/L on two readings at least 24 h apart during pregnancy.

meetings. The top contributing AMOSS hospitals with renal services were identified, with targeted communication by SJ to lead nephrologists to ensure awareness of processes for referring patients.

Data collection and logic validation

AMOSS data collectors captured data post-birth using a web-based system. A general AMOSS survey and a renal-specific survey, AMOSS surveillance, data collection and validation workflow have previously been described.²⁰ Some data items were common to all AMOSS studies; however, the renal-specific survey was created specifically for this study, with some data items aligning with the ANZDATA registry.

Incidence and outcome measures

The primary aim was to report the incidence of maternal kidney conditions in the AMOSS cohort. Secondary outcomes included perinatal, maternal obstetric/renal outcomes, management and model of care.

Data analysis

Descriptive methods were used to report case demographic and clinical data. Case reviews were undertaken to map individual patient progress/model of care. All statistical analyses were performed using SPSS 28.0 software (IBM Corporation).

RESULTS

Case reporting

From 58 case notifications, 23 cases were included (Figure S1), substantially below the expected minimum case number of 80.²⁰ Cases were drawn from 12 hospitals in five states: South Australia ($n = 8$ cases: Flinders Medical Centre, Women's and Children's Hospital, Lyell McEwin Hospital); New South Wales ($n = 5$: Royal North Shore Hospital, Dubbo Base Hospital, Liverpool Hospital, St George Hospital); Queensland ($n = 4$: Townsville Hospital, Mater Mothers' Hospital, Brisbane); Victoria ($n = 3$: The Royal Women's Hospital, Monash Medical Centre); Western Australia ($n = 3$: King Edward Memorial Hospital for Women). No cases were reported from Northern Territory, Tasmania or the Australian Capital Territory.

Maternal demographics

Maternal demographic data are shown in Table S1. Most women were Australian-born, Caucasian, of normal body mass index, non-smoking and aged 25–39 years. Ten women (43.5%) had pre-existing hypertension. A quarter of women were nulliparous; of multiparous women, 61% had a previous caesarean section.

Maternal kidney disease

Women with kidney transplants constituted 52.2% of the cases, including one also dialysed during pregnancy (Table 2). Only one woman receiving chronic dialysis was reported. Two women had kidney disease newly diagnosed in the index pregnancy. The remainder were women with known advanced CKD preconception. No cases of AKI were reported.

The causes of kidney disease reflected that in the non-pregnant population for this age group: predominantly glomerular disease, reflux nephropathy or diabetic nephropathy. In addition, events during the index pregnancy causing kidney dysfunction were captured, most commonly pre-eclampsia and blood loss. Antihypertensive and immunosuppression medication use in pregnancy was common (Table S2).

Of two women with newly diagnosed CKD, kidney function data were provided for one case (serum creatinine 172 $\mu\text{mol/L}$ in the second trimester, 201 $\mu\text{mol/L}$ in the third trimester, 136 $\mu\text{mol/L}$ at birth and 152 $\mu\text{mol/L}$ at discharge). The other case was likely CKD presenting as severe pre-eclampsia with HELLP syndrome (haemolysis, elevated liver enzymes and low platelets) and anuric kidney failure; however, laboratory data were incomplete.

Maternal kidney transplantation

Twelve women had a functioning kidney transplant at conception. In 11 women, pregnancy occurred after their first transplant. One woman had a kidney-pancreas transplant. No women had a transplant biopsy in the 12 months preceding pregnancy.

The mean preconception serum creatinine was 123 $\mu\text{mol/L}$; the mean estimated glomerular filtration rate was 57 mL/min/m^2 (Table 2). Transplanted women had better kidney function (CKD Stages 1–2) compared to the other women in the cohort (by definition, CKD Stages 3B–5 or dialysis). One woman commenced dialysis during the pregnancy due to biopsy-proven transplant rejection and failure. Three women had rejection during pregnancy; only one underwent biopsy. Rejection was treated by increasing existing immunosuppression ($n = 3$) and methylprednisolone ($n = 1$).

Antenatal models of care and health service use

Most women had their first antenatal visit by 19 weeks with only two late presentations (Table 3). Nephrologists were involved in nearly 70% of cases preconception; all remained involved during pregnancy care. Most women were managed in a high-risk public maternity service. Over a third of women had a non-delivery-related antenatal hospital admission, usually by the early third trimester. Two women were transferred to another hospital to access renal services, none were transferred for neonatal or maternal intensive care.

TABLE 2 Maternal kidney disease characteristics

	N = 23	%
Renal history prior to pregnancy		
Functioning kidney transplant	12	52.2
Preconception eGFR (mean ± SD) [†]	57.5 ± 22.7	
Preconception serum creatinine, μmol/L (mean ± SD) [‡]	123.5 ± 49.1	
Chronic maintenance dialysis preconception	1	4.3
Known preconception kidney disease	21	91.3
Known preconception chronic kidney disease Stage 3B-5 (non-dialysis or non-transplant)	8	34.8
Preconception eGFR (mean ± SD) [§]	34.6 ± 18.0	
Preconception serum creatinine, μmol/L (mean ± SD) [¶]	199.3 ± 46.5	
Kidney impairment diagnosed for the first time during this pregnancy ^{††}	2	8.7
Kidney biopsy during this pregnancy ^{††}	1	4.3
Pre-existing kidney disease – cause ^{§§}		
Glomerulonephritis	6	26.1
Reflux nephropathy	4	17.4
Polycystic kidney disease	1	4.3
Congenital renal disease	1	4.3
Diabetic nephropathy	6	26.1
Hypertension	7	30.4
Interstitial nephritis	1	4.3
Pregnancy complications contributing to a kidney event		
Pre-eclampsia	4	17.4
Placental abruption	1	4.3
Haemolytic uraemic syndrome	1	4.3
Cortical necrosis	1	4.3
Antepartum haemorrhage	1	4.3
Postpartum haemorrhage	2	8.7
Poor fluid intake causing dehydration	1	4.3
Nephrotoxic drugs	1	4.3

[†]Missing data n = 2.[‡]Missing data n = 1.[§]Missing data n = 3, preconception serum creatinine within six months prior to estimated date of conception.[¶]Missing data n = 1.^{††}Based on clinician diagnosis.^{§§}Missing data n = 5.^{§§}Women may have more than one cause of kidney disease. eGFR, estimated glomerular filtration rate.

Maternal and obstetric outcomes and management

The main medical complication was hypertension, more common in non-transplanted women (Table 4). Pre-eclampsia was reported in 21.7%. Over half of the cases received antihypertensive therapy

TABLE 3 Antenatal models of care

	N = 23	%
Gestational age at first antenatal visit (weeks)		
First trimester <14 weeks	13	56.5
Second trimester	10	43.5
Nephrology involvement		
Renal physician involvement prior to pregnancy	16	69.6
Renal physician involvement during pregnancy	18	78.3
Lead maternity carer at booking		
Public hospital maternity care	2	8.7
High-risk public hospital maternity care	18	78.3
General practitioner	2	8.7
Private obstetrician	1	4.3
Lead maternity carer at birth		
Public hospital maternity care	3	13.0
High-risk public hospital maternity care	19	82.6
Private obstetrician	1	4.3
Antenatal hospital admission (other than for delivery)	8	34.8
Gestational age in weeks at first admission, median (range)	29 (18–35)	
Site of care for the kidney condition		
Renal unit	15	65.2
Obstetric unit	11	47.8
Transferred to another hospital [†]	2	8.7

[†]Both cases were transferred to access renal services.

during pregnancy; 74% received antihypertensive therapy at any stage (Table S3). Aspirin use was common (83%). Antibiotics, heparin and anaemia therapy (erythropoietin and/or iron) were used in 25–35%.

Almost all labouring women had labour induced. The caesarean section rate was 62% overall and higher in transplanted women. No category one caesarean sections²⁷ were reported; the majority were category three or four, indicating low maternal or fetal risk.

Birth and postpartum monitoring, outcomes and complications are shown in Table 4. Blood pressure monitoring during labour/delivery was nearly universal. Over 73% of women had urine output monitored, 65% with an indwelling catheter placed. Cardiotocography monitoring was highly utilised, more commonly in non-transplanted women. Other major complications, including oliguria, hyperkalaemia, blood transfusion and severe hypertension, were uncommonly reported. There were no maternal deaths.

Post-discharge clinical follow-up was with nephrology in 91.3%. However, 43% also had follow-up in a high-risk obstetric clinic. General practitioners (87%) or other providers (21.7%) were also engaged in follow-up care.

TABLE 4 Pregnancy and birth outcomes in women with kidney disease in pregnancy

	Transplant <i>N</i> (%)	Chronic kidney disease <i>N</i> (%) [†]	Total <i>N</i> (%)
Total number	12 (100.0)	11 (100.0)	23 (100.0)
Pre-eclampsia	2 (16.7)	3 (27.3)	5 (21.7)
Pre-eclampsia features			
Hypertension, $\geq 140/90$ mmHg	1 (50.0)	3 (100.0)	4 (80.0)
Proteinuria, urine protein creatinine ratio > 30 mg/mmol	0 (0.0)	3 (100.0)	3 (60.0)
Low platelets ($<100,000 \times 10^9/L$)	0 (0.0)	1 (33.3)	1 (20)
High uric acid	1 (50.0)	2 (66.7)	3 (60.0)
Renal impairment	1 (50.0)	2 (66.7)	3 (60.0)
Liver function derangement	0 (0.0)	1 (33.3)	1 (20.0)
Headache	1 (50.0)	1 (33.3)	2 (40.0)
Upper abdominal or right upper quadrant pain	1 (50.0)	1 (33.3)	2 (40.0)
Vomiting	1 (50.0)	0 (0.0)	1 (20.0)
New-onset proteinuria in this pregnancy	1 (8.3)	3 (27.3)	4 (17.4)
Hypertension during this pregnancy	5 (41.7)	7 (77.8)	12 (57.1)
Gestational diabetes	2 (16.7)	0 (0)	2 (9.5)
Gestational hypertension	0 (0.0)	1 (9.1)	1 (4.3)
Threatened premature labour	1 (8.3)	2 (18.2)	3 (13.0)
Chorioamnionitis	0 (0.0)	1 (9.1)	1 (4.3)
Antepartum haemorrhage	0 (0.0)	1 (9.1)	1 (4.3)
Urinary tract infection during this pregnancy	0 (0.0)	3 (27.3)	3 (13)
Asymptomatic bacteriuria	1 (8.3)	0 (0)	1 (4.3)
Labour and delivery			
Labour	5 (41.7)	5 (45.5)	10 (43.5)
Spontaneous membrane rupture [‡]	2 (40.0)	1 (20.0)	3 (30.0)
Induction of labour [‡]	4 (80.0)	5 (100.0)	9 (90.0)
Augmentation of labour [‡]	0 (0.0)	3 (60.0)	3 (30.0)
Birth by caesarean section	8 (66.7)	6 (54.5)	14 (60.9)
Urgency of caesarean section [§]			
Category 1 ²⁷	0 (0.0)	0 (0.0)	0 (0.0)
Category 2	0 (0.0)	2 (33.3)	2 (14.3)
Category 3	4 (50.0)	2 (33.3)	6 (42.9)
Category 4	2 (25.0)	1 (16.7)	3 (21.4)
Not stated	2 (25.0)	0 (0.0)	2 (14.3)
Monitoring during delivery			
Blood pressure monitoring	10 (83.3)	10 (90.9)	20 (87.0)
Urine output monitoring	7 (58.3)	10 (90.9)	17 (73.9)
Indwelling bladder catheter during labour/postpartum	7 (58.3)	8 (72.7)	15 (65.2)
Arterial line	1 (8.3)	1 (9.1)	2 (8.7)
Cardiac monitoring	4 (33.3)	3 (27.3)	7 (30.4)
Cardiotocography	4 (33.3)	8 (72.7)	12 (52.2)
Complications at birth or postpartum			
Oliguria	0 (0.0)	3 (27.3)	3 (13.0)
Hypertension	0 (0.0)	5 (45.5)	5 (21.7)
High potassium	0 (0.0)	1 (9.1)	1 (4.3)
Transfusion	1 (8.3)	4 (36.4)	5 (21.7)

[†]Include only preconception kidney disease.[‡]Denominator – women who had labour.[§]Denominator – women who had caesarean section.

Perinatal outcomes

Detailed perinatal outcomes are reported in Table S3. There were 23 births with two perinatal deaths (one stillbirth and one neonatal death). There was a high rate of preterm birth, low birthweight, need for infant resuscitation and respiratory support, and admission to neonatal intensive care. Major infant complications were generally related to prematurity (Table S3 footnote). Most babies were discharged directly home.

DISCUSSION

This is the first nationwide study exploring significant maternal kidney disease in Australia. We established, tested the feasibility and defined limitations of a centralised reporting approach for a complex medical condition in pregnancy, eg kidney disease. Our findings support efforts to establish obstetric nephrology data systems across Australia to understand current practice trends and drivers of clinical outcome.

Our case series confirmed the well-known maternal case-mix, pregnancy complexities, and high rates of adverse outcomes in pregnant women with kidney disease.^{2,3} We also captured novel data on models of care, pregnancy management practices, medication use, hospitalisations, renal-specific outcomes, and complications. We have revealed previously unavailable insights into current clinical practices and health care utilisation. For example, we found that nephrology input was provided in only 70% of cases, indicating potential barriers to specialised care. Alternatively, it may reflect the presence of obstetric physicians within high-risk pregnancy services, although this was not specifically captured. Nearly 35% of women had a non-birth-related antenatal hospital admission. We observed that, despite the risk of acute decline in kidney function, urine output monitoring during labour and birth occurred in the majority but was not universal. Given postpartum oliguria in transplant recipients is an emergency due to potential ureteric transplant injury, it was reassuring that best-practice recommendations for urine output monitoring¹³ were followed in the majority of cases. However, over 50% underwent bladder catheterisation, not essential for urine output monitoring, and which may unnecessarily introduce infection risk,²⁸ highlighting an area for clinical practice improvement. We reassuringly observed a high uptake of aspirin therapy for pre-eclampsia risk reduction, often poorly implemented in real-world studies. We have also reported detailed patterns of drug use in pregnancy, particularly high usage of drugs for hypertension and renal anaemia management. Overall, these examples underscore why data collections tailored for specific conditions have enormous potential value to evaluate specialised clinical care and outcomes.

Although this study leveraged a well-established surveillance system purposefully designed for systemic capture of rare pregnancy conditions,²¹ the primary outcome of incidence of

significant maternal kidney events within Australian AMOSS hospitals was not determined due to lower-than-expected reporting rates for each kidney disease category. Over 12 months, only 12 of 260 such hospitals reported cases, mostly tertiary care centres. We excluded 40% of notifications for duplication or not meeting inclusion criteria. Of the final 23 cases, most were women with kidney transplants and advanced CKD; only one case had chronic dialysis preconception, with no cases of AKI in pregnancy. This likely underrepresents the true national caseload, estimated *a priori* at a minimum of 80 cases based on local and international data for CKD, dialysis, transplant and AKI in pregnancy.^{2,3,5,8,16,20,28} No cases were reported from Tasmania, the Australian Capital Territory, and Northern Territory; absence of any cases is unlikely over a 12-month period. Few cases were reported from high-population states (Queensland, Victoria, and Western Australia). Limited resources prevented study extension or additional strategies to support case ascertainment.

Lower-than-expected reporting highlights barriers to establishing effective surveillance for pregnancy-related kidney disease across jurisdictions. The study was extensively promoted within the AMOSS and nephrology networks to maximise exposure, but it is evident cases were still missed. However, most cases originated from South Australia and New South Wales, where the investigators were based. All tertiary obstetric hospitals in South Australia reported cases due to direct engagement by lead investigator SJ. Conversely, some high-risk pregnancy centres with nephrology services did not report any cases, despite an expectation of some cases over 12 months. It is likely that other cases occurred in Australia but were managed by clinicians who did not connect with AMOSS coordinators or report the cases, either through lack of awareness, time or resources. This emphasises the importance of having a local clinical champion in actively seeking cases, particularly for specialised medical conditions.^{21,24} AMOSS has now closed, but additional resources to augment awareness of future research studies and research systems such as prospective databases and registries could include exposure in educational sessions, departmental meetings and other communications. For example, at the ANZDATA registry, a program of educational videos and advertising of the parenthood dataset via newsletters and at scientific meetings has been rolled out to improve reporting.

Reflecting the complexity of defining kidney disease, we observed higher reporting rates for easily 'labelled' conditions, such as pre-existing CKD and transplant recipients. Conversely, new kidney impairment during pregnancy, including significant AKI, poses challenges for recognition.⁸ The transient nature of AKI, with difficulties in interpretation of laboratory results, may lead to under-recognition. Diagnosis of kidney disease sometimes occurs postpartum and is therefore missed. Our data show that some women did not have nephrology services involved in their pregnancy care, despite known kidney disease; access to nephrology input may be variable and limited in some regions, which may hamper diagnosis. Additionally, routine testing of kidney function

in the first trimester is not performed in most countries, including Australia, despite calls for its implementation.¹⁴ Collectively, these factors contribute to under-recognition of kidney disease in pregnancy.

Case ascertainment and data quality pose challenges for future data infrastructure on pregnancy and kidney disease.¹⁸ There is usually a trade-off between data depth and collection burden.²⁹ In this study, the expanded data scope with intricate renal-specific data likely affected completeness. The AMOSS study on rheumatic heart disease in pregnancy required an extensive network of clinical and organisational stakeholders and significant resources over two years for case identification, including embedding prompts in antenatal booking records and interrogating health information systems.²⁴ This level of effort was not possible for this study, nor sustainable in real-world practice. Similar challenges exist in the ANZDATA renal registry parenthood data, where introducing more complex data elements have reduced data completeness.²⁹ Finally, there is the burden associated with having multiple disease-specific data collections for the Australian maternity cohort. This would not be sustainable and would likely worsen under-reporting. This reflects the need for system-wide solutions that leverage appropriate resources and technologies to support high-quality data collection across a range of conditions.

We have leveraged the renal-specific data survey from this study to enhance data systems for obstetric nephrology research in Australia. Some elements were adopted into the ANZDATA registry parenthood dataset in 2018.²⁹ The survey was adapted for an ongoing state-wide cohort study of CKD in pregnancy in South Australia.³⁰ Future strategies must transition this data capture into electronic medical records (EMRs) to enable automated data capture and streamlined data extraction.¹⁸ This is already embedded in the state-wide EMR in SA. Ultimately, collaborations between expert centres in Australia to create a nationally aligned, standardised minimum dataset will facilitate pooled analyses with greater case numbers and power.

In conclusion, this first-ever national prospective study of significant kidney diseases in pregnancy in Australia, we observed likely under-reporting to AMOSS. Understanding kidney conditions in pregnancy necessitates diverse data sources: local data collection integrated into EMR, state-level perinatal data collections, national clinical renal registries. Improving data infrastructure will enable definition of disease-specific and maternal risk factors, track trends and practice patterns over time, and advanced care for pregnant women with kidney diseases.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Table S1. Maternal demographic characteristics.

Table S2. Medication use in women with kidney disease in pregnancy.

Table S3. Perinatal outcomes for babies born to women with significant kidney disease in pregnancy.

Figure S1. Case notification and inclusion.