

ANZ
DATA



AUSTRALIA &
NEW ZEALAND
DIALYSIS & TRANSPLANT
REGISTRY

ANZDATA SPECIAL REPORT

Parenthood Survey 2022

Summarising the findings from the
annual ANZDATA parenthood survey
data collection in December 2022

CONTENTS

Introduction	3
Purpose of the Parenthood Survey	3
Methods	4
Descriptive Data - Parenthood Events in Women Receiving KRT	5
Descriptive Data - Parenthood Events in Men Receiving KRT	8
Conclusions	10
Additional Resources	10

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With special thanks to the parenthood working group members for their invaluable contributions and support.

[BACK TO CONTENTS](#)

INTRODUCTION

This is the third of the ANZDATA “Special reports” series. These reports aim to complement existing output (such as the Annual Report) and provide an opportunity to release material that is of relevance to contributors but does not fit readily within an annual reporting structure, or suitable for publication in a peer-reviewed research journal. These reports are prepared and reviewed internally. We hope to allow publication of material that is of interest and relevance outside of the existing formats.

This report provides summary information about key parenthood survey responses, to inform contributing units in Australia and New Zealand and others about parenthood outcomes in women and men receiving kidney replacement therapy (KRT; chronic dialysis or kidney transplantation) for kidney failure. Further substantial work is underway in this area with the newly established ANZDATA parenthood working group and links to additional resources are provided at the end of this report.

We encourage all units to report parenthood events. If you need help with completing the ANZDATA parenthood data collection please contact anzdata@anzdata.org.au.

PURPOSE OF THE PARENTHOOD SURVEY

Pregnancies in women receiving KRT are relatively uncommon¹ but remain an important goal for women². These pregnancies are complex and remain at high-risk of adverse outcomes such as early pregnancy loss, pre-eclampsia, hypertension, prematurity and low birthweight, affecting both the mother and the baby^{3,4,5,6,7,8,9}.

Men receiving KRT are subject to impaired fertility, although this is largely restored post-transplantation¹⁰. The long-term use of immunosuppressive medications may have an impact on sperm production and the potential fetotoxic effects of these medications are a key concern for individuals’ post-transplantation¹¹.

The parenthood data collection within the ANZDATA registry has laid the foundation for our understanding of parenthood in women³⁻⁹ and men¹¹ with kidney failure in Australia, substantially informing evidence-based clinical practice. This report provides the latest findings of this data collection informing data contributors, clinicians, and patients on what to expect in these pregnancies.

1. (Hewawasam, et al., 2021)
2. (Jesudason, et al., 2020)
3. (Hewawasam, et al., 2020)
4. (Tang, et al., 2020)
5. (Wylid, Clayton, Kennedy, Alexander, & Chadban, 2015)
6. (Jesudason, Grace, & McDonald, 2014)
7. (Shahir, Briggs, Katsoulis, & Levidiotis, 2013)
8. (Wylid, Clayton, Jesudason, Chadban, & Alexander, 2013)
9. (Levidiotis, Chang, & McDonald, 2009)
10. (Mallett, et al., 2014)
11. (Jesudason, et al., 2020)
12. (Danner, et al., 2023)

METHODS

ANZDATA has collected parenthood data since 1968, with over 2500 events reported thus far. Parenthood outcome data is collected for women who have conceived while receiving KRT, or have commenced dialysis during their pregnancy. Initially, data collection was limited to pregnancy outcome (live or still birth, spontaneous abortion or surgical termination), date of fetal birth or loss, and gestational age. A specific parenthood survey was introduced in 2001 to formalise this data collection, and capture information on estimated date of conception, date of outcomes, pregnancy outcome, medical complications during pregnancy (i.e., pre-eclampsia or gestational diabetes), fetal outcome, neonatal survival, graft outcome (creatinine prior to conception and 3 months post-partum) and birthweight. In 2017, the survey was further expanded to enhance the depth of data on gestational age, congenital abnormalities, fetal gender, renal function at delivery, immunosuppression at conception, labour and delivery, medical complications including diabetes, hypertension, and pre-eclampsia as well as specific data on transplant and dialysis treatments in pregnancy.

In addition to maternal parenthood events, data is collected for men who have a parenthood event while receiving KRT. Prior to 2017, this was limited to estimated date of conception, date of outcomes, pregnancy outcome, fetal outcome, neonatal survival, and birthweight. Since 2018, ANZDATA also collects gestational age, congenital abnormalities, fetal gender, renal function at conception and immunosuppression at conception.

A national consumer advisory group helped shape what data should be presented in this report, based on their priorities.

ANZDATA parenthood dataset was recently validated against the births captured in mandated state-based perinatal datasets, and evaluated for data completeness over time¹¹². The findings suggest that it is a robust dataset for its parenthood-related data.

1. (Hewawasam, et al., 2021)
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9. (Levidiotis, Chang, & McDonald, 2009)
10. (Mallett, et al., 2014)
11. (Jesudason, et al., 2020)
12. (Danner, et al., 2023)

DESCRIPTIVE DATA

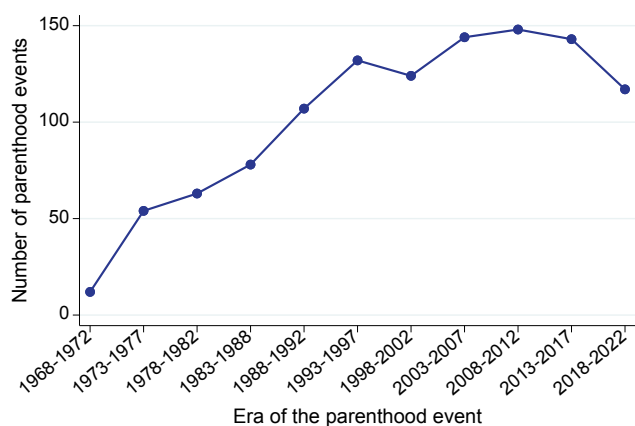
PARENTHOOD EVENTS IN WOMEN RECEIVING KRT

In this report, basic descriptive data are presented for key survey items.

Total number of parenthood events in women reported to ANZDATA during 1968-2022

In general, maternal parenthood events have shown a consistent increase over the years. However, there is a decline in the number of parenthood events observed since 2018. This is possibly due to a reduction or delay in reporting rather than a decrease in actual events. This has led to a series of initiatives within ANZDATA to raise awareness.

Figure 1
Total number of parenthood events in women reported to ANZDATA during 1968-2022



Total number of parenthood events for women by treatment modality at parenthood event during 2018-2022

The vast majority of women receiving KRT had a parenthood event with a kidney transplant (Table 1). Pregnancy whilst receiving haemodialysis is a much rarer event. No pregnancies were reported for women receiving peritoneal dialysis since 2020.

Table 1
Total number of events parenthood events for women by treatment modality at parenthood event during 2020-2022, n (%)

Treatment	2020	2021	2022	Total
Haemodialysis	4 (14.29)	10 (33.33)	0 (0.00)	14 (17.72)
Kidney transplantation	24 (85.71)	20 (66.67)	21 (100.00)	65 (82.28)
Total	28 (35.44)	30 (37.97)	21 (26.58)	79 (100.00)

Maternal characteristics

Women who had a parenthood event during 2020-2022 had a median age of 32 years at the time of conception (Table 2).

Table 2
Maternal age at conception, 2020-2022, median (IQR)

Treatment	n	Age, years
Haemodialysis	14	32 (30-37)
Kidney transplantation	65	33 (29-36)
Total	79	32 (29-36)

Conception type

Since 2020, the majority of women receiving haemodialysis and women with a kidney transplant conceived naturally (Table 3).

Table 3
Parenthood events for women by conception type in each parenthood event during 2020-2022, n (%)

Treatment	Haemodialysis	Kidney transplantation	Total
IVF	1 (7.69)	4 (7.02)	5 (7.14)
Natural	12 (92.31)	51 (89.47)	63 (90.00)
Unknown	0 (0.0)	2 (3.51)	2 (2.86)
Total	13 (18.57)	57 (81.43)	70 (100.00)

Pre-eclampsia

Fifty percent of transplanted women had pre-eclampsia, compared to approximately 18% of women receiving haemodialysis (Table 4).

Table 4
Incidence of pre-eclampsia by modality during 2020-2022, n (%)

Delivery type	Haemodialysis	Kidney transplantation	Total
Pre-eclampsia	2 (18.18)	26 (50.00)	28 (44.44)
No pre-eclampsia	9 (81.82)	26 (50.00)	35 (55.56)
Total	11 (17.46)	52 (82.54)	63 (100.00)

Pregnancies ≥ 20 weeks' gestation were included

Delivery type

Approximately 75% of transplanted delivered via a caesarean, with over a third being elective (Table 5). Similarly, over 50% of dialysed women delivered via a caesarean, with nearly half of these being elective.

Table 5
Delivery types by modality during 2020-2022, n (%)

Delivery type	Haemodialysis	Kidney transplantation	Total
Vaginal	6 (46.15)	13 (25.49)	19 (29.69)
Elective caesarean	3 (23.08)	18 (35.29)	21 (32.81)
Emergency caesarean	4 (30.77)	20 (39.22)	24 (37.50)
Total	13 (20.31)	51 (79.69)	64 (100.00)

Spontaneous abortions (<20 weeks' gestation) and pregnancy terminations were excluded

Fetal outcomes for babies born to mothers receiving KRT

During 2020-2022, 93% of babies of women receiving haemodialysis and 86% of babies of women with a kidney transplant had a live birth outcome (Table 6). Babies of women receiving haemodialysis had a median gestation of 33.5 weeks and a median birthweight of 2500g, while babies of women with a kidney transplant were delivered at a median of 35 weeks with a median birthweight of 2360g (Table 7). The majority of the babies born to women receiving haemodialysis or with a kidney transplant were born preterm (<37 weeks' gestation).

Table 6
Birth outcome, 2020-2022, n (%)

Treatment	Haemodialysis	Kidney transplantation	Total
Live birth	14 (93.33)	61 (85.92)	75 (87.21)
Spontaneous abortion	0 (0.00)	6 (8.45)	6 (6.98)
Surgical termination	1 (6.67)	4 (5.63)	5 (5.81)
Total	15 (17.44)	71 (82.56)	86 (100.0)

Table 7
Gestational age and birthweight, live born babies, 2020-2022, median (IQR)

Treatment	n	Gestational age (weeks)	n	Birthweight (grams)
Haemodialysis	14	33.5 (30.2-35)	11	2500 (1560-2676)
Kidney transplantation	61	35 (32-37)	57	2360 (1810-2913)
Total	75	35 (31-37)	68	2383 (1590-2868)

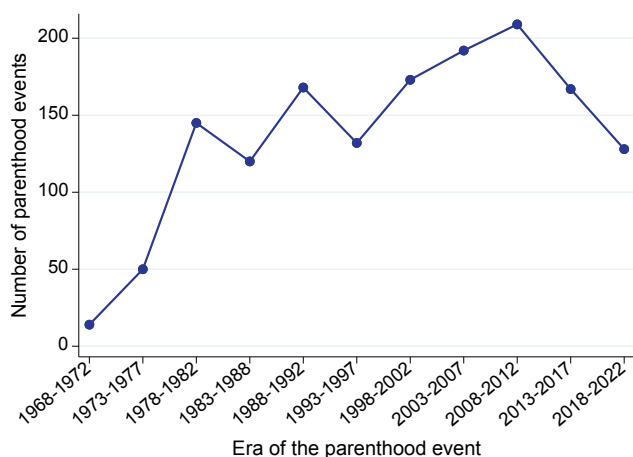
DESCRIPTIVE DATA

PARENTHOOD EVENTS IN MEN RECEIVING KRT

Total number of parenthood events for men reported to ANZDATA during 1968-2022

Overall, paternal parenthood events have demonstrated an upward trend over the years. However, there is a notable decreased in the number of parenthood events observed since 2013. This is possibly attributed to a reduction or delay in reporting rather than a decrease in actual events.

Figure 2
Total number of parenthood events for men reported to ANZDATA during 1968-2022



Total number of parenthood events for men by treatment modality at conception

The vast majority of men receiving KRT had a parenthood event with a kidney transplant (Table 8). Parenthood whilst receiving haemodialysis is a much rarer event. Very few parenthood events were reported for men receiving peritoneal dialysis since 2020.

Table 8
Total number of parenthood events for men by treatment modality at conception, 2020-2022, n (%)

Treatment	2020	2021	2022	Total
Haemodialysis	6 (23.08)	3 (11.54)	3 (15.00)	12 (16.67)
Peritoneal dialysis	1 (3.85)	1 (3.85)	2 (10.00)	4 (5.56)
Kidney transplantation	19 (73.08)	22 (84.62)	15 (75.00)	56 (77.78)
Total	26 (36.11)	26 (36.11)	20 (27.78)	72 (100.00)

Paternal characteristics

Men who had a parenthood event during 2020-2022 had a median age of 34 years at the time of conception (Table 9).

Table 9
Paternal age at conception, 2020-2022, median (IQR)

Treatment	n	Age (years)
Haemodialysis	11	32 (30-39)
Peritoneal dialysis	3	36 (33-45)
Kidney transplantation	54	34.5 (29-39)
Total	68	34 (29-39)

Conception type

Since 2020, approximately 70% of men receiving haemodialysis and men with a kidney transplant reported a natural conception (Table 10).

Table 10
Conception type in each parenthood event, 2020-2022, n (%)

Treatment	Haemodialysis	Peritoneal dialysis	Kidney transplantation	Total
IVF	1 (10.00)	0 (0.00)	7 (13.46)	8 (12.12)
Natural	7 (70.00)	1 (25.00)	36 (69.23)	44 (66.67)
Unknown	2 (20.00)	3 (75.00)	9 (17.31)	14 (21.21)
Total	10 (15.15)	4 (6.06)	52 (78.79)	66 (100.00)

Fetal outcomes for babies born to fathers receiving KRT

During 2020-2022, all babies fathered by men receiving KRT reported a live birth outcome (Table 11). Babies of these men were born at term with a normal birthweight (Table 12).

Table 11
Birth outcome, 2020-2022, n (%)

Treatment	Haemodialysis	Peritoneal dialysis	Kidney transplantation	Total
Live birth	12 (100.00)	4 (100.00)	56 (100.00)	72 (100.00)
Total	12 (100.00)	4 (100.00)	56 (100.00)	72 (100.00)

Table 12
Gestational age and birthweight, 2020-2022, median (IQR)

Treatment	n	Gestational age (weeks)	n	Birthweight (grams)
Haemodialysis	11	38.5 (38-40)	8	3177.5 (2785-3700)
Peritoneal dialysis	3	39 (38.5-40)	4	3387.5 (3082.5-3670)
Kidney transplantation	54	39 (38-40)	50	3370.5 (2878-3620)
Total	68	39 (38-40)	62	3342.5 (2878-3620)

For live born babies

CONCLUSIONS

In recent years, there has been a decrease in reported parenthood events to ANZDATA, potentially influenced by factors such as lack of awareness and reduced reporting to ANZDATA. While live birth outcomes were >87% for women on KRT, their babies remain at a higher risk due to prematurity and low birthweight. Conversely, babies of men on KRT demonstrated excellent fetal outcomes within normal parameters. Continuous collection of parenthood data in this cohort is crucial for evidence-based pre-pregnancy planning and counselling.

ADDITIONAL RESOURCES

Websites and video resources:

https://www.anzdata.org.au/anzdata/research/registry-projects/#uagb-tabs__tab8

<https://www.pkra.com.au/>

<https://kidney.org.au/your-kidneys/living-with-kidney-disease/health-and-wellbeing/pregnancy>

<https://www.anzdata.org.au/anzdata/about/working-groups/parenthood-working-group/>

Previous publications using the ANZDATA parenthood dataset

<https://www.pkra.com.au/publications-2022>

<https://www.anzdata.org.au/anzdata/publications/scientific-articles/>

ADDITIONAL RESOURCES



Access to form - ONLINE entry simpler and preferred



ANZDATA Parenthood Outcome Form



Why?

ANZDATA holds one of the largest datasets on parenthood with kidney failure & can help guide counselling, decision-making, and further research*



Who?

Data from both **FEMALE & MALE** patients who are receiving chronic dialysis (>90 days) or with a kidney transplant



What?

- Pregnancy and fetal outcomes
- Labour and delivery
- Kidney function and treatment details



How?

- Simple **ELECTRONIC FORM** with guiding prompts accessed via ANZDATA website (preferred) OR
- Paper-based form (PH-Parenthood Survey)#



When?

- Suggest commencing data entry when patient is first pregnant/known to father pregnancy AND
- Complete form after pregnancy ends

Prepared by **ANZDATA Parenthood Working Group**
For more information or questions, contact anzdata@anzdata.org.au

*Link to publications via: https://www.anzdata.org.au/anzdata/research/registry-projects/#uagb-tabs_tab8

#Link to paper form via: <https://www.anzdata.org.au/wp-content/uploads/2021/02/ParenthoodOutcomeForm.pdf>



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