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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - MIXED METHODS**

# Feminizing care pathways: Mixed-methods study of reproductive options, decision making, pregnancy, post-natal care and parenting amongst women with kidney disease

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## Abstract

**Aims:** To identify the needs, experiences and preferences of women with kidney disease in relation to their reproductive health to inform development of shared decision-making interventions.

**Design:** UK-wide mixed-methods convergent design (Sep 20–Aug 21).

**Methods:** Online questionnaire ( $n=431$ ) with validated components. Purposively sampled semi-structured interviews ( $n=30$ ). Patient and public input throughout.

**Findings:** Kidney disease was associated with defeminization, negatively affecting current (sexual) relationships and perceptions of future life goals. There was little evidence that shared decision making was taking place. Unplanned pregnancies were common, sometimes influenced by poor care and support and complicated systems. Reasons for (not) wanting children varied. Complicated pregnancies and miscarriages were common. Women often felt that it was more important to be a “good mother” than to address their health needs, which were often unmet and unrecognized. Impacts of pregnancy on disease and options for alternates to pregnancy were not well understood.

**Conclusion:** The needs and reproductive priorities of women are frequently overshadowed by their kidney disease. High-quality shared decision-making interventions need to be embedded as routine in a feminized care pathway that includes reproductive health. Research is needed in parallel to examine the effectiveness of interventions and address inequalities.

**Impact:** We do not fully understand the expectations, needs, experiences and preferences of women with kidney disease for planning and starting a family or deciding not to have children.

Women lack the knowledge, resources and opportunities to have high-quality conversations with their healthcare professionals. Decisions are highly personal and related

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to a number of health, social and cultural factors; individualized approaches to care are essential.

Healthcare services need to be redesigned to ensure that women are able to make informed choices about pregnancy and alternative routes to becoming a parent.

**Patient or Public Contribution:** The original proposal for this research came from listening to the experiences of women in clinic who reported unmet needs and detailed experiences of their pregnancies (positive and negative). A patient group was involved in developing the funding application and helped to refine the objectives by sharing their experiences. Two women who are mothers living with kidney disease were co-opted as core members of the research team. We hosted an interim findings event and invited patients and wider support services (adoption, fertility, surrogacy, education and maternal chronic kidney disease clinics) from across the UK to attend. We followed the UK national standards for patient and public involvement throughout.

#### KEYWORDS

kidney disease, mixed-methods, nursing, parenting, pregnancy, qualitative, shared decision making, survey, women

## 1 | INTRODUCTION

Women make up 50% of the global population and have unique healthcare needs (Institute of Medicine, 2009; National Institute of Child Health and Human Development, 2016; National Library of Medicine, 2022). Yet, “gender gaps” associated with generic approaches to the clinical management of multiple diseases and healthcare pathways are increasing (Caruso et al., 2019). Known gender gaps leading to inequalities include unequal access to services, less positive experiences of care and support and poorer health outcomes. Women are also underrepresented in health research and rarely included as a separate group for analysis (Allen & Sesti, 2018). Some claim women have become so “invisible” in big data that it has effectively resulted in a global-scale research bias (Sperber, 2021). Far less is known about health conditions that only affect women and gynaecological health in general (World Economic Forum, 2017). Reasons for these disparities are complex (Temmerman et al., 2015) and more recent reports published by the World Health Organization (WHO) link women's health inequalities to wider socio-economic issues, embedded cultural differences, stereotyped gender roles and unequal power relationships including physical, sexual and emotional violence (Royal College of Nursing, 2022; WHO, 2022). In the United Kingdom (UK), the National Health Service (NHS) has received recent criticism highlighting that women have been disadvantaged for generations living with a healthcare system that is designed by men, for men (Winchester, 2021). This gender disadvantage happens despite around half of doctors and the vast majority of nurses being women. In response, the first UK government-led national women's health strategy was commissioned. Due to be published in 2022, it will include plans to improve quality and accessibility of education, self-care and shared decision making, ensure that health needs are met throughout women's lives (including workplace health), levelling

### COVID considerations

The study was funded in January 2020 and opened as planned in September 2020. COVID-specific considerations were added to the protocol and ethical considerations. The entire study was delivered virtually. Due to time and resources, the survey was always designed as online only so the main changes needed were to the interviews which were switched to virtual either via teams/zoom or telephone. Study team meetings were via Teams as was an interim findings event. We were also able to take the opportunity to add some COVID-specific questions to the survey and add it as a topic to the interview schedule. We report the outcomes of these additions and the specific impacts of COVID on women with CKD and their family planning elsewhere.

up research and addressing women's needs in the wake of the COVID-19 pandemic (Department of Health and Social Care, 2021).

In addition to gender gaps associated with health systems and clinical management, women are also over-represented globally in non-communicable diseases (Bikbov et al., 2018). In 2021, the WHO published their “6 priorities for women in health”, which included access to quality sexual and reproductive health and reducing non-communicable diseases in women, including chronic kidney disease (CKD; WHO, 2021). CKD is progressive, there is no cure, only treatment such as dialysis or transplant. Recent research also indicates that women behave very differently from men when making decisions about their future treatments options, for example, population-level data indicate that more men are on a kidney

replacement therapy, but yet more women have a diagnoses of kidney disease (Antlanger et al., 2019). In the UK, women with CKD are looked after by multi-disciplinary healthcare professionals including specialist nurses and advanced care practitioners (Shi et al., 2018). Their unique experiences living with CKD are not well understood and evidence-based interventions to support these women across complex decisional and care pathways including planning for children, pregnancy and motherhood remain critically lacking (Mc Laughlin et al., 2022).

## 2 | BACKGROUND

Chronic kidney disease is classified by level of function from stage 1 (mild) to stage 5 (severe) (Kidney Research UK, 2022). When most advanced, dialysis or a transplant is necessary (National Kidney Foundation, 2013). Despite the adverse consequences of CKD, many people experience little to no symptoms until their function has fallen to a very low level (Mayo Clinic, 2022). Although CKD can affect fertility, pregnancy is possible at any stage of kidney disease, including while on dialysis or with a transplant (K.S. Wiles et al., 2018). Pregnancies in women with CKD are at high risk of complications, which can affect both the mother and her developing baby. Specific concerns include the teratogenic risk of pre-existing treatment, pre-eclampsia, intra-uterine growth retardation and prematurity. There is an increased risk of miscarriage and later stillbirth. If the baby is significantly premature, admission to the special care baby unit may be required, and there may be subsequent developmental issues associated with prematurity. Delivery is more likely to be associated with medical intervention. It is therefore recommended that pregnancies are carefully planned and monitored with the involvement of a multi-disciplinary team (MDT) of healthcare professionals including nephrologists, specialist nurses, specialist obstetricians and additional psycho/social support services where needed (Horsager-Boehrer, 2019). Once pregnant, women may be cared for by a midwife who specializes in high-risk pregnancies. It may also be relevant to discuss the heritability of specific forms of kidney disease (National Kidney Foundation, 2022).

Women with CKD will need to consider these factors and more when thinking about becoming pregnant. Studies exploring women's perspectives while considering a pregnancy highlight complex health and social dilemmas such as decisional conflict, uncertainty and balancing family roles (Tong, Jesudason, et al., 2015). Recent clinical trials exploring the impact of CKD stage 3–5 on pregnancy outcomes have aimed to move away from collecting and presenting outcome data as a whole and towards developing tools to better support women by answering “what are the risks of pregnancy for me”? (Wiles, 2021). However, an updated systematic review of women's experiences and interventions to support them also found that the majority of recent research tends to have a narrower focus on pregnancy outcomes (K. Wiles et al., 2020). The so-called “alternate options”, for example, adoption, surrogacy and fostering are scarcely reported in the literature, nor are experiences of interventions to

enhance pregnancy options such as egg preservation and in vitro fertilization. To address some of these gaps, an updated qualitative evidence synthesis was undertaken that reported little change in the management of women's reproductive health in 20 years, no evidence-based interventions and large gaps concerning the expectations, goals, values and experiences of women with kidney disease who may (or may not) want to start a family. A new health systems model based on other health conditions with established personalized reproductive care packages, for example, cancer was developed (Mc Laughlin et al., 2022).

### 2.1 | Shared decision making

Shared decision making is a process whereby health professionals provide understandable information, discuss the pros and cons associated with different treatment options and fully involve people in treatment decisions, taking into account their personal circumstances and preferences (Elwyn et al., 2012). This enables people to make more informed decisions that align with their preferences and thus fit better with their identity, become more active and empowered in their own healthcare, to have better relationships with their healthcare professionals, and to feel more satisfied with the choices that they make (Health Foundation, 2012).

The impetus for this research was clinical and informed by patient and public input which indicated that women were not getting the focused information and support to make preference-based reproductive choices. To inform the development and implementation of interventions to facilitate shared decision making in this context, we first needed to understand how women with CKD currently make decisions about starting (or enlarging) a family, their experiences of engaging in shared decision making during their interactions with nurses, healthcare professionals and services and their needs and preferences for support with these often complex and emotive decisions.

## 3 | THE STUDY

### 3.1 | Aim and objectives

To identify the needs, experiences and preferences of women with kidney disease in relation to their reproductive health to inform development of shared decision-making interventions by:

1. Identifying needs and preferences of women of reproductive age with kidney disease by improving our understanding of how women make decisions about pregnancy, and investigating associations between pregnancy, health, well-being and psychosocial contexts.
2. Constructing a theoretical framework for decision making in relation to pregnancy, an essential first step in the development of a preconception shared decision-making intervention for use in clinical practice.

TABLE 1 Purposive sampling framework.

	Women who would like children/more children/currently pregnant	Women who are uncertain if they want children	Women who would not like any children	Women who would not like any <i>more</i> children	Women who would like to have children but by not being pregnant/ other
<b>Clinical demographics</b>					
Transplant	3	1	1		2
Currently on dialysis	1		1		
CKD 1 and 2 (early stage/no symptoms/low risk)	4	1		3	1
CKD 3–5 (moderate/late stage, deferral may be advised until post-transplant)	2	1	3	3	2
<b>Had prior discussions with healthcare professionals about having children</b>					
Yes	5	2	3	4	4
No	5	1	2	2	1
<b>Want to have discussion with healthcare professionals about having children</b>					
Yes	9	3	1		4
No	1		4	6	2
<b>Additional considerations</b>					
Women from ethnic minority backgrounds					
Women who reported "usual qualifications at 18" or lower fitting any of the above					
Women who completed the survey in Welsh and were Welsh speakers					

Abbreviation: CKD, chronic kidney disease.

### 3.2 | Theoretical framework

We underpinned the research with the MAGIC (Making Good Decisions in Collaboration), three talk model of shared decision making (Elwyn et al., 2017; Supplementary File S1). We also incorporated behaviour change theories adapted from clinical psychology (the Behaviour Change Wheel [BCW]) and implementation science (Theoretical Domains Framework [TDF])—tools designed to develop interventions to influence or change behaviours—to learn more about what changes might be needed and where they may be most likely to have an effect (Cane et al., 2012; Michie et al., 2011).

### 3.3 | Design

A mixed-methods convergent design was used to collect data from women of reproductive age in the UK with CKD, learn more about their personal experiences of pregnancy, decision making and care and support. Data were subsequently integrated to further refine a health systems model based on established personalized reproductive care packages in other health conditions, developed in a preceding qualitative evidence synthesis (Mc Laughlin et al., 2022).

We conducted a UK-wide 12-month (Sep 2020–Aug 2021) study with an online survey made up of closed and open questions including validated tools (Decision self-efficacy scale and Autonomy Preference Scale; Elwyn et al., 2013; Morandi et al., 2017) and follow-up semi-structured interviews with a sample of respondents. Findings were then used to develop actionable points for practice and service improvement.

The mixed-methods design was chosen as it allows for multiple and multi-layered perspectives on complex issues to be explored and is increasingly used in health services research as a way to better understand contemporary healthcare issues across rapidly diversifying health systems (Tariq & Woodman, 2013). It is also good at ensuring that patient experiences are embedded in interventions by integrating qualitative and quantitative perspectives (Regnault et al., 2018). Mixed-methods approaches can also be helpful where there is a dearth of evidence as they often aim to use different data sources to better understand the scope of the problem (Shorten & Smith, 2017). We followed the UK national standards for patient and public involvement throughout (NIHR, 2018).

### 3.4 | Sample/participants

All women aged 18–50 resident in the UK and diagnosed with kidney disease were eligible to take part. We initially aimed to recruit a sample of  $n=500$  online self-complete surveys and  $n=30$  follow-up interviews with a maximum variation of women purposively sampled (Table 1; Palinkas et al., 2015).

### 3.5 | Data collection

Full details of all data collection tools including the complete survey questions, topic guides and pathways to recruitment are available in the published protocol (Phillips et al., 2021). In the following sections, we report a summary of the methods used.

### 3.5.1 | Online survey

The online survey was carried out using Online Surveys (formerly known as Bristol Online Survey, <https://www.onlinesurveys.ac.uk>), and was open to enrolment from 1 Sep 2020 to 3 Aug 2021. The survey was adapted from ongoing research into pregnancy decisions and cystic fibrosis (Duckers, 2019), and asked about women's kidney disease (including cause, stage and treatment), pregnancy choices and current circumstances, experiences of pregnancy including perceived impact on general health and well-being, communication with health and social care professionals, contraception and birth control, information needs, support networks and demographic details. At the end, women had the option to share their contact details for a potential follow-up interview. We describe the measures in further detail in Box 1.

### 3.5.2 | Survey sampling and recruitment

The study was initially opened across Wales. We used the national all Wales kidney data register (VitalData) to identify potential participants. A cover letter and link to the online survey were sent by post to every person fitting the inclusion criteria in Wales (ca.  $n=2300$ ). NHS staff were tasked with signposting to the online survey during clinics, putting bookmarks in clinic notes to read while waiting for appointments and putting posters up in waiting rooms and dialysis units to help advertise. Clinical members of the research team (nephrologists, kidney social workers) proactively encouraged women in their care to take part in the survey and sometimes asked these women for help to promote the study to other patients in their social networks.

In addition to direct recruitment through the NHS kidney services in Wales, the survey was made available across the UK via social media (Twitter and Facebook), publicized through kidney charity partners (Kidney Wales, Kidney Care UK, Paul Popham Kidney Fund, Polycystic Kidney Disease Charity), wider charity partners (Lupus UK, Fair Treatment for Women in Wales, Endometriosis UK, Diabetes UK) and the Rare Disease Registry, Radar. The study was also advertised via direct mail outs by charities who agreed to send directly to their mailing list and alongside two case studies published in the UK's leading kidney charity magazines (Kidney Matters, Kidney Care UK and Kidney Life National Kidney Federation, NKF). The team also compiled a mailing list of NHS staff and wider stakeholders which was added to overtime and produced a monthly newsletter with updates as a way to keep partners engaged and advertise for people to take part. Further details of recruitment including a timeline of events are provided in Supplementary File S2.

### 3.5.3 | Interviews

Women who completed the online survey and had indicated that they would be interested in a follow-up interview and fitted the

purposive sampling frame (Table 1) were initially contacted via telephone (or email if no contact number was provided). Semi-structured interviews including visual aids, for example, timelines and colour coding specific narratives to feelings and perceptions over time were designed to empower women to share what mattered to them. These had been used in previous similar studies and elicited positive responses (Goldenberg et al., 2016). When contacted, the study was explained in further detail and women were invited to take part at a time and date convenient to them. The topic guide and visual timeline were shared prior to the interviews via email. Informed consent (verbal or written) was taken before each interview. Interviews were offered in Welsh or English. English interviews ( $n=28$ ) were undertaken by an experienced female researcher with a PhD. Interviews in Welsh ( $n=2$ ) were undertaken by an experienced kidney social worker who was also a core member of the research team. Most people who were spoken to consented to an interview. Three dropped out due to time commitments, rearranged clinic appointments or recent bereavement.  $N=23$  interviews were undertaken on Teams/Zoom and  $n=7$  via telephone. All interviews were audio-recorded, that is, video was not recorded during video calls. All women were interviewed once, either alone or while looking after their very young children. Detailed fieldnotes were taken and each interview lasted around 60 min. We stopped recruiting when  $n=30$  interviews (the initial target sample) had been completed and the team felt that data saturation was reached. Interviewers had no known prior relationship with participants. However, following one follow-up call, it became clear on introductions that the participant did know the researcher through mutual professional contacts. The participant was offered an interview with a different researcher, they felt that this was unnecessary and were happy to participate. Women were thanked for their participation and asked if they would like to receive a report of the research once completed.

## 3.6 | Data analysis

### 3.6.1 | Survey

Analysis of the quantitative data was carried out using SPSS.v.27. Descriptive analysis was used to provide an overview of the clinical and demographic characteristics of the survey participants, and their well-being, shared decision-making preferences and information needs. We fitted multivariable regression models with the CollaboRATE mean score and extent to which preferences for having children had been considered by women's healthcare team as the outcome variables and the following predictors: Decision Self-efficacy total score, ENRICHED Social Support total score, age, perceived general health, on dialysis (yes/no), have had a transplant (yes/no), education (college educated/not college educated) and family status (have children already/do not have children). The "enter" method of regression was used with missing cases excluded listwise. A multivariable regression model was also fitted with

**BOX 1 Measures.***The Control Preference Scale*

General preference for involvement in decision making was assessed using a single item from the Control Preferences Scale (Degner et al., 1997). We asked "Ideally, how involved would you like to be in decisions about the management of your disease?" Women selected one of the following responses: I prefer to leave all decisions regarding treatment to my doctor, I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion, I prefer that my doctor and I share the responsibility for deciding which treatment is best for me, I prefer to make the final decision about my treatment after seriously considering my doctor's opinion or I prefer to make the decision about which treatment I receive. A single item was included to assess general experiences of incorporation of preferences for starting (or enlarging) a family into medical decision making. Participants were asked, "Have your kidney health and social care team considered whether or not you would like to have children when talking about your treatment options (e.g. types of medication, dialysis and transplant)?" This was rated from 0 (not considered at all) to 4 (fully considered).

*Decision Self-efficacy Scale*

Women's confidence in their ability to make informed decisions about having children was assessed using seven items from the Decision Self-efficacy Scale (DSE) (O'Connor, 1995). The items related to two components of decision making: ability to obtain information and ability to ask questions. The four items of the DSE relating to self-efficacy relating to decisions were not included, as the focus was on decisions about having children. Items were rated on a five-point scale from 0 (not at all confident) to 4 (very confident). The item scores were summed, divided by 7, and multiplied by 25 to provide a total score ranging from 0 to 100, with higher scores indicating higher self-efficacy.

*CollaboRATE measure*

Women were asked to rate a conversation they had with a health professional about their options for starting a family using the CollaboRATE measure (Elwyn et al., 2013). This included three items relating to how much effort was made to 1. help them understand your options about having children and managing your conditions, 2. listen to the things that matter most to you and 3. include what matters most to them in choosing what to do next? The items were rated from 0 (no effort was made) to 9 (every effort was made). The mean score of the three items was calculated to provide an overall score, ranging from 0 to 9, with higher scores indicating more shared decision making.

*Information needs*

The measures of unmet information needs were adapted from previous studies investigating pre-conception decision making for women with rheumatological conditions (Ackerman et al., 2015). Women who were considering having children or were undecided were asked how important it was for them to have more information on 11 topics that were relevant to reproductive choices. These were scored from 0 (not important at all) to 4 (extremely important). Topics included sex and relationships, fertility, risk of passing on their illness, other options for starting a family (e.g. adoption), preparing for pregnancy, risk of miscarriage or still birth, options for giving birth and breastfeeding. Women were then asked how they would prefer to receive the information they required. Cronbach's alpha for the information needs items was high ( $\alpha=0.91$ ) and as such, the items were summed to produce a total reproductive options-related information needs score.

*Social support*

Social support was assessed using the measure from the ENRICHED study (ENRICHED Investigators, 2001; Hoskings, 2000; Vaglio et al., 2004). It is a seven-item scale, with the first six items relating to ability to obtain social support from various sources when needed, rated from 0 (none of the time) to 4 (all of the time). The seventh item related to whether or not the individual is married or living with a partner (yes/no). This measure was included to assess whether broader social support might influence women's confidence in making decisions about having children and managing their disease, as well as influencing their ability to cope with the process of starting/enlarging a family and caring for young children. A total score was derived by summing items 1, 2, 3, 5 and 6 of the scale as described by the ENRICHED investigators, (ENRICHED Investigators, 2001) with low perceived social support being defined as having a score of  $\leq 2$  on at least 2 of the 5 items, and a total score of  $\leq 18$ . As the COVID-19 pandemic began while this study was ongoing, an additional item was included in this section of the survey to investigate whether the pandemic was perceived to have had an effect on social support: "Has Covid-19 had an impact on your contact with people you feel close to and that you can trust and confide in"?

Decision Self-efficacy which may be an intermediary variable for shared decision making, using the same method and predictor variables. The models were then repeated with the addition of the total reproductive options information needs scores, which only applied to women who wanted to have children or were undecided. Based on Green's (Green, 1991) rule of thumb for testing individual predictors,  $N=104+m$  (where  $m$  is the number of predictors), a minimum sample size of 113 would be required for these analyses. Free text from the surveys was uploaded into NVivo and analysed in the same way as the interview transcript data (see below).

### 3.6.2 | Interviews

Interviews were transcribed verbatim and uploaded into NVivo 11 pro (Nvivo, 2015). We used the five-stage framework method (familiarization, identifying themes, indexing, charting, mapping and interpretation) to organize and code interview data into a narrative to help better understand women's personal experiences (Ritchie & Lewis, 1980). Data were also analysed thematically against the BCW and TDF frameworks specifically to help explain the ways shared decision-making interventions could be adapted or modified to better support women in relation to their reproductive health.

### 3.7 | Data integration

Qualitative and quantitative data were collected concurrently, analysed separately and discussed collaboratively (at core team meetings and stakeholder events) (Fetters et al., 2013; Figure 1). Findings were brought together through a matrix that was used as the mechanism of data integration following the principles of mixed-methods framework synthesis, mapping BCW, TDF domains, intervention functions, policy categories and behaviour change techniques to the sources of evidence, alongside a summary statement of what needed to change to bring about good shared decision making (Supplementary File S3). We used the Good Reporting of a Mixed

Methods Study (GRAMMS) framework and The Standards for Reporting Qualitative Research (SRQR) checklist to report results and findings (O'Brien et al., 2014; Roslyn, 2013).

### 3.8 | Validity and reliability/rigour

As previously described, validated measures were used in the survey. Discussion of emerging themes began as soon as data became available to share with the core research team at monthly meetings. This started with demographic survey data and samples of free text, followed by interview transcripts (Lincoln & Guba, 1985). We used the four-dimension criteria (credibility, dependability, confirmability and transferability) as qualitative markers of rigour throughout (Lincoln & Guba, 1985). Detailed fieldnotes were often read out to the team who were then able to share their expertise and perspectives to help further contextualize data, share their experiences (clinical, academic and personal) and advise on ways to develop the maximum variation sample. We hosted an additional core team afternoon session to present early findings and discuss as a team. Initial data from the survey and interviews were presented at a key stakeholder interim findings meeting which included expert wider input from adoption, surrogacy and fertility services in the UK, kidney charity partners who were developing education tools to support women and pilot clinical interventions with dedicated services to support women with kidney disease in England. This group also had opportunity to listen to interim data and input their particular perspectives. We published the video and transcripts of the interim findings event online (Horsager-Boehrer, 2019).

#### 3.8.1 | Reflexivity

The MDT core research team included clinicians, psychologists, social workers, academics, third-sector partners and women living with kidney disease. The team were all female who had various perspectives and experiences which revealed the ways women's

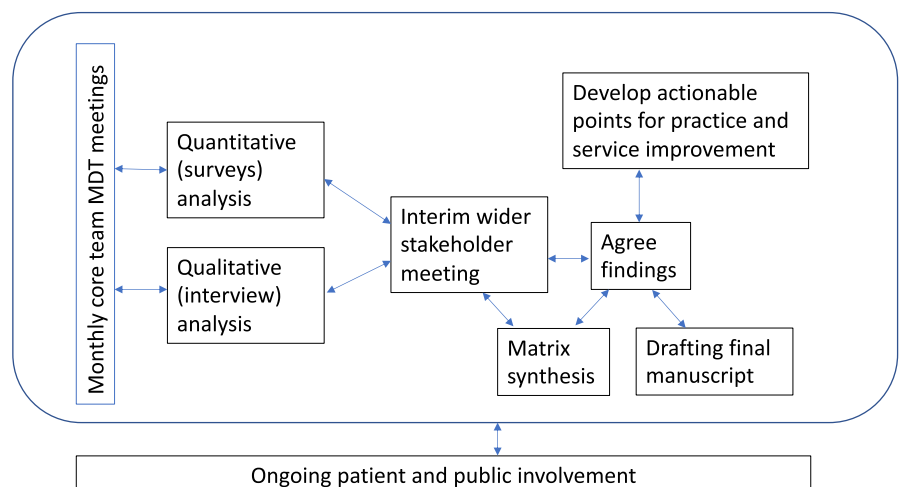


FIGURE 1 Matrix integration.



reproductive health needs were not always being met. Biases were resolved through whole team discussion, recording detailed field notes as well as regularly returning to the data to confirm or deny key themes.

### 3.9 | Ethical considerations

Ethical issues included covering sensitive topics such as pregnancies, miscarriages, stillbirths and bereavement. We produced an "Ethical Considerations, Practical strategies and Distress Protocol" and signposted to third-sector support services (stillbirth, neo natal and relationship counselling) at the end of the survey and interview. Members of the research team were experienced in similar studies and studies involving bereavement. The study received full ethical approval. Wales REC 1 committee 20/WA/0157. A more detailed account of ethical considerations is in the published protocol (Phillips et al., 2021).

## 4 | FINDINGS

The online survey was completed by 431 people aged between 18 and 50 years (mean age = 35.23 years, SD 7.85). The majority of participants identified as being women ( $n=427$ , 99.1%) and were heterosexual ( $n=390$ , 90.5%). People who were married, in a civil partnership or living with a partner ( $n=309$ , 71.7%), were college educated ( $n=330$ , 77.6%) and were of white ethnicity ( $n=397$ , 92.1%) were over-represented compared with the UK general population (ONS, 2017, 2019, 2020; Welsh Government, 2020). Full demographic characteristics and self-reported health of survey and interview participants are summarized in Supplementary File S4.

### 4.1 | Information needs

Just over half of the women who completed the survey had a conversation with a health professional about their preferences for having children, with a similar proportion feeling that they had enough information to enable them to make a decision about whether they would like to have children. Around half of women felt that health professionals should raise this topic, indicating that there is a need for clinicians to be proactive in starting these conversations, but many women (43.2%) also felt that women should be the ones to initiate these conversations. While a variety of health professionals may contribute to supporting women with their decisions about having children, doctors and specialist nurses within kidney care teams in particular are likely to play a key role (Table 2).

Women who were considering having children or were undecided ( $n=273$ ) had a range of unmet information needs. The perceived importance of getting information on different topics is summarized in Figure 2.

TABLE 2 Women's reproductive options information needs ( $n=431$ ).

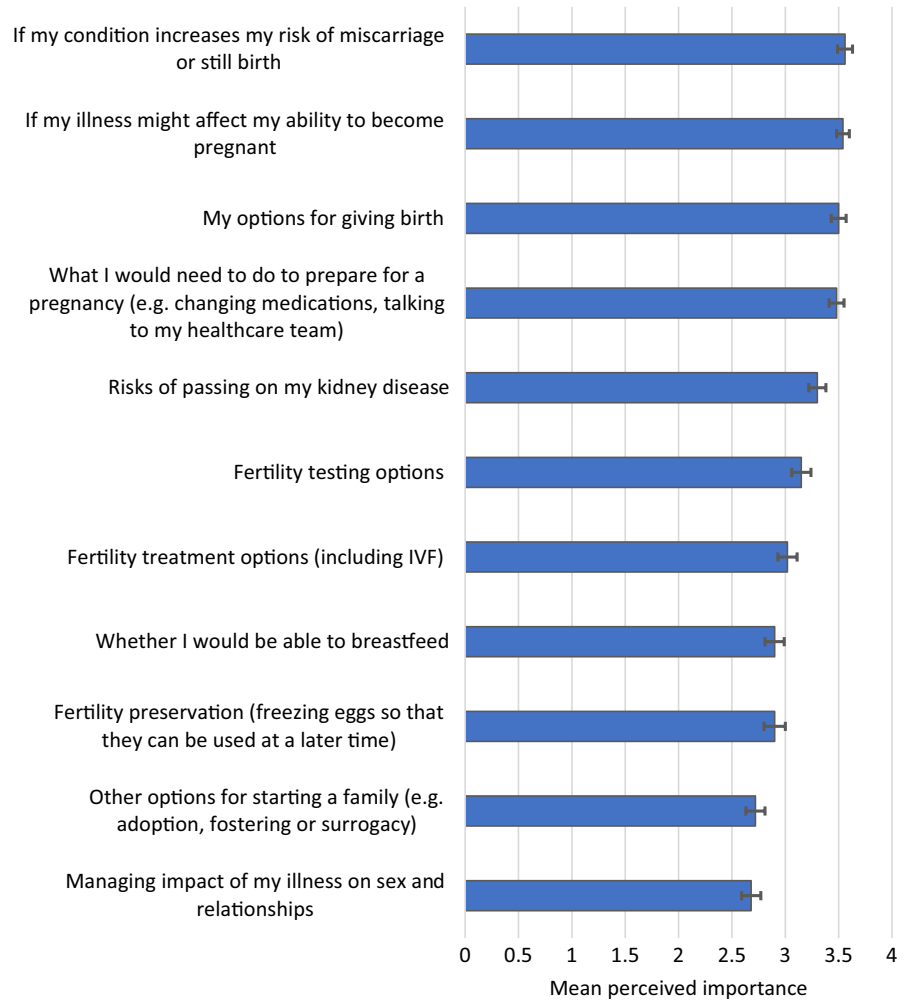
Variable	Category	n	%
Have any health professionals discussed your preferences for having children with you?	Yes	237	55
	No	194	45
Do you feel that you have enough information from your healthcare professionals to help you decide whether or not you would like to have children?	Yes	224	52.0
	No	105	24.4
	Not sure	94	21.8
	Missing	8	1.9
Have any health professionals discussed your contraceptive options with you?	Yes	304	70.5
	No	122	28.6
	Missing	5	1.2
Do you feel that you have enough information about your contraceptive options?	Yes	331	76.8
	No	48	11.1
	Not sure	44	10.2
	Missing	8	1.9
Would you like to have a conversation with your health professionals about decisions regarding having children?	Yes	204	47.3
	No	216	50.1
	Missing	11	2.6
Who would you like to speak with about making your decision about whether or not to have children? (NB multiple selections could be made for this item)	Kidney doctor	285	66.1
	Kidney specialist nurse	136	31.6
	Counsellor/ Psychologist	76	17.6
	GP	61	14.2
	Other	32	7.4
Who would you like to bring up the topic of having children? (NB multiple selections could be made for this item)	The healthcare professional	213	49.4
	You	186	43.2
	Other	14	3.2

The most important information needs from women's perspectives related to the risks of pregnancy loss, options for giving birth, preparing for pregnancy, the potential impact of their CKD on their ability to conceive and the risk of passing on their illness to their children.

### 4.2 | Shared decision making

Very few women (4.4%) preferred to leave decisions about their treatment entirely up to their doctor, indicating a high level of desire to engage in shared decision making. However, women often perceived that their preferences for having children were not adequately considered by their healthcare teams. Where conversations about preferences for having children had taken place, the

**FIGURE 2** How important it is for you to have more information for each topic (0—not important at all to 4—extremely important).



CollaboRATE scores indicated that there was a high degree of effort made to consider women's needs and preferences and to explain their options to them. However, there was variation in women's experiences and the CollaboRATE scores did not reach the “gold standard” of 9 (every effort was made) on these encounters, indicating that there is some room for improvement. Scores on the relevant measures are summarized in [Table 3](#).

### 4.3 | Multivariable regression analysis

Multivariable models were fitted to investigate the independent association of variables of interest with the shared decision-making measures included in the survey: CollaboRATE, perceptions of the degree to which health and social care professionals had taken into account their preferences for having children when making decisions about treatments, and decision self-efficacy. Model summary statistics are provided below. Beta ( $\beta$ ) values and significance of each variable entered into the models are provided in [Supplementary File S5](#).

The multivariable linear regression models for CollaboRATE mean score for women who had a conversation with a health professional about their options for having children was statistically significant ( $F_{9,227}=4.733, p<.001, \text{Adjusted } R^2=.125$ ). The only significant

association in this model was Decision Self-Efficacy score ( $\beta=.034, 95\% \text{ confidence interval [CI] } 0.023, 0.046$ ).

The model fitted for the extent to which women felt that their preferences for having children had been considered by their health and social care team when deciding on their treatment options was also statistically significant ( $F_{9,421}=12.906, p<.001, \text{Adjusted } R^2=.199$ ). Decision Self-Efficacy was the strongest association in this model ( $\beta=0.025, 95\% \text{ CI } 0.019, 0.030$ ). Having children already ( $\beta=0.368, 95\% \text{ CI } 0.017, 0.719$ ) and considering having children rather than having decided not to have children ( $\beta=.406, 95\% \text{ CI } 0.027, 0.785$ ) were associated with increased perceived consideration of their preferences for having children by their health and social care team.

The model for Decision Self-Efficacy score was also statistically significant ( $F_{8,422}=3.818, p<.001, \text{Adjusted } R^2=.05$ ). Social support was the only significant association in the model ( $\beta=1.227, 95\% \text{ CI } 0.633, 1.821$ ).

#### 4.3.1 | Adjusted models for information needs

The regression models were adjusted to include only women who were considering having children or were undecided who had

TABLE 3 Summary statistics for shared decision-making measures.

Shared decision-making measure	N	Mean	Range	Standard deviation
Have your kidney health and social care team considered whether or not you would like to have children when talking about your treatment options (e.g. types of medication, dialysis, transplant)? (All participants, higher scores = more consideration)	431	1.99	0–4	1.69
Decision Self-Efficacy Scale Total (All participants, higher scores = more self-efficacy)	431	69.15	0–100	28.03
CollaboRATE score (People who have had a conversation with a health professional about their options for having children only, higher scores = more collaboration)	222	6.70	1–9	2.39
Unmet information needs total (Women who were considering having children or had not decided yet only, higher scores = greater information needs)	273	34.88	0–44	9.57
			N	%
Preference for involvement in decision making	I prefer to leave all decisions regarding treatment to my doctor		19	4.4
	I prefer that my doctor makes the final decision about which treatment will be used, but seriously considers my opinion		83	19.3
	I prefer that my doctor and I share the responsibility for deciding which treatment is best for me		237	55.0
	I prefer to make the final decision about my treatment after seriously considering my doctor's opinion		81	18.8
	I prefer to make the decision about which treatment I receive		8	1.9

completed an additional set of questions on their reproductive options information needs. Adjusted models for CollaboRATE mean score ( $F_{9,265} = 3.176, p < .001, \text{Adjusted } R^2 = .067$ ) and for consideration of preferences for having children by their health and social care team ( $F_{9,265} = 8.142, p < .001, \text{Adjusted } R^2 = .190$ ) and Decision self-efficacy ( $F_{8,266} = 3.809, p < .001, \text{Adjusted } R^2 = .076$ ) were all statistically significant.

No significant associations were found between total information needs and any of the three outcome variables. Decision Self-efficacy remained a significant association in both the CollaboRATE ( $\beta = .019, 95\% \text{ CI } 0.010, 0.027$ ) and consideration of women's preferences ( $\beta = 0.024, 95\% \text{ CI } 0.017, 0.031$ ) models. There was a significant independent association between social support and consideration of women's preferences ( $\beta = 0.046, 95\% \text{ CI } 0.04, 0.087$ ), but there was no longer a statistically significant relationship between having children already and consideration of women's preferences ( $\beta = 0.050, 95\% \text{ CI } -0.374, 0.474$ ). In the Decision Self-efficacy model, social support remained a significant association ( $\beta = 1.111, 95\% \text{ CI } 0.413, 1.809$ ) and an additional association with having children already was observed ( $\beta = 7.346, 95\% \text{ CI } 0.079, 14.61$ ).

#### 4.4 | Qualitative interviews

$N = 30$  interviews were undertaken and explored women's decision making, planning for pregnancy (including unplanned pregnancies, pregnancy loss and alternate options for starting or expanding a

family), impacts of changes in treatment on motherhood, experiences of healthcare and support, psycho/social support (including partner, family and friends), current circumstances and future goals. Detailed demographics are reported in Supplementary File S4 and are representative of the overall survey sample. We report the qualitative thematic analysis below, with key themes presented as overall barriers to starting a family from the women's perspectives. We identified seven themes:

##### 1. Kidney disease deprived women of their femininity.

Women perceived kidney disease as something that took away, or was in the process of taking away, their womanhood. This included both their relationship with their current partners and possible (future) sexual relationships and had a negative impact on women's daily living including experiences of pregnancy planning, motherhood and parenting.

Women often recalled that their sex life was a real challenge. Loss of libido caused by treatment, and inhibitions often as a result of changes to physical appearance, for example, weight gain/loss and scarring negatively impacted sexual relationships. Bedrooms were described more like hospital settings (including bleeps from machines and smells of sterile equipment) and many women felt that partners became less sexually attracted to them due to treatment burden.

"it was so awful being on dialysis, the tubes sticking out of me, the machine beeped through the night, it honestly smelt like a hospital, who wants to have sex

in that...he (partner) didn't admit it at the time but he said afterwards that he was too scared to touch me, that I would break, he saw me as this fragile thing...”(P03, F, 18–35, High School qualification age 18, not married/living with a partner, has children, thinking about having more, transplant).

In cases where women were single or had relationships that broke down, many felt overwhelmed at the thoughts of starting a new (intimate) relationship in particular discussions about having children.

“I don't know what I am I going to do, I mean how do you bring this up, it is not exactly first date talk but at the same time if I want to have a baby I need to bring it up straight away. I can't exactly lie about my situation” (P22, 18–35, mixed race, single, uncertain CKD stage, college degree, works parttime).

## 2. Women do not know what they do not know.

For many women, their kidney disease had an unknown cause, disease progression was unclear, future treatment and reproductive options were not well understood or spoken about and future health was an unresolved issue. These uncertainties directly impacted women's perception of their capacity and capability to have and raise a child, leaving them unconfident to start and engage in a conversation about reproductive options and choices with their healthcare team. Many women expressed confusion and worry about their future treatment plans in relation to reproductive health.

“I mean I just never thought about it really. Nobody mentioned it but now I have a job, am settled we are starting to think about it. On my next appointment I want to bring it up, but I have no idea where to start”. (P02, F, 18–35, College degree, never been pregnant, lives with partner, on dialysis).

“I just feel so in limbo now – we will see what my appointment brings tomorrow but I do not know what is possible or not and I don't really trust what has already been said as it is contradictory and there has been no continuity to date.” (P-FN04, F, 36–50, higher degree or professional qualification, married or in civil partnership, no children/wants fertility treatment).

## 3. Motivations and subsequent behaviours for when and if to have children were highly heterogeneous.

Motivations for having or not having children varied and there were multiple influences on these decisions including health, psycho/social and environmental factors which made planning for children appear complicated, daunting and even frightening for women. Linked to this, we found that unplanned pregnancies were common

and influenced by many factors but in particular perceived lack of helpful opportunities to discuss their specific preferences and goals for having a family.

Many women reported fear and anxieties over what *might have come up* (e.g. told that they could not have children, to wait, that their kidney had failed and this is what needs to be a priority, and/or judged for even wanting a child in the first place) in a conversation with a healthcare professional as rationale for an unplanned pregnancy. Some started to have conversations but in-between had an unplanned pregnancy. Others felt that their diagnosis was either so rare or so removed from being able to have a pregnancy (e.g. born without a womb or early onset menopause) that they felt too worried or overwhelmed with fears of what a pregnancy, and a conversation about having children might involve that they defaulted to what they saw as an easier option—to not discuss anything. Some women reported initial conversations as frustrating and unhelpful and sometimes even perceived the unplanned pregnancy as a type of revenge for poor care.

“well they were not really listening to me, so I said right I will just do it and then they will have to just deal with it” (P-FN05, F, 18–35, college or university diploma or degree, no partner, wants to become pregnant).

Many women felt embarrassed and even ashamed by their perceived ignorance and this had potential to result in an unplanned pregnancy.

“I honestly feel so embarrassed, I mean at my age I should know, right? But I have honestly no idea what my options are.” (P17, 18–35, high school qualification, CKD stage 3, never been pregnant, in a relationship, never been pregnant, wants to have children).

Often women were unaware that their kidney disease may require carefully planned pregnancies and took the position that it would happen as a natural progression in their lives. Some were unaware that they had kidney disease and found out while they were pregnant or soon afterwards.

We found that tipping points for wanting and not wanting (more) children were similar but had different reasons. These are expanded and explained in [Box 2](#). Often, women either assumed that they could not have a pregnancy or were told that they could not and so never fully considered starting a family. Other women went to extensive lengths to have a pregnancy. If unsuccessful, this was followed by many years of trauma, loss and grief until they felt that they had given all they could and accepted that it was just not going to happen for them.

## 4. Women had no experiences of integrated family planning in their care pathway and there was no evidence of validated guidance, support or tools to help from the women's perspective.

**BOX 2 Motivations on decisions for having a family, key tipping points.****Women who said no to any (more) children**

*Health (especially post-transplant).* Many women did not want to put their kidney at further risk or harm their (new) kidney

*Age.* Many women felt too old to carry or raise a child

*Partner.* Partners either did not want children or the partner did not want to risk further harm to the women (especially if they already had a child via pregnancy)

*Family.* Family members did not want to risk increased harm to women's health

*Single.* Some women did not want to have a child without a partner

*Sense of security (finance, job, house).* Some women said that they felt finally settled in life and did not want to change or disturb their current circumstances

*Systems too hard.* Some women reported that navigating the various healthcare systems and processes too overwhelming and either disengaged from the process or never felt confident enough to start it

*Balancing medications.* Many women said that they had long-term and ongoing issues with balancing their medications to manage their disease. The thoughts of disrupting this was too much for some to think about a pregnancy

*Passing on disease (personal views and wider judgements).* Some women with hereditary kidney disease said that they would not want to risk passing it on. Others although they may have wanted a child said that wider social judgements made them reconsider

*Do not want to be heartbroken (again).* Many felt the thoughts of trying and not having a baby too much to take on. This was especially the case if women had already suffered a loss

*Societal pressures.* Many women said that they felt judged as selfish for wanting a pregnancy which would cause a risk to their kidney, their health or passing the disease on and so elected not to have a pregnancy

**Women who said yes they wanted (more) children**

*Health (especially post-transplant).* Many women felt that they had been given a new life and an increased chance of having a successful pregnancy. Women who had previously especially poor health or had a complicated pregnancy experience felt that this was their chance for a "normal" pregnancy

*Age.* Many women felt that they were getting too old, running out of time and these anxieties increased with clinical setbacks (e.g. delays to transplant)

*Partner.* Many women felt pressure from their partners to have a pregnancy. In spite of many women's preference for a family but not by pregnancy (e.g. adoption/surrogacy). Some women often bowed to a theoretical plan of having a pregnancy first and then exploring alternate options

*Family.* Some women reported how devastated their family would be if they did not have a child. Some women also reported high anxiety at the thoughts of bringing up that they may not have (or may not want to have) children. Women often felt that family members did not understand their disease condition or the risks involved. We saw some evidence that this was especially difficult for women from ethnic minority backgrounds

*Single.* Some women saw this as an opportunity to have a family irrespective of having a partner

*Sense of security (finance, job, house).* Some women felt that they had reached a stage where they felt settled and secure and ready to have and raise a child

*Systems too hard.* Some women described the process of having a pregnancy as the final step, that they come this far it seemed silly or a waste of everybody's time to stop now

*Always wanted children.* Some women said that their primary role and goal in life was always to be a mother and there was nothing stopping them

*Everybody has one, now it is my turn.* Some women felt that their social networks were suddenly decreasing or being reconfigured and this was now their opportunity to have a child

*Did not want to have any regrets.* Although some women said that they did not necessarily want a pregnancy now, many said that they did not want to regret not trying in the future

*Societal pressures.* Many women felt that as women, it was their duty to have a pregnancy and that is what is expected of them in life, irrespective of their kidney disease

Many women felt that they were the ones bringing up discussions about reproductive options. Women often described having to work hard and over a long time to "get up the courage to go and bring it up" and to progress onto a pathway or treatment plan which they

found met their individual needs. Many women felt that healthcare professionals were afraid to bring up reproductive conversations due to the increased risk to their kidneys, uncertain outcomes and that they would become more complicated patients.

"healthcare professionals naturally want to keep us healthy and avoid any complications, I mean that is what she said, 'it is not something we recommend but if it is what you want we will go with it' and now I have my plan." (P02, 18–35, college diploma, works fulltime, on dialysis, married, never been pregnant, wants to have a pregnancy).

Sometimes women felt that the reproductive health plans they were presented with were more of an "ideal picture", rather than mapped to what their current circumstances were and what they wanted in the short to interim term. However frequently the "ideal picture" did not happen and it caused increased anxiety due to perceptions of running out of time.

"I feel like I have been sold one picture - I would be transplanted in a few months, then maybe wait a year and then baby time, but here I am two years on and no sign of a transplant, I feel in limbo" (P-FN04, F, 36–50, higher degree or professional qualification, married or in civil partnership, no children/wants fertility treatment).

Women consistently reported that they did not know where to go for information that was relevant to them and their current circumstances. Chance encounters with social media groups and posting questions on chats were frequently described as the most helpful, some women said that this is where they first heard a pregnancy with kidney disease was even possible. When women wanted to start discussions varied significantly and there did not appear any patterns related to CKD stage, age or any other demographics. Women as young as 18 wanted a full detailed pregnancy plan and many women were considering pregnancies later in life (often after their career and home buying status had settled) and many women had progressed well into their 40s without ever considering a pregnancy just assuming that it would happen. In some cases women with inherited kidney disease were prompted to think about it following their parents' progression into kidney failure.

"It really was only this year as my Dad is now being worked up for transplant that I have started to think about it. I'm in my last year of Uni, I have a boyfriend and we just assumed we would have children, but now I'm thinking and I have no idea what my options are, I need to go and find out, but I don't know where to start" (P17, 18–35, at university, CKD stage 3, partner, never been pregnant, wants to have a pregnancy).

Women often found routine clinics/check-ups unhelpful with regard to pregnancy planning, they were too short and/or were seeing too many different healthcare professionals to progress conversations. Re-explaining their current circumstances or future preferences sometimes became so frustrating women disengaged from (trying to pursue) their reproductive goals. In contradiction, some women had the same

nephrologist for years and still did not feel that they could have helpful discussions about having children. Sometimes women had discussed options, started on a pregnancy pathway but due to changes in personal circumstances decided not to have children (e.g. career progression or travelling opportunities) and in these cases, some women felt guilt and hesitated to tell their kidney care team that they had changed their mind about having children.

"All of these resources and discussions have gone on and now I have changed my mind, I feel like I have wasted everybody's time, like I need to have a baby to thank my kidney doctor or something, I know it is crazy but sometimes I feel pressure to gift them with a baby at the end of all this!". (P27, 18–35, higher degree, fulltime employment, CKD stage 3, changed mind about having children, does not want any children).

Women's recommendations for when to start discussions varied considerably from as soon as they are adults, when given a diagnosis, starting treatment or thinking about having a family. Sometimes women's recollection of when they first heard about pregnancy was a negative experience and frequently reported feeling unprepared, not ready to discuss, uncomfortable discussing, embarrassed or confused.

"I remember the doctor first brought it up in front of my parents, he said something like oh if she is ever planning on getting pregnant we need to talk about that, I just remember wanting the ground to swallow me up" (P23, 18–35, unemployed, uncertain of disease stage, had a termination, wants children in the future).

"The first time I remember it being mentioned was with my medication, they said I am putting you on this but listen it is really important you do not get pregnant. That has stayed with me through to now I even feel a bit of resentment to my (medication), it has even affected my sex life over the years, I've been so worried about not getting pregnant, I don't actually think I've ever had a normal sex life" (P27, 18–35, higher degree, fulltime employment, CKD stage 3, changed mind about having children, does not want any children).

At the same time, some women felt that they had to over qualify the fact that they did not want children and felt annoyed that the question kept coming up from multiple and often unqualified or unhelpful sources.

"I mean, I've had other doctors, other specialists, that have nothing to do with pregnancy saying to me, 'You're getting on a bit now, so if you want children I think you should just get on with it.' Or I've had the other way around, which is, 'Oh, so you're trying to get pregnant? Aren't you a bit old for that?' You just get to a point where you go, really? Does that actually

have anything to do with you? I don't think it does. You're a man and you can do it for as long as you want, so just back off" (P29, 36–50, high school, not married/living with a partner, never been pregnant/does not want children).

5. *Complicated pregnancies, miscarriages and stillbirths were common and women frequently reported unmet health and social care needs as a result.*

Women reported pregnancies as a roller coaster of worry about their (transplanted) kidney, baby, partner, family and health and mental well-being. Often, it was described as exhausting, a state of always working without respite. Very few women said that they received specialist care for these needs during or post pregnancy. Many women felt that their pregnancy care was often too focused on the risk to their kidneys and as a result many women felt that they missed out on a "normal" route (e.g. home births, routine midwife appointments and even social events such as baby showers) but this was sometimes balanced with getting to spend more time with their baby, for example, more time to listen to babies heartbeat and more scan pictures.

6. *Mothers' unmet and often unrecognized needs resulted in high(er) health risk behaviours and this was especially evident in new mothers.*

Women reported a whole spectrum of experiences from having a child made life worth living to developing chronic anxiety and some women's health deteriorated to the point that they almost died. Many women in hindsight either struggled to recognize that they were not OK or acknowledge that they lacked the confidence to reach out for support. Many women's unmet mental health needs or new health-care needs were offset by being a (new) mother, "my quality of life has improved beyond any words but my kidneys have been adversely affected" but many women felt that such a fear of not being a good enough mom that they commonly overlooked their health needs. Lack of energy, incapacity to nurse or "not being able to reach out when they need me as I am stuck on my machine" were key sources of frustrations. Sometimes, it was first-time mothers who appeared less likely to reach out but always in hindsight wish they had.

"I was just so tired back then but I was so determined – it is silly now looking back but I remember getting a taxi to the top of the hill just so that I could walk my son into school". (P24, 36–50, University degree, works fulltime, has children, does not want anymore).

Women often reported a lack of understanding from partner, family and friends and this caused tensions and tendencies to increase high risk behaviours. Mothers with older children sometimes reported that their stays in hospital resulted in anxieties for their children.

"My youngest still worries about me, every time I go to hospital I have to say "don't worry I will be back at this time" and she is really worried about me having another baby – that I will not come home and what will happen to her. We have had to sit down and talk about it but she is only 11"(P-FN05, F, 18–35, college or university diploma or degree, no partner, having one or more children/wants to become pregnant).

7. *Options for alternates to pregnancy were not well understood or routinely discussed.*

Some women interviewed reported that their first choice/preference for having children would be an alternate to pregnancy (e.g. adoption, fostering, surrogacy) but this was not how conversations or experiences tended to progress.

"it is more like a treadmill of options until you run out, with pregnancy first, fostering last and everything else somewhere in between, nobody has ever sat down and had detailed discussions about the various options and what they involve for me" (P12, 36–50, higher degree, works fulltime, CKD stage 3, has been pregnant but no children, wants children but not necessarily a pregnancy).

Wider service providers often felt ill-equipped to manage women with CKD as by the time they saw them they had experienced significant (mental) health trauma. Many women described their experiences with wider services as unhelpful and many never progressed into the system due to their kidney disease automatically excluding them as potential candidates.

"Once they get to our door they have been through such emotional and often physical trauma we are providing grief counselling, trying to manage expectations, and at the same time we do not know anything about their kidney disease. Then everything has to start again for these women, it is often just too much" (stakeholder engagement).

#### 4.5 | Integrated key findings and developing actionable points for improving practice

We have mapped the principal integrated quantitative and qualitative findings using the BCW and TDF in [Box 3](#), which includes a set of actionable points and associated questions to support stakeholders as a first step to addressing women's unmet needs (Michie et al., 2014).

**BOX 3 Behaviour change wheel, theoretical domains framework and actionable questions for practice.***Stage 1*

- Define the problem in behavioural terms

Women with CKD are making uninformed and uneducated decisions about family planning and pregnancy, and in some cases are putting themselves and their foetus at risk of serious harm.

- Select the target behaviour

Evidence-informed pre-conception education, counselling and shared decision making between women (their partners) and members of the kidney MDT to ensure that the woman makes the best evidence-informed decision for her.

- Specify the target behaviour

Target behaviours include engagement by women and their partners with high-quality pre-conception education and counselling to agree an individually tailored approach to family planning and pregnancy through evidence-informed shared decision making.

- Identify what needs to change

Incorporation of family planning and pregnancy issues, education and counselling into the routine CKD care pathway; development of high-quality family planning and pregnancy education materials for women and their partners, further training of the MDT to incorporate counselling and education skills into the routine care pathway, development of integrated kidney and maternity care for the woman and her baby, implementation of a core outcome set, monitoring and surveillance of mother and baby outcomes over time; development of research priorities and an associated research programme to further enhance the evidence base for shared decision making. Development of peer support groups for women, their partners and families. Greater integration of primary care (GPs), midwives (including community support) into the care pathway so that care and support are seamless across boundaries. Increased awareness and understanding of alternate options to pregnancy across the NHS kidney care pathway. Additional clarity and guidance for wider services (adoptions, fostering, surrogacy, fertility) to better support women with CKD make informed decisions and gain access to their services.

Stages 2 (identify intervention options) and 3 (identify content and implementation options) are presented as a detailed matrix in Supplementary File S3 with additional sources of evidence.

Finally, we have produced a series of actionable questions designed to proactively and quickly engage changes in clinical practice and better support women with CKD who want to start a family.

*Actionable Questions**Individual nurse/professional*

- Am I up to date on clinical practice guidelines for reproductive options (including non-pregnancy options), if not, do I have a plan for upskilling?
- Am I integrating a model of shared decision making, (including tools and resources) with women in my routine practice?
- Do I adequately introduce and prepare women for shared decision making (e.g. sharing resources and tools and encourage patients to prepare their “ask three questions” before clinics)?

*Services health—does your service*

- Introduce reproductive conversations as part of routine clinical care and signpost to further information and sources of support?
- Routinely engage with wider services, for example, fertility preservation and options clinics and seek to connect CKD patients to these services?
- Have a specific care pathway for women who want a pregnancy, are currently pregnant or post-natal care?
- Have a patient peer support group to help women in their decision making?
- Have a partner, family and friends peer support group to better understand risks and potential outcomes?
- Have a specific counselling/bereavement care support service to connect women to?
- Contribute to research on this topic, for example, registering women in clinical trials, supporting NICE guideline updates etc.

*Services wider (GPs, midwives, adoption, fostering, surrogacy)—does your service*

- Have up-to-date and accessible guidelines on women with kidney disease who are thinking about starting a family.
- Routinely signpost to expert education programs and sources of support.
- Seek to better understand the needs of women and address any barriers to them becoming parents, for example, assessment criteria for adoption/fostering.



## 5 | DISCUSSION

Women were highly motivated to engage in shared decision making, but this was not always happening in practice—partly because in many cases conversations about whether the women wished or were planning for a pregnancy simply were not taking place. When conversations about preferences for having children were taking place, there was a reasonable degree of shared decision making, but there was room for improvement. On the level of individual women, decision self-efficacy was important in engaging in shared decision making—although we do not know what the direction of this relationship was—that is, were they engaging in more shared decision making because they were more confident or were they more confident because they had more (positive) experiences of shared decision making (or both).

Wider social support was independently associated with decision self-efficacy, which may be indicative of stronger social networks contributing to generally better well-being and self-esteem and/or provides women with an opportunity to consider and discuss their options with their informal support network. Those who were considering having children or had not decided yet had a high level of unmet information needs on a range of topics relating to their reproductive options.

Having a high level of information needs was not independently associated with the shared decision-making outcomes. This could be for a number of reasons—some women, for example, may have high information needs because they are highly motivated and engaged in decisions about their health whereas others may be struggling to find information and thus less likely to engage in shared decision making. It is likely that educational interventions alone will not shift the power dynamics in consultations nor will they increase the availability of opportunities to engage in conversations with health professionals—so while knowledge is an important foundation for shared decision making, it is not sufficient in itself to make it happen (Joseph-Williams et al., 2014).

Our models were statistically significant and did explain some of the variance in shared decision-making outcomes, but a lot of the variance was left unexplained, highlighting the need to look at clinical and system-related factors in supporting shared decision making, rather than just focusing on the patient. Shared decision making should ideally take place routinely as “business as usual”, but recent evidence suggests that despite substantial investment and developments of multiple decision aids and resource packs for patients and staff, shared decision making has yet to be widely adopted (Elwyn, 2019). Complicated healthcare pathways, cultural biases, staff training (including confidence and experience using shared decision making), modifying patient expectations, language and cultural communication barriers, a lack of adaption across all management levels are just some of the known complications to adopting shared decision making in routine practice (Mc Laughlin, 2021). Specialist CKD nurses appear to be following the medical and disease orientated focus of care and care pathways

and are not consistently including women's reproductive health as part of their remit.

As other studies have shown, women's reproductive health, their ambitions and life goals are not always considered alongside their kidney disease (Jesudason & Tong, 2019). Previous research identified some of the complex decisions women need to make and their desires for more control (Tong, Brown, et al., 2015). We have found that discussions about pregnancies (timing, content, mode of delivery) are not always working and highlighted additional needs across the care pathways including wider services. Recent studies have also shown an overreliance on shared decision making to bring about change when often the basic infrastructure including resources (staff and administration), bias, culture, training, etc. are not yet well enough established to adapt (Elwyn, 2019; Mc Laughlin, 2021). This research confirms these barriers in relation to women's reproductive health and CKD.

### 5.1 | Suggestions for future research and unanswered questions

New research is needed into the health and reproductive care of women with kidney disease to address inequalities including agreed sets of core outcome measures, intervention development, controlled trials of their effectiveness, and additional patient and public involvement to start to build up new feminized healthcare pathways including new understandings of what works, for whom and why. Additional research is needed to better represent ethnic minority perspectives and if additional measures are needed for best support, for example, language and cultural differences. Ongoing research is needed to address how actions, decisions and perceptions change over time, for example, the needs of younger women as they transition into adulthood and adult healthcare services, and perspectives of women in later life including their specific health needs, for example, menopause. Some recent interventions such as One Key Question may be amenable to adaption for women with kidney disease, especially to support healthcare professionals to modify their behaviours to include reproductive health conversations as routine. Any such intervention would need to account for the specific needs of women with CKD as well as available staff and resources to implement at scale (Song et al., 2021; Stulberg et al., 2020).

### 5.2 | Strengths

As far as the authors are aware, this was the largest single survey with women with CKD and their reproductive health to date. A strength is the mixed-method design to capture detailed experiences of a highly personal topic. Additional patient and public input enabled further perspectives on wider services, their current policies and practices. Although the study took place in a UK healthcare setting, outcomes should be applicable to similar healthcare contexts.

### 5.3 | Limitations

We originally estimated around 5000 women were in the Welsh Vital-Data system, and this was actually closer to 2300. We had planned to contact women in Wales twice to invite to take part, but this was impractical as most women did not have email contact details. Due to time and resources we were unable to include the healthcare professionals' perspectives, younger adults (under 18) and older adults (over 51). Participants were predominately white and not representative of the UK population—this may be explained by the focus on Wales which has a predominately white population. Ethnic minority and social deprivation perspectives are a noted gap. Nonetheless, there is currently no evidence to suggest that these groups are any better supported to contraindicate the findings in our sample. The study took place during COVID and multiple lockdowns which may have negatively affected recruitment. Four hundred and thirty-one surveys were completed out of a 500 target, interviews did not appear to be negatively affected. We found the BCW and TDF had limitations for especially complex interventions with multiple goals and potential outcomes. Some of the domains appeared repetitive, stakeholders did not always see connections with the categories and the phenomenon of interest and many outcomes seemed to apply to more than one category.

## 6 | TERMINOLOGY DECLARATION

This study is situated in the context of women's reproductive health, which relates to the diagnosis and treatment of diseases that affect those with female physiology. The sample of women was largely derived from a medical database that used the biological and medical classifications of male and female. We use terms such as woman, women, female and feminine throughout as this was the language used by the participants themselves and best describes the phenomena of interest, the study cohort, the findings and unmet need. In particular, we refer to the need for feminizing the kidney care pathway and make the case that traditional kidney care pathways were not designed to accommodate female reproductive health for women with female physiology. By feminizing a care pathway, we mean to make the care pathway more characteristic of or associated with those with female physiology. The *Journal of Advanced Nursing* is also a global nursing journal and the language used needs to be easily translated and universally understood by the global nursing readership, for whom English is not a first language. We do however acknowledge that the terms used are gendered and some people who have female reproductive physiology do not identify as women and some people with male reproductive physiology identify as women. A sensitive and individually tailored approach is needed to support the enhancement of gender inclusivity within the general framework of women's reproductive health for those with female physiology.

## 7 | CONCLUSION

There are limited resources available for education and support for women's reproductive health within the context of CKD, and what is available does not address the highly personal decision making, multiplicity of options, heterogeneity of kidney disease in addition to cultural and social contexts—which are changing at pace particularly in a global context. Nurses and other healthcare professionals need (re)training and upskilling to implement high-quality and more personalized shared decision making for women with CKD. Service commissioners need to identify opportunities in the care pathways to introduce reproductive health as routine and where there are gaps either adapt existing interventions or develop new ones. New research and an increased clinical and nursing emphasis, in particular the ways specialist nurses can facilitate and implement change, are needed to address the health inequalities in women with CKD uncovered in this study.

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## CONFLICT OF INTEREST STATEMENT

Noyes (co-author) is an editor for JAN. No other authors declare any conflict of interest.

## PEER REVIEW

The peer review history for this article is available at <https://www.webofscience.com/api/gateway/wos/peer-review/10.1111/jan.15659>.

## DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

## ETHICS STATEMENT

The study received full ethical approval. Wales REC 1 committee 20/WA/0157.

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