

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

Noyes, Jane; McLaughlin, Leah

Journal of Advanced Nursing

E-pub ahead of print: 31/03/2023

Peer reviewed version

Cyswllt i'r cyhoeddiad / Link to publication

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA): Noyes, J., & McLaughlin, L. (2023). Feminising care pathways: Mixed-methods study of reproductive options, decision making, pregnancy, post-natal care and parenting amongst women with kidney disease. *Journal of Advanced Nursing*. Advance online publication.

Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

. Users may download and print one copy of any publication from the public portal for the purpose of private study or research.

- You may not further distribute the material or use it for any profit-making activity or commercial gain
 You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

2 Short informative title

1

3 4

5

6 7

8

Main file

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

short running title

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

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 guality sexual and

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

reproductive health and reducing noncommunicable diseases in women, including Chronic Kidney
 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
- 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
- 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
- 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,

- 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
- 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
- 118 interventions to support them also found that the majority of recent research tends to have a
- 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.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
- 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

We underpinned the research with the MAGIC (Making Good Decisions in Collaboration), three talk
 model of shared decision-making. (Elwyn et al., 2017) (Supplemental file.1) We also incorporated
 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).
- 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 01^{st} Sep $20 03^{rd}$ 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
- 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
- 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 stating 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 preconception 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 stating 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

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

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

- 218 help to promote the study to other patients in their social networks.
- 219

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), publicised 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

- 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
- 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
- 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
- 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
- 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
- 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
- interventions could be adapted or modified to better support women in relation to their
- 285 reproductive health.
- 286

287 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) (Fig.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 technique's to the sources of
- evidence, alongside a summary statement of what needed to change to bring about good shared
- 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
- report results and findings. (O'Brien et al., 2014; Roslyn, 2013)
- 297

298 Validity and reliability/Rigour

- 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,
- dependability, confirmability, and transferability) as qualitative markers of rigour
- 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
- 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
- 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
- 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)

330

331 FINDINGS

332

333 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, 227 02.1%) were consistent as a second with the UK as a second sec
- 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)
- 340

341 Information needs

- 342 Just over half of the women who completed the survey had a conversation with a health
- 343 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
- 345 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
- 350 role. (Table.2)
- 351

352 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 issummarised in Fig.2.
- 355

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.

359

360 Shared decision-making

- Wery 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
- 363 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
- 365 CollaboRATE scores indicated that there was a high degree of effort made to consider women's
- 366 needs and preferences and to explain their options to them. However, there was variation in
- 367 women's experiences and the CollaboRATE scores did not reach the 'gold standard' of 9 (every effort 368 was made) on these encounters indicating that there is some room for improvement. Scores on the
- 369 relevant measures are summarised in Table.3
- 370

371 Multivariable regression analysis

- 372 Multivariable models were fitted to investigate the independent association of variables of interest
- 373 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
- 376 statistics are provided below. Beta values and significance of each variable entered into the models
- are provided in supplemental file. 5.
- 378 The multivariable linear regression models for CollaboRATE mean score for women who had a
- 379 conversation with a health professional about their options for having children was statistically

significant (F_{9,227} = 4.733, p<0.001, Adjusted R square = 0.125). The only significant association in this
 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

was the strongest association in this model (Beta = 0.025, 95% CI 0.019, 0.030). Having children
 already (Beta = 0.368, 95% CI 0.017, 0.719) and considering having children rather than having

- already (Beta = 0.368, 95% Cl 0.017, 0.719) and considering having children rather than having
 decided not to have children (Beta = 0.406, 95% Cl 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 (F8,422 = 3.818, p<0.001,
- 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

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 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration of women's preferences (Beta = 0.024, 95\% CI 0.010, 0.027) and consideration (Beta = 0.024, 95\% CI 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010, 0.010

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% Cl 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,
- and inhibitions often as a result of changes to physical appearance e.g. weight gain/loss and scarring
 negatively impacted sexual relationships. Bedrooms were described more like hospital settings
- 420 inegatively impacted sexual relationships. Bedrooms were described more like hospital settings 427 (including bleeps 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 bleeped 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..."(PO3,
433 f, 18-35, High School qualification age 18, not married/living with a partner, has children, thinking about having more,
434 transplant)

435

443

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.

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

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.

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)

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)

460460461461Anterogenous461

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 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 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

475 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.
- 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 had485 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).
- 491 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
- 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
- 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	Health (especially post-transplant). Many women felt that
not want to put their kidney at further risk or harm their	they had been given a new life and an increased chance of
(new) kidney.	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. Many women felt pressure from their partners to
partner did not want to risk further harm to the women	have a pregnancy. In spite of many women's preference for
(especially if they already had a child via pregnancy).	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	Family . Some women reported how devastated their family
harm to women's health.	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	Single. Some women saw this as an opportunity to have a
without a partner.	family irrespective of having a partner.
Sense of security (finance, job, house). Some women	Sense of security (finance, job, house). Some women felt
said that they felt finally settled in life and did not want	that they had reached a stage where they felt settled and
to change or disturb their current circumstances.	secure and ready to have and raise a child.
Systems too hard. Some women reported that	Systems too hard. Some women described the process of
navigating the various healthcare systems and processes	having a pregnancy as the final step, that they come this far
too overwhelming and either disengaged from the	it seemed silly or a waste of everybody's time to stop now
process or never felt confident enough to start it	is seenied sing of a waste of everybody s time to stop now.
Balancing medications Many women said they had long	Always wanted children Some women said their primary
term and ongoing issues with balancing their medications	role and goal in life was always to be a mother and there
to manage their disease. The thoughts of disrupting this	was nothing stopping them
was too much for some to think about a pregnancy	
Passing on disease (personal views and wider	Everyhedy has one new it is my turn. Some women felt
iudgements) Some wemen with bereditary kidney	that their social networks were suddenly decreasing or being
disease said they would not want to rick passing it on	that their social networks were suddenly decreasing of being
disease said they would not want to risk passing it on.	recomputed and this was now their opportunity to have a
Others although they may have wanted a child said that	child.
wider social judgments made them reconsider.	
Do not want to be neartbroken (again). Many feit the	Did not want to have any regrets. Although some women
thoughts of trying and not having a baby too much to	said they did not necessarily want a pregnancy now, many
take on. This was especially the case if women had	said that they did not want to regret not trying in the future.
already suffered a loss.	
Societal pressures. Many women said they felt judged as	Societal pressures. Many women felt that as women it was
selfish for wanting a pregnancy which would cause a risk	their duty to have a pregnancy and that is what is expected
to their kidney, their health or passing the disease on and	of them in life, irrespective of their kidney disease.
so elected not to have a pregnancy.	
502	
5034. Women had no experiences of integrated family	planning in their care pathway and there was no
504 evidence of validated guidance, support or tools	to help from the women's perspective.
505	
506 Many women felt that they were the ones bringing	ng 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
508 bring it up" and to progress onto a pathway or tro	eatment plan which they found met their individual
509 needs. Many women felt that healthcare profess	ionals were afraid to bring up reproductive
510 conversations due to the increased risk to their k	idneys, uncertain outcomes and that they would
511 become more complicated patients.	
512	
513 "healthcare professionals naturally want to keep us he	althy and avoid any complications, I mean that is what
514 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
515 plan." (p02, 18-35, college diploma, works fulltime, on dial	ysis, married, never been pregnant, wants to have a pregnancy)
	the description of the second of the second of the second se
51/ Sometimes women feit that the reproductive hea	aith plans they were presented with were more of
518 an ideal picture, rather than mapped to what th	eir current circumstances were and what they
wanted in the short to interim term. However fre	equently the lideal picture did not happen and it
520 caused increased anxiety due to perceptions of ri	unning out of time.
521 522 ((15.1))	
522 "I feel like I nave been sold one picture - I would be tra	nspiantea in a jew months, then maybe wait a year and
525 then baby time, but here I am two years on and no sig.	n of a transplant, i jeel in iimbo".(P-FNU4, f, 36-50, higher ershin, no children/wants fertility treatment)
	נואווא, אס טוווערטין אעוונא זברטווגי גרפענוופווגן
526 Women consistently reported that they did not k	now where to go for information that was relevant
527 to them and their current circumstances. Chance	e 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
- 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
- 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

"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)

- 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
- 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.
- 550 nes 551
- "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)
- 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
- 578 getting on a bit now, so if you want children r think you should just get on with it. Of 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

5845. Complicated pregnancies, mis carriages and stillbirths were common and women585frequently 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 *"I was just so tired back then but I was so determined – it is silly now looking back but I remember getting a*609 *taxi to the top of the hill just so that I could walk my son into school"*. (p24, 36-50, University degree, works
610 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.

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

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.

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)

Wider service providers often felt ill-equipped to manage women with CKD as by the time they sawthem 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)

640

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 preconception 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 nonpregnancy 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

- 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
- 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
- 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
- 6/1 decision-making. It is likely that educational interventions alone will not shift the power dynamics in 672 consultations per will they increase the availability of opportunities to oppose in conversations with
- 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
- 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

- and care pathways and are not consistently including women's reproductive health as part of their
 remit.
- 689

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

- 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
- 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's699 reproductive health and CKD.
- 700

701 \qquad 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

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.

726 Limitations

727

725

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 Theorical 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

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

771 772 773	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.
774	
775 776 777	Conflicts of interest statement is an editor for JAN. No other authors declare any conflict of interest.
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	, c
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	
802	References
803	
804	Ackerman, I. N., Jordan, J. E., Van Doornum, S., Ricardo, M., & Briggs, A. M. (2015). Understanding the
805	information needs of women with rheumatoid arthritis concerning pregnancy, post-natal care and early
806	parenting: A mixed-methods study. BMC Musculoskeletal Disorders, 16(1).
808	NTTPS://doi.org/10.1186/S12891-015-0657-4
808	Anten, J., & Sesti, F. (2016). Health mequalities and women-dualessing annet needs.
810	Aresté-Fosalba, N., Reisæter, A. V., Cases, A., Travnor, J. P., Kramar, R., Massy, Z., Jager, K. J., & Hecking,
811	M. (2019). Sex differences in kidney replacement therapy initiation and maintenance. <i>Clinical Journal of</i>
812	the American Society of Nephrology, 14(11), 1616–1625. https://doi.org/10.2215/CJN.04400419
813	Bikbov, B., Perico, N., & Remuzzi, G. (2018). Disparities in Chronic Kidney Disease Prevalence among Males and
814	Females in 195 Countries: Analysis of the Global Burden of Disease 2016 Study. Nephron, 139(4), 313–
815	318. https://doi.org/10.1159/000489897
816	Blumenthal, J. A. et al. (2001). Enhancing recovery in coronary heart disease (ENRICHD): baseline
ð1/ 819	cnaracteristics. The American Journal of Cardiology, 88(3), 316–322. https://doi.org/10.1016/S0002- 0140/01/01652.6
810 810	5145(UI)UI022-0 Cane L. O'Connor D. & Michie S. (2012). Validation of the theoretical domains framework for use in
820	behaviour change and implementation research Implementation Science 7(1) 1–17
821	https://doi.org/10.1186/1748-5908-7-37/TABLES/3
822	Caruso, B. A., Sommer, M., & Phillips-Howard, P. A. (2019). All of women's health needs are worthy of
823	attention. The Lancet, 393(10186), 2119. https://doi.org/10.1016/S0140-6736(19)30957-2

- Begner, L., Sloan, J., & Venkatesh, P. (1997). The Control Preferences Scale. *Can J Nurs Res*, 29(3), 21–43.
 https://pubmed.ncbi.nlm.nih.gov/9505581/
- Bepartment of Health and Social Care. (2021). Women's Health Strategy: Call for Evidence GOV.UK.
 https://www.gov.uk/government/consultations/womens-health-strategy-call-for-evidence/womens health-strategy-call-for-evidence
- Bevelopment, N. I. of child health and human. (2016). What health issues or conditions are specific to women
 only? | NICHD Eunice Kennedy Shriver National Institute of Child Health and Human Development.
 https://www.nichd.nih.gov/health/topics/womenshealth/conditioninfo/whatconditions
- B32 Duckers, J. (2019). *CF PROSPER*. https://cfprosper.yolasite.com/
- 833 Elwyn, G. (2019). *Glyn Elwyn: Expecting too much of "patient decision aids" The BMJ*.
- 834 https://blogs.bmj.com/bmj/2019/12/02/glyn-elwyn-expecting-too-much-of-patient-decision-aids/
- Elwyn, G., Barr, P. J., Grande, S. W., Thompson, R., Walsh, T., & Ozanne, E. M. (2013a). Developing
 CollaboRATE: a fast and frugal patient-reported measure of shared decision making in clinical
 encounters. *Patient Education and Counseling*, *93*(1), 102–107.
 https://doi.org/10.1016/J.PEC.2013.05.009
- Elwyn, G., Barr, P. J., Grande, S. W., Thompson, R., Walsh, T., & Ozanne, E. M. (2013b). Developing
 CollaboRATE: A fast and frugal patient-reported measure of shared decision making in clinical
 encounters. *Patient Education and Counseling*, *93*(1), 102–107.
- 842 https://doi.org/10.1016/j.pec.2013.05.009
- Elwyn, G., Durand, M. A., Song, J., Aarts, J., Barr, P. J., Berger, Z., Cochran, N., Frosch, D., Galasiński, D.,
 Gulbrandsen, P., Han, P. K. J., Härter, M., Kinnersley, P., Lloyd, A., Mishra, M., Perestelo-Perez, L., Scholl,
 I., Tomori, K., Trevena, L., ... Weijden, T. Van der. (2017). A three-talk model for shared decision making:
 multistage consultation process. *BMJ*, *359*, 4891. https://doi.org/10.1136/BMJ.J4891
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd,
 C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal of General Internal Medicine*, *27*(10), 1361. https://doi.org/10.1007/S11606-012-2077-6
- Fetters, M. D., Curry, L. A., & Creswell, J. W. (2013). Achieving Integration in Mixed Methods Designs—
 Principles and Practices. *Health Services Research*, *48*(6 Pt 2), 2134. https://doi.org/10.1111/1475 6773.12117
- Goldenberg, T., Finneran, C., Andes, K. L., & Stephenson, R. (2016). Using participant-empowered visual
 relationship timelines in a qualitative study of sexual behaviour. *Global Public Health*, *11*(5–6), 699–718.
 https://doi.org/10.1080/17441692.2016.1170869
- Green, S. B. (1991). How Many Subjects Does It Take To Do A Regression Analysis. *Multivariate Behavioral Research*, 26(3), 499–510. https://doi.org/10.1207/S15327906MBR2603_7
- 858 Group, P. D. A. R. (1995). User Manual-Decision Self-Efficacy Scale Definition. www.ohri.ca/decisionaid.
- 859 Health Foundation. (2012). *Helping people share decision making | The Health Foundation*.
- https://www.health.org.uk/publications/helping-people-share-decision-making
 Horsager-Boehrer, R. (2019). *Kidney disease and pregnancy: It's challenging, but possible | Your Pregnancy Matters | UT Southwestern Medical Center*. https://utswmed.org/medblog/kidney-disease-pregnancy/
- Hoskings, J. D. (2000). Enhancing recovery in coronary heart disease patients (ENRICHD): study design and
 methods. The ENRICHD investigators. *American Heart Journal*, *139*(1 Pt 1), 1–9.
 https://doi.org/10.1016/S0002-8703(00)90301-6
- Jesudason, S., & Tong, A. (2019). The patient experience of kidney disease and pregnancy. In *Best Practice and Research: Clinical Obstetrics and Gynaecology* (Vol. 57, pp. 77–88). Bailliere Tindall Ltd.
 https://doi.org/10.1016/j.bpobgyn.2018.12.003
- Joseph-Williams, N., Elwyn, G., & Edwards, A. (2014). Knowledge is not power for patients: a systematic review
 and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling*, *94*(3), 291–309. https://doi.org/10.1016/J.PEC.2013.10.031
- 872 Kidney Research UK. (2022). Stages of kidney disease Kidney Research UK.
- 873 https://kidneyresearchuk.org/kidney-health-information/stages-of-kidney-disease/
- Lincoln, Y., & Guba, E. G. (1985). *Naturalistic inquiry*. Sage Publications.
- 875 Mayo clinic. (2022). Chronic kidney disease Symptoms and causes Mayo Clinic.

https://www.mayoclinic.org/diseases-conditions/chronic-kidney-disease/symptoms-causes/syc 20354521

- 878Mc Laughlin, L., Neukirchinger, B., & Noyes, J. (2022). Interventions for and experiences of shared decision-879making underpinning reproductive health, family planning options and pregnancy for women at high risk
- 880 or with kidney disease: systematic review and qualitative framework synthesis. *BMJ Open*.

- Mclaughlin, Leah;, Neukirchinger, B., & Noyes, J. (2022). Interventions for and experiences of shared decision making underpinning reproductive health, family planning options and pregnancy for women with
 kidney disease: systematic review and qualitative framework synthesis. *BMJ Open*.
- Mclaughlin, Leah. (2021). Understanding the low take-up of home-based dialysis through a shared decision making lens: A qualitative study. *Health Expectations*.
- Medicine, I. of. (2009). *Meeting the Unique Health Needs of Women and Children*.
 https://www.ncbi.nlm.nih.gov/books/NBK219847/
- Michie, S., Atkins, L., & West, R. (2014). *The behaviour change wheel : a guide to designing interventions*. 329.
 Michie, S., van Stralen, M. M., & West, R. (2011). The behaviour change wheel: A new method for
- kichie, S., van Straten, M. M., & West, R. (2011). The behaviour change wheel: A new method for
 characterising and designing behaviour change interventions. *Implementation Science*, 6(1), 42.
 https://doi.org/10.1186/1748-5908-6-42
- Morandi, S., Golay, P., Vazquez-Montes, M., Rugkåsa, J., Molodynski, A., Yeeles, K., & Burns, T. (2017). Factorial
 structure and long-term stability of the autonomy preference index. *Psychological Assessment, 29*(1),
 110–115. https://doi.org/10.1037/pas0000327
- National Kidney Foundation. (2013). Choosing A Treatment For Kidney Failure | National Kidney Foundation.
 https://www.kidney.org/atoz/content/choosingtreat
- National Kidney Foundation. (2022). *Genetics and Kidney Disease | National Kidney Foundation*.
 https://www.kidney.org/atoz/content/genetics-kidney-disease
- National Library of Medicine. (2022). Women's health: MedlinePlus Medical Encyclopedia.
 https://medlineplus.gov/ency/article/007458.htm
- 901 NIHR. (2018). UK Standards for Public Involvement The UK Standards. https://sites.google.com/nihr.ac.uk/pi 902 standards/standards
- 903 Nvivo. (2015). *NVivo Pro | QSR International for Windows purchased 2015*.
- 904 http://www.qsrinternational.com/nvivo/nvivo-products/nvivo-11-for-windows/nvivo-pro
- 905 O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative
 906 research: A synthesis of recommendations. *Academic Medicine*, *89*(9), 1245–1251.
 907 https://doi.org/10.1097/ACM.0000000000388
- 908 ONS. (2017). Graduates in the UK labour market: 2017 Office for National Statistics.
- 909 https://www.ons.gov.uk/releases/graduatesintheuklabourmarket2017
- 910 ONS. (2019). Research report on population estimates by ethnic group and religion Office for National
 911 Statistics.
- 912 https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimate 913 s/articles/researchreportonpopulationestimatesbyethnicgroupandreligion/2019-12-04
- 914 ONS. (2020). Population estimates by marital status and living arrangements, England and Wales Statistical
 915 bulletins Office for National Statistics.
- 916https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimate917s/bulletins/populationestimatesbymaritalstatusandlivingarrangements/previousReleases
- Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful
 sampling for qualitative data collection and analysis in mixed method implementation research.
 Administration and Policy in Mental Health, 42(5), 533. https://doi.org/10.1007/S10488-013-0528-Y
- Phillips, R., McLaughlin, L., Williams, D., Williams, H., Noyes, J., Jones, C., Oleary, C., Mallett, C., & Griffin, S.
 (2021). Engaging and supporting women with chronic kidney disease with pre-conception decision making (including their experiences during COVID 19): A mixed-methods study protocol. *Journal of Advanced Nursing*, 77(6), 2887–2897. https://doi.org/10.1111/JAN.14803
- Regnault, A., Willgoss, T., & Barbic, S. (2018). Towards the use of mixed methods inquiry as best practice in
 health outcomes research. *Journal of Patient-Reported Outcomes 2018 2:1, 2*(1), 1–4.
 https://doi.org/10.1186/S41687-018-0043-8
- Ritchie, J., & Lewis, J. (1980). *Qualitative research practice : a guide for social science students and researchers*.
 Sage Publications.
- Roslyn, C. (2013). Lessons from the field: Applying the good reporting of a mixed methods study (GRAMMS)
 framework.
- 932 https://www.researchgate.net/publication/288167427_Lessons_from_the_field_Applying_the_good_re 933 porting_of_a_mixed_methods_study_GRAMMS_framework
- Royal College of Nursing. (2022). Womens health | Clinical Topics | Royal College of Nursing.
 https://www.rcn.org.uk/clinical-topics/womens-health
- 936Shi, Y., Xiong, J., Chen, Y., Deng, J., Peng, H., Zhao, J., & He, J. (2018). The effectiveness of multidisciplinary care937models for patients with chronic kidney disease: a systematic review and meta-analysis. International

- Urology and Nephrology, 50(2), 301. https://doi.org/10.1007/S11255-017-1679-7
 Shorten, A., & Smith, J. (2017). Mixed methods research: expanding the evidence base. *Evidence-Based*
- 940 *Nursing*, 20(3), 74–75. https://doi.org/10.1136/EB-2017-102699
- Song, B., White VanGompel, E., Wang, C., Guzman, S., Carlock, F., Schueler, K., & Stulberg, D. B. (2021). Effects
 of clinic-level implementation of One Key Question[®] on reproductive health counseling and patient
 satisfaction. *Contraception*, 103(1), 6–12. https://doi.org/10.1016/J.CONTRACEPTION.2020.10.018
- Sperber, S. (2021). Invisible women: Exposing data bias in a world designed for men. *Gender, Work & Organization*, 28(5), 1985–1989. https://doi.org/10.1111/GWAO.12649
- Stulberg, D. B., Datta, A., White VanGompel, E., Schueler, K., & Rocca, C. H. (2020). One Key Question[®] and the
 Desire to Avoid Pregnancy Scale: A comparison of two approaches to asking about pregnancy
 preferences. *Contraception*, 101(4), 231–236. https://doi.org/10.1016/J.CONTRACEPTION.2019.12.010
- 949
 Tariq, S., & Woodman, J. (2013). Using mixed methods in health research. JRSM Short Reports, 4(6),

 950
 204253331347919. https://doi.org/10.1177/2042533313479197
- Temmerman, M., Khosla, R., Laski, L., Mathews, Z., & Say, L. (2015). Women's health priorities and interventions. *BMJ*, 351, h4147. https://doi.org/10.1136/BMJ.H4147
- Tong, A., Brown, M. A., Winkelmayer, W. C., Craig, J. C., & Jesudason, S. (2015). Perspectives on pregnancy in
 women with CKD: A semistructured interview study. *American Journal of Kidney Diseases, 66*(6), 951–
 https://doi.org/10.1053/j.ajkd.2015.08.023
- Tong, A., Jesudason, S., Craig, J. C., & Winkelmayer, W. C. (2015). Perspectives on pregnancy in women with
 chronic kidney disease: systematic review of qualitative studies. *Nephrology Dialysis Transplantation*,
 30(4), 652–661. https://doi.org/10.1093/NDT/GFU378
- Vaglio, J., Conard, M., Poston, W. S., O'Keefe, J., Haddock, C. K., House, J., & Spertus, J. A. (2004). Testing the
 performance of the ENRICHD Social Support Instrument in cardiac patients. *Health and Quality of Life Outcomes*, 2. https://doi.org/10.1186/1477-7525-2-24
- Welsh Government. (2020). Adult general health and illness (National survey for Wales): April 2019 to March
 2020 / GOV.WALES. https://gov.wales/adult-general-health-and-illness-national-survey-wales-april 2019-march-2020
- 965 WHO. (2021). *6 priorities for women and health*. https://www.who.int/news-room/spotlight/6-priorities-for-966 women-and-health
- 967 WHO. (2022). *Women's health*. https://www.who.int/health-topics/women-s-health/
- Wiles, K. (2021). Women with kidney disease can be given a personal risk assessment for pregnancy, following
 new research. https://doi.org/10.3310/ALERT_46785
- Wiles, K. S., Nelson-Piercy, C., & Bramham, K. (2018). Reproductive health and pregnancy in women with
 chronic kidney disease. *Nature Reviews Nephrology 2018 14:3, 14*(3), 165–184.
 https://doi.org/10.1038/nrneph.2017.187
- Wiles, K., Webster, P., Seed, P. T., Bennett-Richards, K., Bramham, K., Brunskill, N., Carr, S., Hall, M., Khan, R.,
 Nelson-Piercy, C., Webster, L. M., Chappell, L. C., & Lightstone, L. (2020). The impact of chronic kidney
 disease Stages 3–5 on pregnancy outcomes. *Nephrology Dialysis Transplantation*.
 https://doi.org/10.1093/NDT/GFAA247
- 977 Winchester, N. (2021). *Women's health outcomes: Is there a gender gap?*
- 978 https://lordslibrary.parliament.uk/womens-health-outcomes-is-there-a-gender-gap/
- World Economic Forum. (2017). The health needs of women are being overlooked. It's time to bring this
 injustice to a halt | World Economic Forum. https://www.weforum.org/agenda/2017/06/health-needs-
- 981 of-women-are-being-overlooked-time-to-end-this-injustice/
- 982 983