

Feminising 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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1 **Main file**

2 **Short informative title**

3
4 **Feminising care pathways: Mixed-methods study of reproductive options, decision making,**
5 **pregnancy, post-natal care and parenting amongst women with kidney disease.**

6
7 **short running title**

8
9 Reproductive choices with kidney disease

10
11 **ABSTRACT** (300 words)

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

14 **Design:** UK-wide mixed-methods convergent design (Sep20-Aug21).

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

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

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

28 **Impact:**

29 **What problem did the study address?**

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

32 **What were the main findings?**

33 Women lack the knowledge, resources, and opportunities to have high-quality conversations with
34 their healthcare professionals. Decisions are highly personal and related to a number of health,
35 social and cultural factors; individualised approaches to care are essential.

36 **Where and on whom will the research have impact?**

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

39
40 **Patient or Public Contribution**

41 The original proposal for this research came from listening to the experiences of women in clinic
42 who reported unmet needs and detailed experiences of their pregnancies (positive and negative). A
43 patient group were involved in developing the funding application and helped refine the objectives
44 by sharing their experiences. Two women who are mothers living with kidney disease were co-
45 opted as core members of the research team. We hosted an interim findings event and invited
46 patients and wider support services (adoption, fertility, surrogacy, education and maternal CKD
47 clinics) from across the UK to attend. We followed the UK national standards for patient and public
48 involvement throughout.(NIHR, 2018)

49
50 **Key words:**

51 Women, pregnancy, parenting, shared decision-making, mixed-methods, qualitative, survey, nursing,
52 kidney disease

53

54 INTRODUCTION

55 Women make up 50% of the global population and have unique healthcare needs.(Development,
56 2016; Medicine, 2009; National Library of Medicine, 2022) Yet ‘gender gaps’ associated with generic
57 approaches to the clinical management of multiple diseases and healthcare pathways are
58 increasing.(Caruso et al., 2019) Known gender gaps leading to inequalities include unequal access to
59 services, less positive experiences of care and support, and poorer health outcomes. Women are
60 also underrepresented in health research and rarely included as a separate group for analysis.(Allen
61 & Sesti, 2018) Some claim women have become so ‘invisible’ in big data it has effectively resulted in
62 a global scale research bias.(Sperber, 2021) Far less is known about health conditions that only affect
63 women and gynaecological health in general. (*World Economic Forum*, n.d.) Reasons for these
64 disparities are complex (Temmerman et al., 2015) and more recent reports published by the World
65 Health Organisation (WHO) link women’s health inequalities to wider socio-economic issues,
66 embedded cultural differences, stereotyped gender roles and unequal power relationships including
67 physical, sexual and emotional violence.(Royal College of Nursing, 2022; WHO, 2022) In the United
68 Kingdom (UK) the National Health Service (NHS) has received recent criticism highlighting that
69 women have been disadvantaged for generations living with a healthcare system that is designed by
70 men, for men. (Winchester, 2021) This gender disadvantage happens despite around half of doctors
71 and the vast majority of nurses being women. In response the first UK government-led national
72 women’s health strategy was commissioned. Due to be published in 2022 it will include plans to
73 improve quality and accessibility of education, self-care and shared decision-making, ensure health
74 needs are met throughout women’s lives (including workplace health), levelling up research and
75 addressing women’s’ needs in the wake of the COVID 19 pandemic.(Department of Health and Social
76 Care, 2021)

77

78 In addition to gender gaps associated with health systems and clinical management, women are also
79 over-represented globally in non-communicable diseases.(Bikbov et al., 2018) In 2021 the WHO
80 published their ‘6 priorities for women in health’ which included access to quality sexual and
81 reproductive health and reducing noncommunicable diseases in women, including Chronic Kidney
82 Disease (CKD).(WHO, 2021) CKD is progressive, there is no cure only treatment such as dialysis or
83 transplant. Recent research also indicates that women behave very differently to men when making
84 decisions about their future treatments options, for example population level data indicates that
85 more men are on a kidney replacement therapy but yet more women have a diagnoses of kidney
86 disease.(Antlanger et al., 2019) In the UK women with CKD are looked after by multi-disciplinary
87 healthcare professionals including specialist nurses and advance care practitioners.(Shi et al., 2018)
88 Their unique experiences living with CKD are not well understood and evidence based interventions
89 to support these women across complex decisional and care pathways including planning for
90 children, pregnancy and motherhood remain critically lacking. (Mc Laughlin and Noyes 2022)

91

92 BACKGROUND

93 CKD is classified by level of function from stage 1 (mild) to stage 5 (severe).(Kidney Research UK,
94 2022) When most advanced, dialysis or a transplant are necessary.(National Kidney Foundation,
95 2013) Despite the adverse consequences of CKD many people experience little to no symptoms until
96 their function has fallen to a very low level.(Mayo clinic, 2022) Although CKD can affect fertility,
97 pregnancy is possible at any stage of kidney disease, including while on dialysis or with a
98 transplant.(K. S. Wiles et al., 2018) Pregnancies in women with CKD are at high risk of complications,
99 which can affect both the mother and her developing baby. Specific concerns include the teratogenic
100 risk of pre-existing treatment, pre-eclampsia, intra-uterine growth retardation and prematurity.
101 There is an increased risk of miscarriage and later stillbirth. If the baby is significantly premature,

102 admission to the special care baby unit may be required, and there may be subsequent
103 developmental issues associated with prematurity. Delivery is more likely to be associated with
104 medical intervention. It is therefore recommended that pregnancies are carefully planned and
105 monitored with the involvement of a multi-disciplinary team (MDT) of healthcare professionals
106 including nephrologists, specialist nurses, specialist obstetricians, and additional psycho/social
107 support services where needed.(Horsager-Boehrer, 2019) Once pregnant, women may be cared for
108 by a midwife who specialises in high risk pregnancies. It may also be relevant to discuss the
109 heritability of specific forms of kidney disease.(National Kidney Foundation, 2022)

110
111 Women with CKD will need to consider these factors and more when thinking about becoming
112 pregnant. Studies exploring women’s perspectives while considering a pregnancy highlight complex
113 health and social dilemmas such as decisional conflict, uncertainty and balancing family roles.(Tong,
114 Jesudason, et al., 2015) Recent clinical trials exploring the impact of CKD stage 3-5 on pregnancy
115 outcomes, have aimed to move away from collecting and presenting outcome data as a whole and
116 towards developing tools to better support women by answering ‘what are the risks of pregnancy
117 for me?’(Wiles, 2021) However, an updated systematic review of women’s experiences and
118 interventions to support them also found that the majority of recent research tends to have a
119 narrower focus on pregnancy outcomes.(Wiles et al., 2020) So called ‘alternate options’ e.g.
120 adoption, surrogacy and fostering are scarcely reported in the literature, nor are experiences of
121 interventions to enhance pregnancy options such as egg preservation and In Vitro Fertilisation (IVF).
122 To address some of these gaps an updated qualitative evidence synthesis was undertaken that
123 reported little change in the management of women’s reproductive health in 20 years, no evidence-
124 based interventions, and large gaps concerning the expectations, goals, values and experiences of
125 women with kidney disease who may (or may not) want to start a family. A new health systems
126 model based on other health conditions with established personalised reproductive care packages
127 e.g. cancer was developed. [REDACTED]

128 129 **Shared decision-making**

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

137
138 The impetus for this research was clinical and informed by patient and public input which indicated
139 women were not getting the focussed information and support to make preference based
140 reproductive choices. To inform the development and implementation of interventions to facilitate
141 shared decision-making in this context, we first needed to understand how women with CKD
142 currently make decisions about starting (or enlarging) a family, their experiences of engaging in
143 shared decision-making during their interactions with nurses, healthcare professionals and services,
144 and their needs and preferences for support with these often complex and emotive decisions.

145 146 **THE STUDY**

147 **Aim and objectives**

148
149 To identify the needs, experiences, and preferences of women with kidney disease in relation to
150 their reproductive health to inform development of shared decision-making interventions by:

151

152 1. Identifying needs and preferences of women of reproductive age with kidney disease by
153 improving our understanding of how women make decisions about pregnancy, and investigating
154 associations between pregnancy, health, well-being and psychosocial contexts.

155 2. Constructing a theoretical framework for decision making in relation to pregnancy, an essential
156 first step in the development of a preconception shared decision-making intervention for use in
157 clinical practice.

158 **Theoretical framework**

159

160 We underpinned the research with the MAGIC (Making Good Decisions in Collaboration), three talk
161 model of shared decision-making. (Elwyn et al., 2017) (Supplemental file.1) We also incorporated
162 behaviour change theories adapted from clinical psychology (the Behaviour Change Wheel, BCW)
163 and implementation science (Theoretical Domains Framework, TDF) – tools designed to develop
164 interventions to influence or change behaviours – to learn more about what changes might be
165 needed and where they may be most likely to have an effect.(Cane et al., 2012; Michie et al., 2011)

166

167 **Design**

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

173

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

179

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

187

188 **Sample/Participants**

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

193

194 **Data collection**

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

198

199 Online Survey

200 The online survey was carried out using Online Surveys (formerly known as Bristol Online Survey,
201 <https://www.onlinesurveys.ac.uk>), and was open to enrolment from 01st Sep 20 – 03rd Aug 21. The
202 survey was adapted from ongoing research into pregnancy decisions and Cystic Fibrosis (Duckers,
203 2019), and asked about: women’s kidney disease (including cause, stage and treatment), pregnancy
204 choices and current circumstances, experiences of pregnancy including perceived impact on general
205 health and well-being, communication with health and social care professionals, contraception and
206 birth control, information needs, support networks and demographic details. At the end women had
207 the option to share their contact details for a potential follow up interview. We describe the
208 measures in further detail in Box 1.

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, 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). (Group, 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., 2013a) 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. to listen to the things that matter most to you, and 3. to 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 was 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.(Blumenthal, 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, (Blumenthal, 2001) with low perceived social support being defined as having a score of ≤ 2 on at least 2 of the 5 items, and a total score of ≤ 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?.'

209

210 Survey sampling and recruitment

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

219

220 In addition to direct recruitment through the NHS kidney services in Wales, the survey was made
221 available across the UK via social media (Twitter and Facebook), publicised through kidney charity
222 partners (Kidney Wales, Kidney Care UK, Paul Popham Kidney Fund, Polycystic Kidney Disease
223 Charity), wider charity partners (Lupus UK, Fair Treatment for Women in Wales, Endometriosis UK,
224 Diabetes UK) and the Rare Disease Registry, Radar. The study was also advertised via direct mail outs
225 by charities who agreed to send directly to their mailing list and alongside two case studies
226 published in the UK leading kidney charity magazines (Kidney Matters, Kidney Care UK and Kidney
227 Life National Kidney Federation, NKF). The team also compiled a mailing list of NHS staff and wider
228 stakeholders which was added to overtime and produced a monthly newsletter with updates as a
229 way to keep partners engaged and advertise for people to take part. Further details of recruitment
230 including a timeline of events is provided in supplemental file.2. (supplemental file.2)

231

232 Interviews

233 Women who completed the online survey and had indicated that they would be interested in a
234 follow-up interview and fitted the purposive sampling frame (Table. 1) were initially contacted via
235 telephone (or email if no contact number provided). Semi-structured interviews including visual aids
236 e.g. timelines and colour coding specific narratives to feelings and perceptions over time were
237 designed to empower women to share what mattered to them. These had been used in previous

238 similar studies and elicited positive responses.(Goldenberg et al., 2016) When contacted the study
239 was explained in further detail and women were invited to take part at a time and date convenient
240 to them. The topic guide and visual timeline were shared prior to the interviews via email. Informed
241 consent (verbal or written) was taken before each interview. Interviews were offered in Welsh or
242 English. English interviews (n=28) were undertaken by an experienced female researcher with a
243 PhD. Interviews in Welsh (n=2) were undertaken by an experienced kidney social worker who was
244 also a core member of the research team. Most people who were spoken to consented to an
245 interview. Three dropped out due to time commitments, rearranged clinic appointments or recent
246 bereavement. N=23 interviews were undertaken on Teams/Zoom and n=7 via telephone. All
247 interviews were audio-recorded, i.e. video was not recorded during video calls. All women were
248 interviewed once, either alone or looking after their very young children. Detailed fieldnotes were
249 taken and each interview lasted around 60 minutes. We stopped recruiting when n=30 interviews
250 (the initial target sample) had been completed and the team felt data saturation was reached.
251 Interviewers had no known prior relationship with participants. However, following one follow-up
252 call it became clear on introductions that the participant did know the researcher through mutual
253 professional contacts. The participant was offered an interview with a different researcher, they felt
254 this was unnecessary and were happy to participate. Women were thanked for their participation
255 and asked if they would like to receive a report of the research once completed.
256

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.

257 258 **Data analysis**

259 260 Survey

261 Analysis of the quantitative data was carried out using SPSS.v.27. Descriptive analysis was used to
262 provide an overview of the clinical and demographic characteristics of the survey participants, and
263 their well-being, shared decision-making preferences and information needs. We fitted multivariable
264 regression models with the collaboRATE mean score and extent to which preferences for having
265 children had been considered by women's healthcare team as the outcome variables and the
266 following predictors: Decision Self-efficacy total score, ENRICHED Social Support total score, age,
267 perceived general health, on dialysis (yes/no), have had a transplant (yes/no), education (college
268 educated/not college educated), and family status (have children already/do not have children). The
269 'enter' method of regression was used with missing cases excluded listwise. A multivariable
270 regression model was also fitted with Decision Self-efficacy which may be an intermediary variable
271 for shared decision-making, using the same method and predictor variables. The models were then
272 repeated with the addition of the total reproductive options information needs scores, which only
273 applied to women who wanted to have children or were undecided. Based on Green's (Green, 1991)
274 rule of thumb for testing individual predictors, $N=104 + m$ (where m is the number of predictors), a
275 minimum sample size of 113 would be required for these analyses. Free text from the surveys was
276 uploaded into NVivo and analysed in the same way as the interview transcript data (see below).

277 278 Interviews

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

286

287 **Data integration**

288 Qualitative and quantitative data were collected concurrently, analysed separately and discussed
289 collaboratively (at core team meetings and stakeholder events).(Fetters et al., 2013) (Fig.1) Findings
290 were brought together through a matrix that was used as the mechanism of data integration
291 following the principles of mixed-methods framework synthesis, mapping BCW, TDF domains,
292 intervention functions, policy categories and behaviour change technique's to the sources of
293 evidence, alongside a summary statement of what needed to change to bring about good shared
294 decision-making. (Supplemental file.3). We used the Good Reporting of a Mixed Methods Study
295 (GRAMMS) framework and The Standards for Reporting Qualitative Research (SRQR) checklist to
296 report results and findings. (O'Brien et al., 2014; Roslyn, 2013)

297

298 **Validity and reliability/Rigour**

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

314

315 **Reflexivity**

316 The MDT core research team included clinicians, psychologists, social workers, academics, third
317 sector partners and women living with kidney disease. The team were all female who had various
318 perspectives and experiences which revealed the ways women's reproductive health needs were not
319 always being met. Biases were resolved through whole team discussion, recording detailed
320 fieldnotes as well as regularly returning to the data to confirm or deny key themes.

321

322 **Ethical considerations**

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

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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 summarised in supplemental file 4. (supplemental file.4)

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 summarised in Fig.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.

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 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 summarised in Table.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 values and significance of each variable entered into the models are provided in supplemental file. 5.

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

380 significant ($F_{9,227} = 4.733$, $p < 0.001$, Adjusted R square = 0.125). The only significant association in this
381 model was Decision Self-Efficacy score (Beta = 0.034, 95% CI 0.023, 0.046).

382 The model fitted for the extent to which women felt their preferences for having children had been
383 considered by their health and social care team when deciding on their treatment options was also
384 statistically significant ($F_{9,421} = 12.906$, $p < 0.001$, Adjusted R square = 0.199). Decision Self -Efficacy
385 was the strongest association in this model (Beta = 0.025, 95% CI 0.019, 0.030). Having children
386 already (Beta = 0.368, 95% CI 0.017, 0.719) and considering having children rather than having
387 decided not to have children (Beta = 0.406, 95% CI 0.027, 0.785) were associated with increased
388 perceived consideration of their preferences for having children by their health and social care team.

389 The model for Decision Self-Efficacy score was also statistically significant ($F_{8,422} = 3.818$, $p < 0.001$,
390 Adjusted R square = 0.05). Social support was the only significant association in the model (Beta =
391 1.227, 95% CI 0.633, 1.821)

392 *Adjusted models for information needs*

393 The regression models were adjusted to include only women who were considering having children
394 or were undecided who had completed an additional set of questions on their reproductive options
395 information needs. Adjusted models for CollaboRATE mean score ($F_{9,265} = 3.176$, $p < 0.001$, Adjusted R
396 square = 0.067) and for consideration of preferences for having children by their health and social
397 care team ($F_{9,265} = 8.142$, $p < 0.001$, Adjusted R square = 0.190), and Decision self-efficacy ($F_{8,266} =$
398 3.809, $p < 0.001$, Adjusted R square = 0.076) were all statistically significant.

399 No significant associations were found between total information needs and any of the three
400 outcome variables. Decision Self-efficacy remained a significant association in both the CollaboRATE
401 (Beta = 0.019, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI
402 0.017, 0.031) models. There was a significant independent association between social support and
403 consideration of women's preferences (Beta = 0.046, 95% CI 0.04, 0.087), but there was no longer a
404 statistically significant relationship between having children already and consideration of women's
405 preferences (Beta = 0.050, 95% CI -0.374, 0.474). In the Decision Self-efficacy model, social support
406 remained a significant association (Beta = 1.111, 95% CI 0.413, 1.809) and an additional association
407 with having children already was observed (Beta = 7.346, 95% CI 0.079, 14.61).

408 **Qualitative Interviews**

409
410 N=30 interviews were undertaken and explored women's decision making, planning for pregnancy
411 (including unplanned pregnancies, pregnancy loss and alternate options for starting or expanding a
412 family), impacts of changes in treatment on motherhood, experiences of healthcare and support,
413 psycho/social support (including partner, family and friends), current circumstances and future
414 goals. Detailed demographics are reported in supplemental file 4 and are representative of the
415 overall survey sample. We report the qualitative thematic analysis below, with key themes
416 presented as overall barriers to starting a family from the women's perspectives. We identified
417 seven themes:

418 **1. Kidney disease deprived women of their femininity**

419 Women perceived kidney disease as something that took away, or was in the process of taking away,
420 their womanhood. This included both their relationship with their current partners and possible
421 (future) sexual relationships and had a negative impact on women's daily living including
422 experiences of pregnancy planning, motherhood and parenting.
423

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

429
430 *“it was so awful being on dialysis, the tubes sticking out of me, the machine beeped through the night, it*
431 *honestly smelt like a hospital, who wants to have sex in that...he (partner) didn’t admit it at the time but he*
432 *said afterwards that he was too scared to touch me, that I would break, he saw me as this fragile thing...”(P03,*
433 *f, 18-35, High School qualification age 18, not married/living with a partner, has children, thinking about having more,*
434 *transplant)*

435
436 In cases where women were single or had relationships that broke down many felt overwhelmed at
437 the thoughts of starting a new (intimate) relationship in particular discussions about having children.

438
439 *“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*
440 *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”*
441 *(p22, 18-35, mixed race, single, uncertain CKD stage, college degree, works parttime)*

442 443 **2. Women do not know what they do not know**

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

450
451 *“I mean I just never thought about it really. Nobody mentioned it but now I have a job, am settled we are*
452 *starting to think about it. On my next appointment I want to bring it up, but I have no idea where to start”.*
453 *(P02, F, 18-35, College degree, never been pregnant, lives with partner, on dialysis)*

454
455 *“I just feel so in limbo now – we will see what my appointment brings tomorrow but I do not know what is*
456 *possible or not and I don’t really trust what has already been said as it is contradictory and there has been no*
457 *continuity to date.” (P-FN04, f, 36-50, higher degree or professional qualification, married or in civil partnership, no*
458 *children/wants fertility treatment)*

459 460 **3. Motivations and subsequent behaviours for when and if to have children were highly** 461 **heterogenous**

462 Motivations for having or not having children varied and there were multiple influences on these
463 decisions including health, psycho/social and environmental factors which made planning for
464 children appear complicated, daunting and even frightening for women. Linked to this we found
465 that unplanned pregnancies were common and influenced by many factors but in particular
466 perceived lack of helpful opportunities to discuss their specific preferences and goals for having a
467 family.

468
469 Many women reported fear and anxieties over what *might have come up* (e.g. told they could not
470 have children, to wait, that their kidney had failed and this is what needs to be a priority, and/or
471 judged for even wanting a child in the first place) in a conversation with a healthcare professional as
472 rationale for an unplanned pregnancy. Some started to have conversations but in-between had an
473 unplanned pregnancy. Others felt their diagnosis was either so rare or so removed from being able
474 to have a pregnancy (e.g. born without a womb or early onset menopause) that they felt too worried
475 or overwhelmed with fears of what a pregnancy, and a conversation about having children might

476 involve that they defaulted to what they saw as an easier option – to not discuss anything. Some
 477 women reported initial conversations as frustrating and unhelpful and sometimes even perceived
 478 the unplanned pregnancy as a type of revenge for poor care.

479
 480 *“well they were not really listening to me, so I said right I will just do it and then they will have to just*
 481 *deal with it” (P-FN05, f, 18-35, college or university diploma or degree, no partner, wants to become*
 482 *pregnant)*

483
 484 Many women felt embarrassed and even ashamed by their perceived ignorance and this had
 485 potential to result in an unplanned pregnancy.

486
 487 *“I honestly feel so embarrassed, I mean at my age I should know, right? But I have honestly no idea what my*
 488 *options are.” (p17, 18-35, high school qualification, CKD stage 3, never been pregnant, in a relationship, never been*
 489 *pregnant, wants to have children).*

490
 491 Often women were unaware that their kidney disease may require carefully planned pregnancies
 492 and took the position that it would happen as a natural progression in their lives. Some were
 493 unaware that they had kidney disease and found out while they were pregnant or soon afterwards.

494
 495 We found that tipping points for wanting and not wanting (more) children were similar but had
 496 different reasons. These are expanded and explained in Box.2. Often women either assumed they
 497 could not have a pregnancy or were told they could not and so never fully considered starting a
 498 family. Other women went to extensive lengths to have a pregnancy. If unsuccessful, this was
 499 followed by many years of trauma, loss and grief until they felt they had given all they could and
 500 accepted that it was just not going to happen for them.

501

Box.2 Motivations on decisions for having a family, key tipping points	
Women who said no to any (more) children	Women who said yes they wanted (more) children
Health (especially post-transplant). Many women did not want to put their kidney at further risk or harm their (new) kidney.	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 this was their chance for a “normal” pregnancy.
Age. Many women felt too old to carry or raise a child.	Age. Many women felt they were getting too old, running out of time and these anxieties increased with clinical setbacks (e.g. delays to transplant).
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).	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. Family members did not want to risk increased harm to women’s health.	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 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 did not want to have a child without a partner.	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 said that they felt finally settled in life and did not want to change or disturb their current circumstances.	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 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.	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.
Balancing medications. Many women said 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.	Always wanted children. Some women said their primary role and goal in life was always to be a mother and there was nothing stopping them.
Passing on disease (personal views and wider judgements). Some women with hereditary kidney disease said they would not want to risk passing it on. Others although they may have wanted a child said that wider social judgments made them reconsider.	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.
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.	Did not want to have any regrets. Although some women said 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 said 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.	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.

502

5034. **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.**

504

505

506 Many women felt that they were the ones bringing up discussions about reproductive options.
507 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
508 needs. Many women felt that healthcare professionals were afraid to bring up reproductive
509 conversations due to the increased risk to their kidneys, uncertain outcomes and that they would
510 become more complicated patients.
511

512

513 *"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)

514

515
516
517 Sometimes women felt that the reproductive health plans they were presented with were more of
518 an 'ideal picture', rather than mapped to what their current circumstances were and what they
519 wanted in the short to interim term. However frequently the 'ideal picture' did not happen and it
520 caused increased anxiety due to perceptions of running out of time.

521

522 *"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)

523

524
525
526 Women consistently reported that they did not know where to go for information that was relevant
527 to them and their current circumstances. Chance encounters with social media groups and posting

528 questions on chats were frequently described as the most helpful, some women said that this is
529 where they first heard a pregnancy with kidney disease was even possible. When women wanted to
530 start discussions varied significantly and there did not appear any patterns related to CKD stage, age
531 or any other demographics. Women as young as 18 wanted a full detailed pregnancy plan and many
532 women were considering pregnancies later in life (often after their career and home buying status
533 had settled) and many women had progressed well into their 40s without ever considering a
534 pregnancy just assuming it would happen. In some cases women with inherited kidney disease
535 were prompted to think about it following their parents progression into kidney failure.

536
537 *"It really was only this year as my Dad is now being worked up for transplant that I have started to think about*
538 *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*
539 *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"*
540 *(p17, 18-35, at university, CKD stage 3, partner, never been pregnant, wants to have a pregnancy)*

541
542 Women often found routine clinics/check-ups unhelpful with regard to pregnancy planning, they
543 were too short and/or were seeing too many different healthcare professionals to progress
544 conversations. Reexplaining their current circumstances or future preferences sometimes became so
545 frustrating women disengaged from (trying to pursue) their reproductive goals. By contradiction
546 some women had the same nephrologist for years and still did not feel they could have helpful
547 discussions about having children. Sometimes women had discussed options, started on a
548 pregnancy pathway but due to changes in personal circumstances decided not to have children (e.g.
549 career progression or travelling opportunities) and in these cases some women felt guilt and
550 hesitated to tell their kidney care team that they had changed their mind about having children.

551
552 *"All of these resources and discussions have gone on and now I have changed my mind, I feel like I have wasted*
553 *everybody's time, like I need to have a baby to thank my kidney doctor or something, I know it is crazy but*
554 *sometimes I feel pressure to gift them with a baby at the end of all this!". (P27, 18-35, higher degree, fulltime*
555 *employment, CKD stage 3, changed mind about having children, does not want any children)*

556
557 Women's recommendations for when to start discussions varied considerably from as soon as they
558 are adults, when given a diagnosis, starting treatment or thinking about having a family. Sometimes
559 women's recollection of when they first heard about pregnancy was a negative experience and
560 frequently reported feeling unprepared, not ready to discuss, uncomfortable discussing,
561 embarrassed or confused.

562
563 *"I remember the doctor first brought it up in front of my parents, he said something like oh if she is ever*
564 *planning on getting pregnant we need to talk about that, I just remember wanting the ground to swallow me*
565 *up." (p23, 18-35, unemployed, uncertain of disease stage, had a termination, wants children in the future)*

566
567 *"The first time I remember it being mentioned was with my medication, they said I am putting you on this but*
568 *listen it is really really important you do not get pregnant. That has stayed with me through to now I even feel*
569 *a bit of resentment to my (medication), it has even affected my sex life over the years, I've been so worried*
570 *about not getting pregnant, I don't actually think I've ever had a normal sex life." (P27, 18-35, higher degree,*
571 *fulltime employment, CKD stage 3, changed mind about having children, does not want any children)*

572
573 At the same time some women felt they had to over qualify the fact that they did not want children
574 and felt annoyed that the question kept coming up from multiple and often unqualified or unhelpful
575 sources.

576
577 *"I mean, I've had other doctors, other specialists, that have nothing to do with pregnancy saying to me, 'You're*
578 *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*
579 *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*
580 *where you go, really? Does that actually have anything to do with you? I don't think it does. You're a man and*
581 *you can do it for as long as you want, so just back off." (P-29, 36-50, high school, not married/living with a partner,*
582 *never been pregnant/does not want children)*

583
584
585

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

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

594
595
596

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

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

607
608
609
610
611

"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)

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

615

616 *"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
617 time" and she is really worried about me having another baby – that I won't come home and what will happen
618 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
619 or degree, no partner, having one or more children/wants to become pregnant)*

620
621

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

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

625

626 *"it is more like a treadmill of options until you run out, with pregnancy first, fostering last and everything else
627 somewhere in between, nobody has ever sat down and had detailed discussions about the various options and
628 what they involve for me." (p12, 36-50, higher degree, works fulltime, CKD stage 3, has been pregnant but no children,
629 wants children but not necessarily a pregnancy)*

630

631 Wider service providers often felt ill-equipped to manage women with CKD as by the time they saw
632 them they had experienced significant (mental) health trauma. Many women described their

633 experiences with wider services as unhelpful and many never progressed into the system due to
634 their kidney disease automatically excluding them as potential candidates.

635
636 *“Once they get to our door they have been through such emotional and often physical trauma we are providing*
637 *grief counselling, trying to manage expectations, and at the same time we do not know anything about their*
638 *kidney disease. Then everything has to start again for these women, it is often just too much”. (stakeholder*
639 *engagement)*

641 **Integrated key findings and developing actionable points for improving practice**

642
643 We have mapped the principal integrated quantitative and qualitative findings using the Behaviour
644 Change Wheel and Theoretical Domains Framework in Box 3 which includes a set of actionable
645 points and associated questions to support stakeholders as a first step to addressing women’s
646 unmet needs.(Michie et al., 2014)
647

Box.3

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 is 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 supplemental file 3 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 no, 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 e.g. 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 e.g. 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 e.g. assessment criteria for adoption/fostering.

648

649 **DISCUSSION**

650

651 Women were highly motivated to engage in shared decision-making, but this was not always
652 happening in practice - partly because in many cases conversations about whether the women
653 wished or were planning for a pregnancy simply were not taking place. When conversations about
654 preferences for having children were taking place there was a reasonable degree of shared decision-
655 making, but there was room for improvement. On the level of individual women, decision self-
656 efficacy was important in engaging in shared decision-making - although we don't know what the
657 direction of this relationship was - i.e. were they engaging in more shared decision-making because
658 they were more confident or were they more confident because they had more (positive)
659 experiences of shared decision-making (or both).

660

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

666

667 Having a high level of information needs was not independently associated with the shared decision-
668 making outcomes. This could be for a number of reasons - some women, for example, may have high

669 information needs because they are highly motivated and engaged in decisions about their health
670 whereas others may be struggling to find information and thus less likely to engage in shared
671 decision-making. It is likely that educational interventions alone will not shift the power dynamics in
672 consultations nor will they increase the availability of opportunities to engage in conversations with
673 health professionals - so while knowledge is an important foundation for shared decision-making it is
674 not sufficient in itself to make it happen.(Joseph-Williams et al., 2014)

675
676 Our models were statistically significant and did explain some of the variance in shared decision-
677 making outcomes, but a lot of the variance was left unexplained, highlighting the need to look at
678 clinical and system-related factors in supporting shared decision-making, rather than just focusing
679 on the patient. Shared decision-making should ideally take place routinely as 'business as usual', but
680 recent evidence suggests that despite substantial investment and developments of multiple decision
681 aids and resource packs for patients and staff, shared decision-making has yet to be widely
682 adopted.(Elwyn, 2019) Complicated healthcare pathways, cultural biases, staff training (including
683 confidence and experience using shared decision-making), modifying patient expectations, language
684 and cultural communication barriers, a lack of adaption across all management levels are just some
685 of the known complications to adopting shared decision-making in routine practice.(Mclaughlin,
686 2021) Specialist CKD nurses appear to be following the medical and disease orientated focus of care
687 and care pathways and are not consistently including women's reproductive health as part of their
688 remit.

689
690 As other studies have shown women's reproductive health, their ambitions and life goals are not
691 always considered alongside their kidney disease.(Jesudason & Tong, 2019) Previous research
692 identified some of the complex decisions women need to make and their desires for more
693 control.(Tong, Brown, et al., 2015) We have found that discussions about pregnancies (timing,
694 content, mode of delivery) are not always working and highlighted additional needs across the care
695 pathways including wider services. Recent studies have also shown an overreliance on shared
696 decision-making to bring about change when often the basic infrastructure including resources (staff
697 and administration), bias, culture, training etc are not yet well enough established to adapt.(Elwyn,
698 2019; Leah Mclaughlin, 2021) This research confirms these barriers in relation to women's
699 reproductive health and CKD.

700 701 **Suggestions for future research and unanswered questions**

702
703 New research is needed into the health and reproductive care of women with kidney disease to
704 address inequalities including agreed sets of core outcome measures, intervention development,
705 controlled trials of their effectiveness, and additional patient and public involvement to start to build
706 up new feminised healthcare pathways including new understandings of what works, for whom and
707 why. Additional research is needed to better represent ethnic minority perspectives and if
708 additional measures are needed for best support e.g. language and cultural differences. Ongoing
709 research is needed to address how actions, decisions and perceptions change over time e.g. the
710 needs of younger women as they transition into adulthood and adult healthcare services, and
711 perspectives of women in later life including their specific health needs e.g. menopause. Some
712 recent interventions such as One Key Question may be amenable to adaption for women with
713 kidney disease, especially to support healthcare professionals to modify their behaviours to include
714 reproductive health conversations as routine. Any such intervention would need to account for the
715 specific needs of women with CKD as well as available staff and resources to implement at scale.
716 (Song et al., 2021; Stulberg et al., 2020)

717 718 **Strengths**

719

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

725

726 **Limitations**

727

728 We originally estimated around 5000 women were in the Welsh Vital-Data system, this was actually
729 closer to 2300. We had planned to contact women in Wales twice to invite to take part, but this was
730 impractical as most women did not have email contact details. Due to time and resources we were
731 unable to include the healthcare professionals perspectives, younger adults (under 18) and older
732 adults (over 51). Participants were predominately white and not representative of the UK
733 population – this may be explained by the focus on Wales which has a predominately white
734 population. Ethnic minority and social deprivation perspectives are a noted gap. Nonetheless there
735 is currently no evidence to suggest that these groups are any better supported to contraindicate the
736 findings in our sample. The study took place during COVID and multiple lockdowns which may have
737 negatively affected recruitment. 431 surveys were completed out of a 500 target, interviews did not
738 appear to be negatively affected. We found the Behaviour Change Wheel and Theoretical Domains
739 Framework had limitations for especially complex interventions with multiple goals and potential
740 outcomes. Some of the domains appeared repetitive, stakeholders did not always see connections
741 with the categories and the phenomenon of interest and many outcomes seemed to apply to more
742 than one category.

743

744 **CONCLUSION**

745

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

756

757 **Terminology declaration**

758 This study is situated in the context of women’s reproductive health, which relates to the diagnosis
759 and treatment of diseases that affect those with female physiology. The sample of women was
760 largely derived from a medical database that used the biological and medical classifications of male
761 and female. We use terms such as woman, women, female and feminine throughout as this was
762 the language used by the participants themselves and best describes the phenomena of interest, the
763 study cohort, the findings and unmet need. In particular, we refer to the need for feminising the
764 kidney care pathway and make the case that traditional kidney care pathways were not designed to
765 accommodate female reproductive health for women with female physiology. By feminising a care
766 pathway, we mean to make the care pathway more characteristic of or associated with those with
767 female physiology. The Journal of Advanced Nursing is also a global nursing journal and the
768 language used needs to be easily translated and universally understood by the global nursing
769 readership, for whom English is not a first language. We do however acknowledge that the terms
770 used are gendered and some people who have female reproductive physiology do not identify as

771 women and some people with male reproductive physiology identify as women. A sensitive and
772 individually-tailored approach is needed to support the enhancement of gender inclusivity within the
773 general framework of women’s reproductive health for those with female physiology.
774

775 **Conflicts of interest statement**

776 [REDACTED] is an editor for JAN. No other authors declare any conflict of interest.
777

778 **Ethics**

779 The study received full ethical approval. Wales REC 1 committee 20/WA/0157.
780

781 **Word count**

782 **7791**
783

784 **Supporting materials**

785 **Fig.1** Matrix integration

786 **Fig.2** How important it is for you to have more information for each topic (0 - not important at all to
787 4 - extremely important)
788

789 **Table.1** Purposeful sample framework interviews.

790 **Table.2** Women’s reproductive options information needs

791 **Table.3** Summary statistics for shared-decision making measures
792

793 **Supplemental file 1.** MAGIC

794 **Supplemental file 2.** Recruitment timeline and summary

795 **Supplemental file 3.** COM-B model, TDF domains, intervention functions, policy categories and BCTs
796 mapping

797 **Supplemental file 4.** Summary demographics table (including self-reported health and wellbeing
798 and summary demographics interviews.

799 **Supplemental file 5.** Beta values and 95% confidence intervals for predictor variables entered into
800 the shared decision-making multivariable linear regression models
801

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