

# Patient and Partner Perspectives of Pregnancy-Related Counseling and Information Needs in Women With Kidney Disease: An Australian National Survey



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**Introduction:** The experiences and information needs for reproductive health counseling in women with chronic kidney disease (CKD) are poorly defined, despite the known importance of pregnancy planning in this higher-risk cohort.

**Methods:** Australian adult women with CKD and their partners or family members completed a consumer codesigned survey about experiences of and preferences for pregnancy-related counseling, support, and education. Data were analyzed descriptively and with qualitative content analysis of free-text responses.

**Results:** Responses were received from 102 women (CKD,  $n = 60$ ; dialysis,  $n = 11$ ; transplant,  $n = 26$ ; unsure,  $n = 5$ ) and 17 partners/family members. Pregnancy-related discussions were initiated mostly by women themselves (60.0%) compared to nephrologists (26.7%), and only after conception in 14.7%. Women found pregnancy-related discussions satisfactory (68.0%) and useful (50.7%) but also stressful (66.7%), with only 54.7% feeling in control of decision-making. Information deficits and quality, preformed decisions, clinician-patient disconnect, and burden of decision-making contributed to usefulness and outcomes of pregnancy-related counseling. Women received insufficient information about contraception (not provided in 35.2% of cases), medication safety (40.9%), fetal complications (33.8%) and emotional and psychological impact of pregnancy (73.2%). Women preferred counseling from nephrologists (86.4%), face-to-face settings (79.6%), websites (72.7%), handouts (61.4%), and online support groups (46.6%). High-quality, multiformat information by content experts, peer support, and psychological support were also strongly desired.

**Conclusion:** This study highlights that preconception counseling and information needs of women with CKD are currently not being met. Frameworks and tools to assist patients and clinicians, particularly nephrologists, to initiate and conduct sensitive, useful, and informed shared decision-making (SDM) about pregnancy are urgently needed.

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**KEYWORDS:** counseling; dialysis; kidney disease; preconception; pregnancy; transplant

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Women with CKD of all stages and treatment modalities are at increased risk of adverse maternal and fetal outcomes,<sup>1,2</sup> including preeclampsia, low birth weight, and prematurity.<sup>3,4</sup> In recent times, there has been a shift away from counseling against pregnancy, toward supporting reproductive autonomy through SDM, with better understanding of how women perceive pregnancy risk.<sup>5,6</sup> Previous studies have revealed that

women with CKD face substantial decisional burden when balancing desire for pregnancy with concerns regarding risks to maternal, renal, and fetal health.<sup>6-8</sup> Navigating a safe pathway to pregnancy can be challenging for women with CKD. Preconception counseling should respect patient preferences and values, sensitively inform women of potential risks of pregnancy without catastrophizing and disengaging women, with provision of emotional and medical support. However, evidence-based guidance on best-practice, useful and effective pregnancy-related discussions in CKD is lacking,<sup>8</sup> along with supporting tools and resources to guide both women and clinicians. This gap compounds the known lack of confidence nephrologist have regarding fertility, contraception, and pregnancy-related discussions and management<sup>9</sup>; as well as the challenges nephrologists have identified in delivering equitable care to women with CKD.<sup>10</sup> The perspectives and experiences of women with CKD regarding pregnancy-related discussions should be incorporated in clinical care models for better, patient-centered SDM about pregnancy.<sup>11</sup>

This study, codesigned with consumers, aimed to investigate the experiences of women with CKD and their partners or family regarding current pregnancy-related counseling and education, and elicit preferences for future support and information.

## METHODS

### Study Design

The study was codeveloped with the Parenthood in Kidney Disease Consumer (patients with lived experiences of kidney disease) Advisory Group of the Australian and New Zealand Dialysis and Transplant Registry, now known as Pregnancy and Kidney Research Australia (authors JB, CG, CM, LH, AT, SM, and AW). The term 'consumers' is used to describe patients with lived experiences of kidney disease.

This was a cross-sectional questionnaire-based study in relation to the perspectives of Australian women with CKD and their partners or family, which was conducted from December 2020 to April 2021. We included women >18 years of age with CKD, receiving long-term dialysis treatment, or kidney transplant recipients who consented to complete an English-language online open survey. CKD was self-reported by the selection of appropriate category as follows: "CKD but far away from needing dialysis or transplant," "getting prepared for dialysis and transplant but haven't had it yet," "receiving dialysis," "have received a kidney transplant," or "unsure." Women without CKD were excluded. Hardcopy and electronic flyers ([Supplementary Material 1](#)) with online links and QR codes to the survey were widely and repeatedly

promoted directly to the public via social media and patient organizations. The study was sent to nephrologists and obstetric medicine physicians via direct email and professional groups, with a request that clinicians share the flyer with patients. Women who participated could then invite their partners or family members to complete a separate survey.

The online survey was conducted via SurveyMonkey ([www.surveymonkey.com](http://www.surveymonkey.com)) ([Supplementary Material 2](#)). The survey instrument was designed to minimize bias in responses. Where appropriate, we used Likert Scales and closed questions with precoded responses and categories to facilitate rapid survey completion and analysis. Open-ended free-text questions were also elicited where broader feedback and suggestions were required. Consumers assisted with prioritizing domains of inquiry and the phrasing of questions for clarity and ease of understanding by patients, testing the survey for usability and technical functionality.

Questions were focused on 4 main domains as follows: (i) demographic data, kidney disease, and comorbidities; (ii) experiences of pregnancy-related discussions; (iii) preferences for pregnancy-related counseling and education/information; and (iv) overall participant satisfaction and feedback. All women undergoing the survey were asked questions about information and counseling preferences. The survey used adaptive questioning, for instance, an additional set of questions about past experiences of counseling were revealed if women had previously received pregnancy-related discussions. The partners or family members survey provided the following data: (i) demographic data and relationship to the woman with kidney disease, (ii) attendance and satisfaction with information provided at pregnancy-related discussions, and (iii) preferences for pregnancy-related counseling and education/information.

Only a few questions were mandatory, and participants were able to review and change their answers before submission. Multiple entries from the same IP address were not allowed for the duration of the survey period.

### Ethical Considerations

Ethical approval was obtained from the Central Adelaide Local Health Network Human Research Ethics Committee, Adelaide, South Australia (CALHN: 13683). Participants first accessed the survey and were asked to provide electronic consent before the survey could commence. Participants were informed on the welcome page that the survey evaluated perspectives of pregnancy counseling in women with CKD, that it would take approximately 15 to 20 minutes to complete, that all responses were confidential and anonymous, and that reporting would be on an aggregate level only.

Consent was indicated when respondents ticked the 'Agree' tick box. Participation in the study was voluntary and no incentives were offered.

### Data Protection

No personal information was linked to survey results in any way. The fully deidentified data set is kept on password protected computers to ensure data protection.

### Data Analysis and Reporting

Statistical analysis was performed with Stata software version 16.0 (StataCorp, College Station, TX). The categorical data was presented as count and proportions. Student's *t*-tests or chi-square tests were used to compare subgroups. Logistic regression was used to determine the association between demographical, biological, and environmental factors with women's experiences of pregnancy-related discussions and information needs. Cases with missing data on each item were excluded from that analysis; and for each question, denominators or missing data were outlined in the table footnotes or figure legends. A *P*-value of <0.05 was considered statistically significant. The Checklist for Reporting Results of Internet E-Surveys (CHERRIES) was followed (Supplementary Material 3).<sup>12</sup>

Qualitative content analysis of 4 free-text question responses (shown in Table 3) was performed. A systematic process was employed to review free-text data and process into preliminary codes using subjective interpretation of the content, as per previously published methodology.<sup>13</sup> Inductive content analysis was undertaken by authors AO and SJ, whereby coded responses were categorized into themes, forming subcategories and overarching categories. Discrepancies were resolved

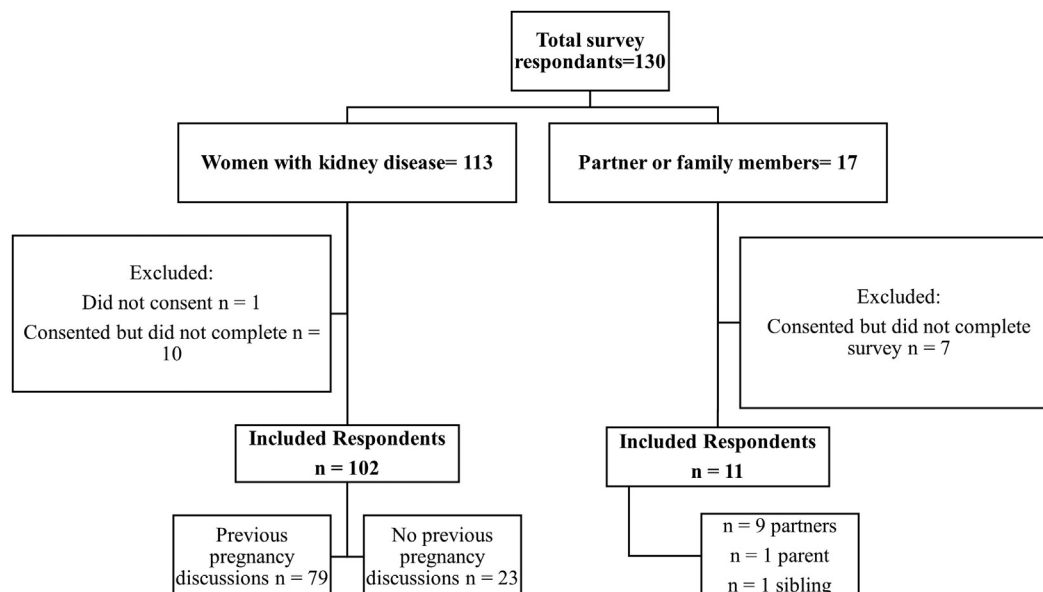
through discussion until consensus. Three separate data reviews were undertaken between investigators to develop the final categories and subcategories.

## RESULTS

### Study Cohort

The survey was accessed by 113 women (102 completions) and 17 partners/family members (11 completions) (Figure 1). Complete participant characteristics are shown in Table 1. Respondents had CKD ( $n = 60$ , 58.8%), were receiving dialysis ( $n = 11$ , 10.8%) or a kidney transplant ( $n = 26$ , 25.5%). The highest (41.2%) age range was 25 to 34 years; and most women were from an English-speaking background (78.4%), had a university degree or higher (58.8%), lived with spouse/partner (84.3%), were from a metropolitan area (60.8%), and from high-medium socioeconomic background (77.9%). Over 85% of respondents were from 4 of 7 Australian states/territories (South Australia, New South Wales, Queensland, and Victoria). Most respondents had a past pregnancy with kidney disease (56.9%), 5.9% were currently planning a pregnancy, or 12.8% were currently pregnant. Only 21.6% were currently not considering pregnancy.

Overall, 25.5% of respondents reported that they had sufficient knowledge about pregnancy with kidney disease, 49.0% had moderate understanding, and 25.5% had insufficient knowledge or would like to know more. Of those who said they had insufficient knowledge or would like to know more, a large proportion (54.5%) were currently not considering pregnancy, 22.2% were currently planning a pregnancy or trying to conceive, and 16.9% have had a past pregnancy or were currently pregnant.



**Figure 1.** Flowchart of survey participants.

**Table 1.** Participant demographics

Characteristics	CKD <sup>a</sup> n = 60	Dialysis <sup>a</sup> n = 11	Transplant <sup>a</sup> n = 26	Total <sup>a</sup> N = 102
	n (%)			
<b>Maternal age category, yrs</b>				
18–24	2 (3.3)	1 (9.1)	2 (7.7)	5 (4.9)
25–34	26 (43.3)	5 (45.4)	9 (34.6)	42 (41.2)
35–45	24 (40.0)	3 (27.3)	8 (30.8)	37 (36.3)
>45	8 (13.3)	2 (18.2)	7 (26.9)	18 (17.7)
<b>Spoken a language other than English</b>				
	13 (21.7)	1 (9.1)	5 (19.2)	22 (21.6)
<b>Highest education</b>				
University degree	40 (66.7)	4 (36.4)	14 (53.9)	60 (58.8)
Trade/Apprenticeship/Certificate/Diploma	15 (25.0)	4 (36.4)	9 (34.6)	29 (28.4)
High school or less	5 (8.3)	3 (27.3)	3 (11.5)	13 (12.8)
<b>Household</b>				
Living with spouse/partner	53 (88.3)	7 (63.6)	23 (88.5)	86 (84.3)
Living with other family/another person	6 (10.0)	3 (27.3)	3 (11.5)	12 (11.8)
Living alone	1 (1.7)	1 (9.1)	0 (0.0)	4 (3.9)
<b>Geographical location</b>				
Metropolitan	41 (68.3)	7 (63.6)	10 (38.5)	62 (60.8)
Regional location	19 (31.7)	4 (36.4)	16 (61.5)	40 (39.2)
<b>Socioeconomic status<sup>b</sup></b>				
High	13 (23.2)	3 (27.3)	4 (16.7)	46 (48.4)
Medium	15 (26.8)	2 (18.2)	9 (37.5)	28 (29.5)
Low	28 (50.0)	6 (54.5)	11 (45.8)	21 (22.1)
<b>Comorbidities</b>				
High blood pressure	35 (58.3)	7 (63.6)	14 (53.8)	58 (56.9)
Heart disease or other	5 (8.3)	2 (18.2)	5 (19.2)	12 (11.8)
Diabetes	1 (1.7)	2 (18.2)	1 (3.8)	4 (3.9)
None	22 (36.7)	1 (9.1)	7 (26.9)	30 (29.4)
<b>Primary kidney disease</b>				
Glomerulonephritis, Lupus Nephritis and IgA Nephropathy	16 (26.7)	3 (27.3)	10 (38.5)	33 (32.3)
Polycystic kidney disease (PKD)	27 (45.0)	0 (0.0)	0 (0.0)	27 (26.5)
Genetic (non-PKD)	3 (5.0)	1 (9.1)	6 (23.1)	10 (9.8)
Reflux nephropathy	2 (3.3)	2 (18.2)	3 (11.5)	7 (6.9)
Other <sup>c</sup>	6 (10.0)	3 (27.3)	4 (15.4)	13 (12.7)
Unsure	6 (10.0)	2 (18.2)	3 (11.5)	12 (11.8)
<b>Stage of kidney disease</b>				
CKD but far away from needing dialysis or transplant	50 (49.0)	-	-	50 (49.0)
Getting prepared for dialysis or transplant but haven't had it yet	10 (9.8)	-	-	10 (9.8)
Unsure	-	-	-	5 (4.9)
<b>Stage of pregnancy journey</b>				
Currently planning a pregnancy	4 (6.7)	0 (0.0)	1 (3.8)	6 (5.9)
Currently trying to conceive (including IVF)	1 (1.7)	1 (9.1)	1 (3.8)	3 (2.9)
Currently pregnant	9 (15.0)	1 (9.1)	2 (7.7)	13 (12.8)
Had a pregnancy with kidney disease in the past	38 (63.3)	4 (36.4)	15 (57.7)	58 (56.9)
Not planning for pregnancy now, but might in the future	6 (10.0)	4 (36.4)	5 (19.2)	15 (14.7)
Not considering pregnancy at all	2 (3.3)	1 (9.1)	2 (7.7)	7 (6.9)

ACT, Australian Capital Territory; CKD, chronic kidney disease; IVF, in vitro fertilization; NSW, New South Wales; NT, Northern Territory; QLD, Queensland; SA, South Australia; Tas, Tasmania; VIC, Victoria; WA, Western Australia.

<sup>a</sup>Five women who responded "unsure" to kidney disease stage were excluded from the CKD, dialysis and transplant sub-columns, but were included in the Total column.

<sup>b</sup>Data missing for n = 7 participants; Socioeconomic status calculated based on postcode: Low, 1-3 Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) decile; medium, 4-7 IRSAD decile; and high, 8-10 IRSAD decile.

<sup>c</sup>Other includes: 5 diabetes; 4 medication related; 1 Focal segmental glomerulosclerosis; 1 Good pastures syndrome; 1 Hemolytic uremic syndrome; 1 Neurogenic bladder; 1 Pelvic urethra junction blockage; 1 Solo kidney; 1 Bilateral duplex ureters.

## Past Experiences and Outcomes of Pregnancy-Related Counseling

Seventy-nine participants had previous pregnancy-related counseling and completed the survey questions related to their past experiences (Table 2).

## Initiation and Timing of Pregnancy-Related Discussions

Most women had 1 to 5 sessions where pregnancy-related discussions occurred. Women were usually the first to initiate discussions about pregnancy (60.0%), with only 26.7% reporting nephrologists raised the topic.

**Table 2.** Experiences of women who received pregnancy-related counseling in the past

Variable	Total N = 79 n (%)
Timing of the first pregnancy discussion with health care providers <sup>a</sup>	
Wanted to start a family	26 (34.7)
First diagnosed with kidney disease	22 (29.3)
Already pregnant	11 (14.7)
Got married/had a long-term partner	5 (6.7)
Started dialysis	3 (4.0)
Had a kidney transplant	3 (4.0)
Other	5 (6.7)
Individual who first brought up the pregnancy discussion <sup>a</sup>	
Patient	45 (60.0)
Nephrologist	20 (26.7)
Primary care physician	4 (5.3)
Partner	2 (2.7)
Other	3 (4.0)
Unsure/hasn't been brought up yet	1 (1.3)
Satisfaction with pregnancy discussions <sup>a</sup>	
Very satisfied	22 (29.3)
Satisfied	29 (38.7)
Not satisfied or dissatisfied	18 (24.0)
Dissatisfied	5 (6.7)
Very dissatisfied	1 (1.3)
Satisfaction with information received during pregnancy discussions <sup>a</sup>	
Very satisfied	17 (22.7)
Satisfied	30 (40.0)
Not satisfied or dissatisfied	20 (26.7)
Dissatisfied	8 (10.7)
Information or discussion about pregnancy helped in decision-making <sup>a</sup>	
Yes	38 (50.7)
No	15 (20.0)
Neutral	22 (29.3)
In control of decision-making during pregnancy <sup>a</sup>	
Yes	41 (54.7)
No	17 (22.7)
Neutral	17 (22.7)
Pregnancy discussions stressful (emotionally/psychologically) <sup>a</sup>	
Yes	50 (66.7)
No	25 (33.3)
Sources used to get information about pregnancy <sup>b</sup>	
Nephrologist	63 (88.7)
Internet	47 (66.2)
Obstetrician	43 (60.6)
Primary care physician	38 (53.5)
Online forums/blogs	26 (36.6)
Friends and family	25 (35.2)
Nursing staff	14 (19.7)
Other patients	12 (16.9)
Genetic counselor	4 (5.6)
Other <sup>c</sup>	7 (9.9)

<sup>a</sup>Data missing, n = 4<sup>b</sup>Data missing, n = 8<sup>c</sup>Others included written literature, Facebook groups, fertility specialists, midwife, psychiatrist, and rheumatologist.

The timing of pregnancy-related discussions most frequently occurred when women wanted to start a family (34.7%), and less frequently at CKD diagnosis.

Notably, 14.7% of discussions occurred for the first time only after women were pregnant.

Within free-text responses (Table 3), the timeliness of counseling was frequently raised as an important issue affecting patient experience. The lack of useful and timely information was identified as a source of stress and suggested area for improvement. Respondents sought information given proactively, to establish preparedness during the prepregnancy, pregnancy and postnatal stages—"pregnancy information needs to be provided much earlier in the diagnosis, especially about risks to transplant" (respondent 53).

### Patient Experiences of Pregnancy-Related Counseling

Most respondents (84.3%) reported being very comfortable or comfortable talking about pregnancy whereas (68.0%) felt satisfied or very satisfied with their experience during pregnancy-related discussions (Table 2). A smaller proportion (50.7%) reported that the information provided was helpful in their decision-making. Only 54.7% felt in control of decision-making, whereas 66.7% found discussions emotionally and psychologically stressful.

Lower education, lower socioeconomic status, older maternal age, and kidney failure requiring kidney replacement therapy were not significantly associated with satisfaction, outcomes, or distress from pregnancy-related discussions (Supplementary Table S1).

Free-text responses exploring these findings further revealed a clear theme of 'clinician-patient disconnect' contributing to the distress of pregnancy-related counseling, with clinicians failing to understand patient priorities or providing choices (Table 3). Women indicated a need to frame discussions with a knowledge and understanding of the patient's perspective—"no-one understood me or was willing to listen to me" (respondent 29). Pressure to terminate pregnancy, medically complex situational stressors and the often overwhelming decision-making burden compounded the psychological toll from pregnancy-related discussions - "it was emotionally exhausting having to make decisions" (respondent 29).

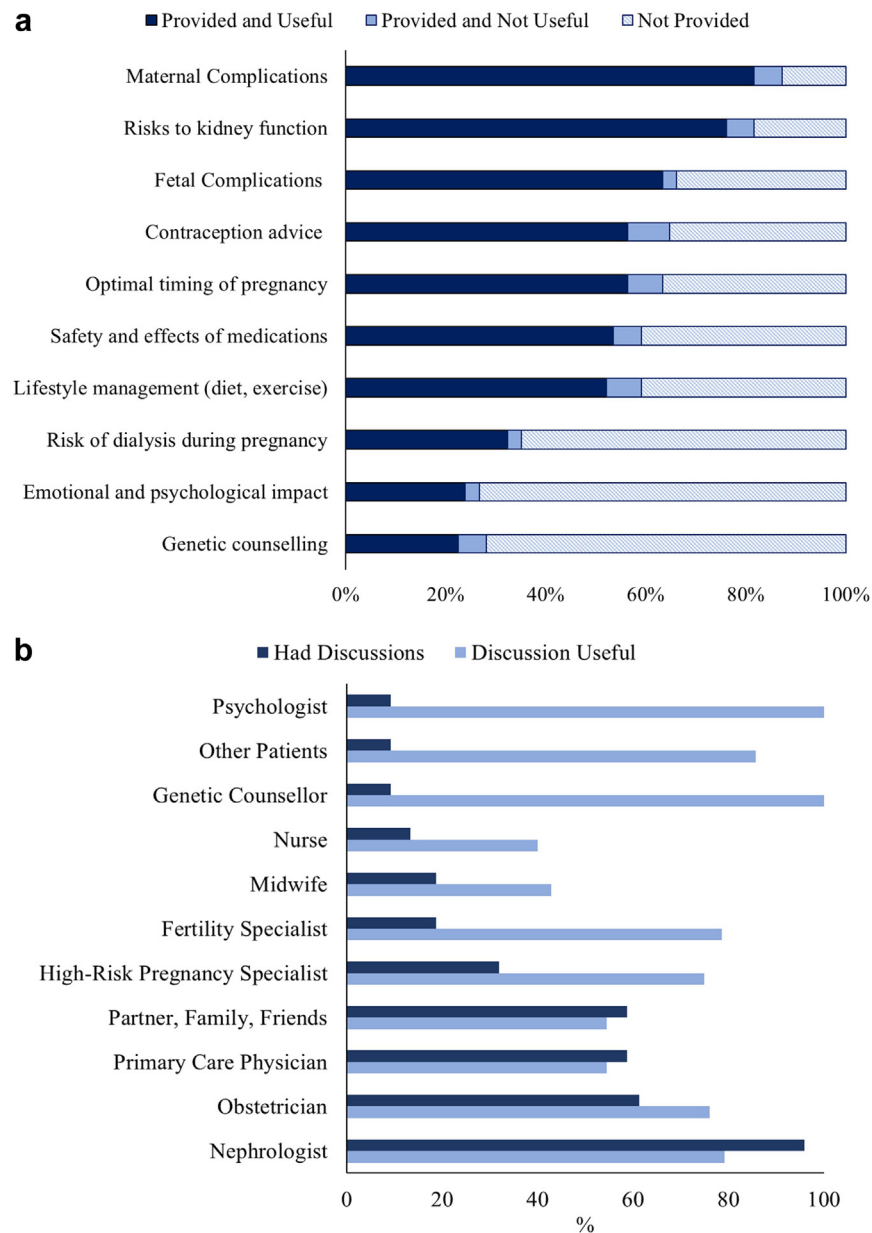
### Information Provided at Pregnancy-Related Discussions

We assessed the scope and usefulness of information provided to the subgroup of women with past experience of pregnancy-related counseling (Figure 2a). For all topics, most women (97.2%–91.6%) who received information reported that this was useful. The most commonly provided information related to maternal complications (87.3%) and risks of pregnancy to kidney function (81.7%). Information on fetal complications, medications including contraception, pregnancy

**Table 3.** Qualitative analysis of free-text responses indicating overarching themes, categories with response frequencies, subcategories, and example of written responses

Theme and main survey question	Category	Responses	Subcategory	Example (respondent ID)
THEME: Usefulness of Pregnancy-related discussions Respondents: 9 Q22. Did the information or discussion about pregnancy you received help in your decision-making, if no, why not?	Suboptimal quality of information	5	Conflicting information	"I have received varying opinions on whether I should get pregnant and it is hard to know who to listen to" (7)
	Preetermined decisions render pregnancy-related discussions less useful	5	Delayed or absent information Patient determination to achieve pregnancy Perceived lack of choice provided by clinicians	"The risks weren't discussed nor alternate treatment" (2) "I was doing it regardless; it just takes time to save the money" (52) "I was basically just told to abort my baby and that was the continuous conversation up until I reached 14 weeks" (39)
THEME: Distress due to pregnancy-related discussions Respondents: 30 24. Did you find the pregnancy discussions stressful (emotionally/psychologically), please comment	Clinicians misunderstanding patient priorities	9	Compromised joy and/or pressure to avoid or end pregnancy	"All I ever dreamed about was being a mother and I felt that journey and excitement was snatched away from me with all the pressure about having an abortion, in the end my pregnancy was successful with complications" (39)
	Importance of timely and adequate information provision	12	Clinician failure to prioritize parenthood Inadequate timely information Stress improved with adequate information	"All anyone truly seemed to care about was my actual kidneys, not the baby, our process afterwards as a family" (56) "I was left with more questions than answers" (2) "Varied between specialists which in the end made us to decide to go with who was more positive and proactive about issues with becoming pregnant" (45)
	Overwhelming complex care and complications	12	Decision-making burden Medical situational stressors	"Emotionally exhausting having to make decisions" (83) "I had complications therefore the discussions were stressful" (22)
THEME: Comprehension of Information delivered in pregnancy-related discussions Respondents: 23 25. In visits where pregnancy-related discussions or information about pregnancy planning was provided, did you feel that you understood the advice or information given? How could the advice/information have been improved?	Delivery of information	17	Communication among key stakeholders	"For there to have been better communication across the hospital which would have allowed me access to service earlier in my pregnancy, then I would have had the time needed to process understand and ask questions if need be" (23)
			Information delivered by experienced experts	"I wish that all kidney patients were given the option of counseling with someone who actually specializes in this area and can look at it with a holistic approach of more than just what's happening to a set of kidneys ..." (56)
	Content of information	10	Information format Timeliness Quality and breadth of information	"Written advice/ information would have been helpful, all information was verbal" (82) "More information BEFORE having children" (63) "I think more up-to-date research needs to be readily available for patients about risk factors etc. I had a fairly unsuccessful transplant 18 months ago was pushing for a second so I could start a family but was told 2 kidney transplants and pregnancy is too risky however there is a lack of research on this so they are just making the decision based on the fact that there isn't much supportive research. I feel very let down about the whole process" (7)
THEME: Improving Information delivered in pregnancy-related discussions Respondents: 32 27. Was there any other information you would have liked? (apart from those outlined in Question 26)	Interpersonal and psychological support	8	Real life experiences Psychological support	"Access to speak to other pregnant transplant patients" (45) "Being offered counseling to help with anxiety and stress. Didn't get pregnant straight away I believe due to stress" (98)
	Improving the absence or sparsity of information	4	-	"I didn't receive most of this information or did not discuss most of the above" (90)
	Early information to improve preparedness	23	Information before pregnancy Information during pregnancy Information after pregnancy	"Different options for pregnancy eg IVF, surrogacy. Pregnancy information needs to be provided much earlier in diagnosis, especially about risks to transplant" (53) "During pregnancy I didn't understand why they were running so many tests compared to my previous pregnancy. No one told me why and so I thought something was wrong, when it wasn't" (42) "I felt there was plenty of information during the pregnancy but the support after my complicated/premature birth due to kidney disease was zero! I think there needs to be a greater acknowledgment of the emotional impact the high risk/premature pregnancies and births have on women" (12)

IVF, in vitro fertilization.



**Figure 2.** Experiences of women who received past pregnancy-related counseling. (a) Content and usefulness of information provided during previous pregnancy discussions ( $N = 75$ , missing  $n = 4$ ). Dark blue bars show the percentage of women who were provided this information and found it useful, light blue bars show the percentage of women who were provided this information and did not find it useful, hashed bars show the percentage of women who did not receive information on this topic at all. (b) Sources of pregnancy discussions ( $N = 71$ , missing  $n = 8$ ). Dark blue bars show the percentage of women who discussed pregnancy with these individuals(s); light blue bars show the percentage of these women who found the discussion useful.

timing, and lifestyle were provided to 59%–66% of women. Most women (73.2%) did not receive information on the emotional and psychological impact of pregnancy, and few received genetic counseling (28.2%). Information on the risk of dialysis during pregnancy was not discussed with 64.8% of respondents; however, 92.0% of women who *did* receive this information found it useful. Of these 46 women, 56.5% were at earlier stages of CKD where dialysis may not be required, but still indicated they wished to receive this information.

Analysis of free-text responses emphasized the critical role of sufficient and clear information in enabling autonomous patient decision-making (Table 3). Receiving conflicting information from various clinicians, or a sparsity of information, rendered pregnancy-related discussions less valuable. Usefulness was further limited when strong preformed decisions were already held. This could be driven by the patient determination to proceed—“I was doing it regardless” (respondent 52), or where clinicians were perceived to be clearly unsupportive of pregnancy—“I was basically just told to

abort my baby and that was the continuous conversation up until I reached 14 weeks” (respondent 39).

A lack of discussion about risks, lack of clinician expertise (particularly from nonspecialist clinicians), conflicting and confusing advice from different parties also influenced the utility of counseling interactions.

### Choice of Clinician for Pregnancy-Related Counseling and Perceptions of Usefulness

Women were asked who they had previous pregnancy discussions with and if this was useful. Almost all women who discussed pregnancy in the past had involved their nephrologist and 79.2 % found nephrologists useful (Figure 2b). Obstetricians; primary care physicians; and family, friends, or partners were involved in discussions with over 60% of women. Discussions with psychologists, other patients, and genetic counselor occurred the least frequently, but were highly rated as useful by women who did access them. Specialist physicians (fertility, pregnancy, or nephrology) were preferred as useful compared to midwives and nurses, who were not frequently involved nor found to be useful for the majority of women.

### Patient Preferences for Pregnancy-Related Discussions and Information Resources

Preferences for future pregnancy-related counseling, information and other supports were elicited from all respondents (Figure 3a–c and Table 3). Women desired more research in this area, and 89.7% found participation in the survey useful. In Figure 4, we summarize suggested clinical frameworks and practice recommendations based on study findings.

### Source of Information

Women had divided opinions on whether patients or nephrologists should *initiate* pregnancy related discussions (Figure 3a). No statistically significant differences were observed in participant demographics, pregnancy planning stage or comfort level in taking about pregnancy, among women who said that they would want to initiate pregnancy discussions themselves compared to their nephrologists initiating these discussions (data not shown). Women had strong preference for counseling to occur predominantly with specialist physicians (nephrologist or obstetrician,  $n = 76$ , 86.4%) and primary care physicians (69.3%) (Figure 3b). Other preferences for information included the internet (46.6%), online forums (33.0%), nursing staff (37.5%), and other patients (34.1%).

In analysis of free-text responses, the delivery of clear and high quality information by clinicians with confidence and expertise in the area was identified as a key element (Table 3). Women also wanted exposure to

real-life experiences from other patients and psychological support throughout the process.

### Scope and Format of Information

The 23 women with no past experience of pregnancy-related counseling were asked to report the value of receiving information on 10 topics relating to pregnancy counseling (Supplementary File S1, Question 33; identical topics to Figure 2a). All of these 10 topics received average scores of 5 to 10 (moderately useful to most useful) and >80% of women gave all topics scores of 5 to 10 (data not shown).

In Figure 3c, we summarize the preferred modes of information delivery. Face-to-face counseling were most desired (79.6%). Respondents also requested a website (72.7%), online (46.6%), or face-to-face (44.3%) support groups. Workshops/forums did not rate highly. Free-text responses indicated the importance of information in multiple formats, provided early, and tailored to each stage of the parenthood journey (Table 3).

### Survey for Partners and Family

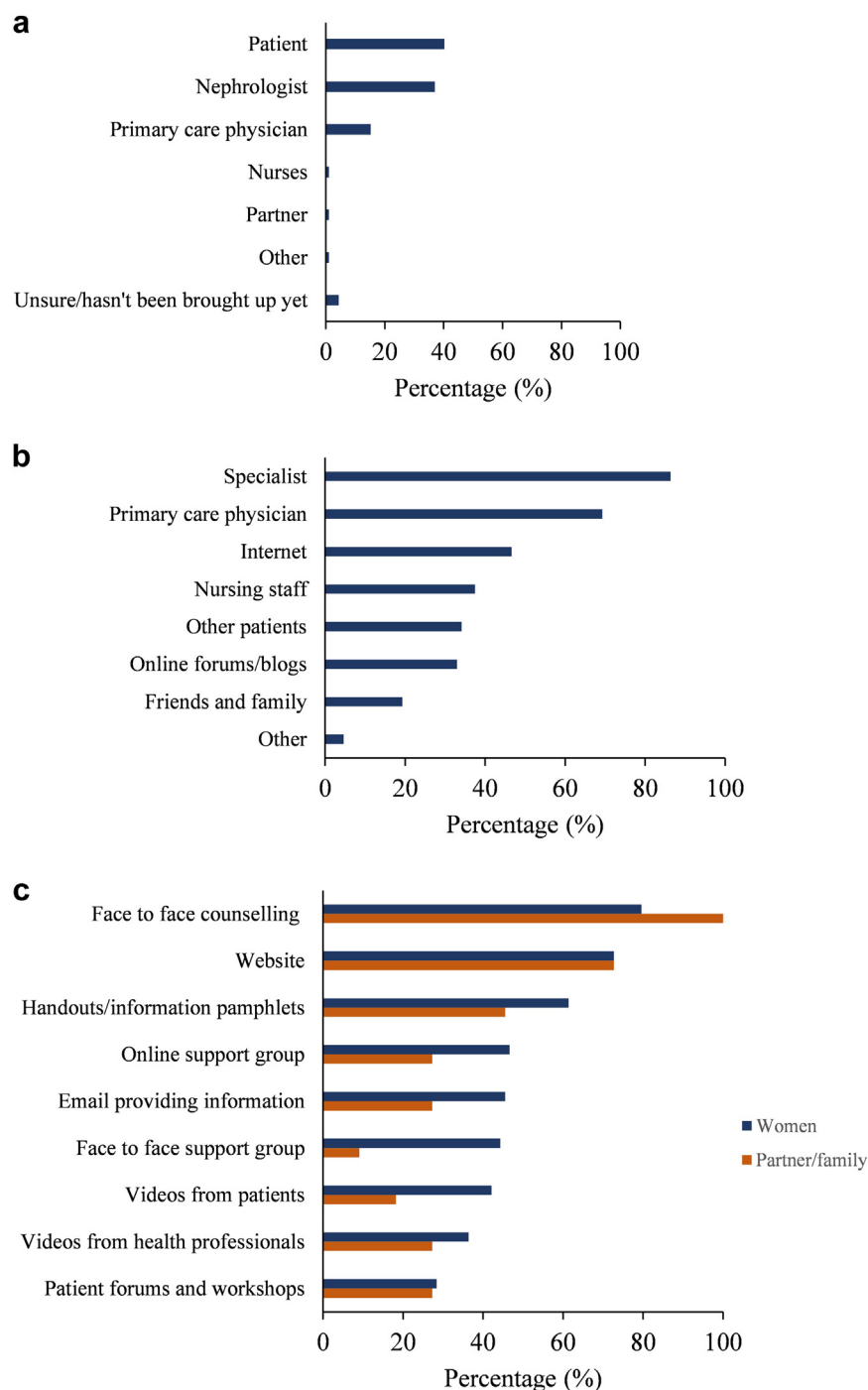
Nine partners and 2 family members responded. Most had attended pregnancy-related discussions (72.7%); however, satisfaction with the information given was low (36.4%). Partners/family members also preferred face-to-face counseling and websites to receive information (Figure 3c). We received 3 free-text responses from partners and family members. These responses highlighted the importance of clear and quality information that enables individuals to understand risks, and the provision of psychological support.

## DISCUSSION

In this large Australia-wide survey evaluating perspectives of pregnancy-related discussions and education in women with CKD, we identified important gaps in counseling and timely and comprehensive information provision. Just over 65% of women reported satisfaction with pregnancy-related discussions; however, two-thirds reported psychological stress, and only half of women felt they had adequate control of their decision-making. Women mostly initiated pregnancy discussions themselves, despite valuing nephrologist input and leadership. Information provided in pregnancy discussions focused on maternal outcomes, despite a wide range of information being valued by respondents. Women preferred information in a face-to-face setting, delivered by specialists or those with expertise, backed by peer support groups and digital content. These findings enabled the formulation of recommendations for future care of women with CKD (Figure 4).

Our study reveals new data on real-world experiences of pregnancy-related counseling in women with

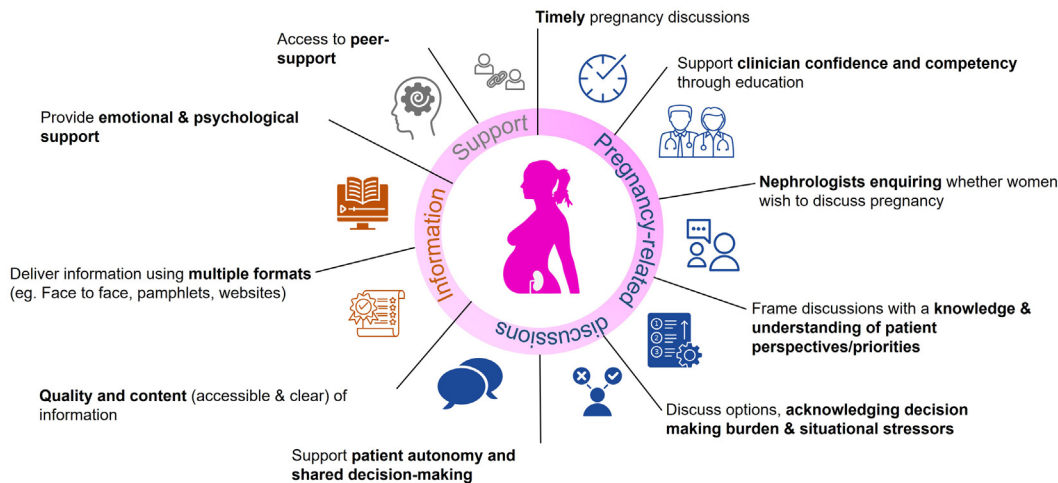




**Figure 3.** Patient preferences for future pregnancy-related counseling. (a) Patient responses regarding who should first bring up pregnancy discussions ( $n = 92$ ). Other – family members, midwife, and genetic counselor. (b) Preferred sources of information ( $n = 88$ ). Participants were able to select multiple options. Other - dietician and genetic counselor. (c) Preferred methods of receiving information, women ( $n = 88$ ) and partner/family members ( $n = 11$ ). Participants could select multiple options.

CKD. We found a minority of women (25.5%) reported having sufficient knowledge, only half found that counseling helped decision-making, and nearly half did not feel they had autonomy. Discussions prioritized the delivery of information on maternal complications and renal outcomes. In contrast, information on contraception, medication safety during pregnancy, fetal complications, genetic counseling, and emotional and

psychological impact of pregnancy was often not provided, despite being highly rated as useful when provided and highly desired. Free-text responses frequently referred to the lack of clear, relevant, and high-quality expert information when navigating pregnancy planning with CKD. These findings echo a study of Japanese transplant recipients reflecting low satisfaction with discussions and desire for more



**Figure 4.** Clinical practice recommendations. Summary of key findings based on women's experiences and preferences for pregnancy-related discussions and information needs.

detailed information even after discussions with medical staff.<sup>14</sup> SDM is a central tenet in CKD care more broadly<sup>11</sup> and for preconception counseling in CKD.<sup>7,15</sup> A recent systematic review suggested achieving SDM about pregnancy in CKD often fails due to lack of preparation, evidence-based-resources, and information.<sup>8</sup> Previous studies highlight that decisional conflicts arise when the strong desire for motherhood is balanced against risks to both maternal and fetal health.<sup>5-8,16</sup> Perception of pregnancy risk is also highly individualized and mediated by information synthesis, psychosocial context, and emotional responses.<sup>6</sup> Therefore, delivery of information and counseling to women determines their experience, engagement, and sense of autonomy. The large proportion of women in our study who experienced loss of feeling in control of decision-making underpins the critical importance of resources and clinical support for effective SDM.

Surveyed women overwhelmingly preferred information to be delivered by their nephrologists, with respondents reflecting that lack of clinician confidence and expertise minimized the value of discussions and SDM. Evaluation of dedicated prepregnancy counseling clinics in the UK revealed that 90% of women found the clinic informative and a positive experience,<sup>17</sup> indicating that specialized services may be the appropriate vehicle for delivering pregnancy-related counseling. Given that such clinics may not be widely accessible, responsibility for effective counseling to support SDM about pregnancy will fall to nephrologists. In our study, nearly all women who experienced pregnancy discussion had involved their nephrologist and 79.2% found this useful. Furthermore, 37.0% of women stated that their nephrologist should be responsible for initiating pregnancy discussions. Patient expectations may not be matched by nephrologist expertise. A survey of North

American nephrologists revealed that lack of guidelines, training, and exposure led to low confidence in counseling about many aspects of women's health.<sup>9</sup> In our survey, many women stated that primary care engagement was also important, although primary care clinician's confidence and expertise is presently unknown and likely also requires augmentation. Finally, timeliness of counseling was frequently raised in free-text responses. Early timing of reproductive health counseling is well-established in guidelines for renal care,<sup>15,18</sup> but in practice may not occur.<sup>9,19</sup> Professional education strategies are required to improve clinical expertise in proactively addressing reproductive health within standard care for women with CKD.

The lack of proactive counseling from nephrologists is further emphasized in our finding that 60.0% of women reported initiating pregnancy-related discussions themselves, most frequently only when pregnancy was desired, and in some cases only after pregnancy. Reduced nephrologist confidence in addressing reproductive health is likely compounded when patients are not equipped with information, tools, or resources to proactively raise parenthood desire. In our study, only one-third of respondents stated that patients should initiate pregnancy discussions, possibly reflecting patient disempowerment, fear or uncertainty, or unawareness that this topic can be raised by patients with their treating clinicians. Nephrologists may need to sensitively elicit whether patients wish to raise pregnancy-related discussions in routine care, and if not, ensure that women are aware they can raise the topic themselves when ready. In response to questions about future information resources, women prioritized face-to-face consultations but also desired information in a range of delivery formats, clinician sources, and other patients. It is clear that future resources to empower and

support women with CKD to navigate parenthood decisions cannot be “one size fits all”; rather, a suite of educational resources and decision aids will better facilitate individualized counseling. The effectiveness of such interventions on achieving meaningful SDM requires evaluation in future research.<sup>8,9,15</sup>

A key finding of this study was that whereas 84.3% of women were comfortable talking about pregnancy, nearly 67% reported pregnancy-related discussions were stressful. Causes of stress and distress included disconnect between clinician and patient views, failure to understand women’s priorities, conflicting information from various clinicians, and pressure to terminate pregnancy. Women stated that the predominant focus on and burden of information about pregnancy risk could be overwhelming. Patients with CKD may have complex and clinically challenging pregnancies with increased adverse outcomes. Conveying risks can be frightening for patients. Therefore, information should be tailored for individual patient’s risk and conveyed sensitively. Interestingly, of women who had been provided information about dialysis, 92.0% found it useful, including even those who were at earlier stages of CKD. This may reflect a desire for more information, or recognition that this topic may be important for other women. Clinicians who are the gatekeepers of information should ask women about their preferences for receiving pregnancy information without preformed assumptions, to avoid distressing women or providing too little information. Catastrophizing of pregnancy risk is well-known to cause distress, whereas communication of positive outcomes with hope and reassurance for possible successful pregnancies is important to women.<sup>7,16</sup> Although helpful for many, multidisciplinary specialized clinics may intimidate some women especially if many doctors are present.<sup>17</sup> Counseling for inherited kidney disease can be particularly fraught with ethical concerns around the implications of genetic testing.<sup>20</sup> Given these challenges with conveying risk, clinician support for pursuing pregnancy emerged from our study as an important element for effective counseling of women. This is currently not clearly occurring in clinical practice. For example, a previous Netherlands study revealed that whereas rates of discussion about pregnancy were high, 90% of nephrologists advised women with CKD against pursuing pregnancy.<sup>19</sup> Therefore, improving counseling skills through clinician education remains a critical component for advancing patient-centered care for women with CKD who desire parenthood (Figure 4).

This is the first survey of Australian women with CKD regarding experiences with and preferences for pregnancy-related counseling. A major strength of the survey was the careful codesign with consumers,

prioritizing questions of greatest relevance. Limitations of this study included those inherent with online surveys in English, limiting participation from non-English-speaking women and those without online access. Only a small percentage of responders were not considering pregnancy, suggesting the survey may have attracted women specifically interested in the subject. The survey was widely promoted for a lengthy duration to improve broad participation; however, the final cohort was predominantly from metropolitan areas, with a high education and socioeconomic status. There was underrepresentation of participants from regional/remote Australia, Northern Territory, and Western Australia, which likely explains the lack of First Nations participants. In response, our research group is leading a further study codesigned with First Nations women to explore reproductive health issues in a culturally sensitive manner using Indigenous research methodologies and governance. Women who completed the survey were asked to invite partners/family members to complete a survey, a strategy designed to reach partners/family members more effectively; however, this only occurred in a minority of cases. Women may have forgotten or felt uncomfortable asking partners and family members. Partner and family members are an important source of support for women, but data drawn from this study is limited by small numbers. We also did not collect information on the time frame from receiving pregnancy counseling or information to completion of the survey, which may have caused recall bias issues for some participants. The sample size was not sufficient to investigate the association between women’s primary cause of kidney disease and pregnancy experiences or preferences. Future research should explore primary kidney disease subgroups, in particular genetic kidney disease and conditions with medication exposures (for example, cyclophosphamide) that may affect fertility. Finally, we did not gather information on the specific model of care accessed by individual women – some women may have accessed specialized obstetric clinics for example.

The findings of this study have provided us with essential information regarding patient preferences and perspectives that will aid future development of resources and clinical guidelines for pregnancy-related counseling for women with CKD. Patients clearly preferred early, timely and expert counseling that was responsive to patient values and goals, underpinned by better information resources. The lack of information and clinician support was a major barrier to true SDM about pregnancy. Proactive leadership, particularly from nephrologists, about reproductive health issues and desires for women with CKD will require further efforts within clinical training, guidelines, and professional education.

## DISCLOSURE

All the authors declared no competing interests.

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## SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

**Supplementary File S1.** Flyer.

**Supplementary File S2.** Surveys.

**Supplementary File S3-**CHERRIES checklist.

**Table S1.** Association between demographical, biological and environmental factors with experiences of pregnancy-related discussions and information needs.

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