

# Using videoconsultations to deliver dietary advice to children with chronic kidney disease; a qualitative study of parent and child perspectives.

This is an accepted manuscript of article published by Wiley in JHND in February 2020 (23-Feb-2020) available at Article DOI: 10.1111/jhn.12750.

## Abstract

**Objective:** Children with chronic kidney disease require specialist renal paediatric dietetic care, regardless of disease severity or geographical location, however under-resourcing makes this challenging. Videoconsultation may offer a solution but research exploring its acceptability is limited. The current study explored parent/carer and child perspectives of videoconsultation as an alternative or supplement to existing regional dietetic care.

**Method:** Children and families using a regional paediatric nephrology service were recruited through purposeful sampling techniques. Renal paediatric dietitians used existing hospital software to host videoconsultations with families. Perspectives were subsequently explored in telephone interviews with the children, their parents and separately with the renal dietitians. Data were transcribed verbatim and an inductive framework analysis conducted.

**Results:** Twelve families took part in the study comprising 13 parents and 5 children (9 months to 14 years). Two renal dietitians were also interviewed. Six themes emerged which were 'Logistics', 'Understanding Information', 'Family Engagement', 'Establishing Trust', 'Willingness to Change' and 'Preferences'. Satisfaction with the videoconsultations was high, with no data security fears and only minor privacy concerns. Parents reported that screen-sharing software enhanced their understanding, generated greater discussion and engagement compared to clinic and telephone contacts. Parents praised efficiencies and improved access to specialist advice, requesting that videoconsultations supplement care. Children preferred videoconsultations outright.

32 **Conclusion:** Dietetic videoconsultations were acceptable to families and perceived  
33 to be a feasible, high quality complement to regional specialist dietetic care.  
34 Enhanced understanding and engagement might improve self-care in adolescents.  
35 The acceptability and feasibility of videoconsultations could address inequitable  
36 regional service provision.

37 **Introduction**

38 Videoconsultation (VC) is an internationally expanding branch of telemedicine that  
39 uses technology for real-time visual and audio patient assessment, monitoring and  
40 care-planning at a distance<sup>(1)</sup>. The United Kingdom (UK) Department of Health<sup>(2)</sup>  
41 recommends its use with patients, driven by increasing populations, perceived  
42 efficiencies and improved technology<sup>(3, 4)</sup>. Use of VC is recommended in the NHS  
43 Sustainability and Transformation Plan<sup>(5)</sup>.

44

45 In the UK, paediatric health networks provide co-ordinated, high quality pathways of  
46 care between general hospitals and specialist children's hospitals, enabling expert  
47 care close to home<sup>(6-8)</sup>. A specialist paediatric renal dietetic service is a requirement  
48 of a UK paediatric nephrology network<sup>(6)</sup> to support biochemical and symptom  
49 management and optimise growth and development<sup>(9)</sup>. Specialist dietetic support in  
50 early and late chronic kidney disease (CKD) reduces morbidity and mortality risk in  
51 infants and children<sup>(10)</sup>.

52 A UK report states that all children with moderate to severe CKD (stages 3-5D)  
53 should have at least one specialist dietetic appointment annually<sup>(6)</sup>. Equitable access  
54 is challenging, despite shared-care services<sup>(11)</sup>. Often only email or telephone  
55 support is provided to families who do not attend the specialist centre and there is  
56 concern that the lack of face-to-face consultations may lead to poor rapport and  
57 reduce opportunities to elicit useful health-related information<sup>(12)</sup>.

58

59 Anecdotally, the use of dietetic VC appears to be growing, although precise figures  
60 are unpublished. Ninety percent of UK children over eight years old regularly access  
61 the internet at home<sup>(13)</sup>. No studies exclusively report VC in a paediatric dietetic  
62 context and research is needed to investigate acceptability to patients, family  
63 members and dietetic professionals. Limited evidence of use in diet therapies is  
64 largely quantitative and relates to adults receiving advice from non-dietetic  
65 healthcare practitioners. This is compiled in a systematic review<sup>(14)</sup>, which concluded  
66 that all forms of telehealth, including VC, contribute to improvements in diet quality  
67 but child and family experiences and perceptions of dietetic VC remain unknown.  
68 The aim of this study was to investigate if virtual dietetic consultations are acceptable  
69 to parents, children and dietetic professionals.

## 70 **Methods and Analysis**

### 71 **Sampling and recruitment**

72 The study was conducted at Bristol Royal Hospital for Children (BRHC), UK and  
73 received ethical approval from the Health Research Authority (17/SC/0480).

74 A purposive, maximum-variation sample<sup>(15)</sup> was selected from the South West  
75 Paediatric Nephrology Network. This network included ten general hospitals who  
76 operate shared care with BRHC, to ensure a broad mix of child ages and CKD  
77 severity was captured across urban and rural locations. Participants were  
78 approached from January to May 2018 by renal dietitians, consultants or specialist  
79 nurses. All families had received previous dietetic support via email, telephone or in-  
80 person, to enable participant comparison of VC to usual care.

### 81 **Equipment and data collection**

82 Existing hospital videoconferencing software (WebEx version 2.82,Cisco), with  
83 screensharing facilities and high security was used to connect a renal dietitian with  
84 families, using personal technology at home. Each VC took 15-30 minutes, and  
85 alongside webcam images, involved the renal dietitian displaying and discussing  
86 growth charts, blood results, diet sheets or feeding regimens via screen-sharing.  
87 Following this, within three working days, parents and children participated in a semi-  
88 structured, recorded telephone interview with a researcher using their speakerphone  
89 facility at home. During this telephone interview, parents and children were asked to  
90 describe their experiences and thoughts on the VC. An interview guide was  
91 developed using patient participant information (PPI) and used to maintain focus on  
92 the research objectives; this included prompts to gain perceptions of understanding,  
93 engagement, technological performance, rapport, concerns and future  
94 communication preferences. After the initial two interviews the guide was amended  
95 to further explore security and privacy concerns.

96 The two renal dietitians who carried out the VCs were interviewed by the researcher  
97 within 3 days of each VC, to enable validation of participant reports of technological  
98 performance, engagement and understanding, thus enhancing trustworthiness via  
99 triangulation of data<sup>(16, 17)</sup>.

100

## 101 **Data analysis**

102 All interviews were transcribed verbatim. Transcripts were read and re-read for  
103 familiarisation with the data and an inductive qualitative framework analysis was  
104 conducted<sup>(18)</sup>. Data organisation was supported by NVivo11 (QSR International).

105 The first stage of the inductive analysis was conducting open coding of a subset of  
106 transcripts; passages of text sentences and paragraphs were individually coded (by  
107 ST and AS) and ascribed attributions (i.e. coding anything seeming relevant from as  
108 many different perspectives as possible). Secondly, ST and AS met to discuss  
109 coding, with differences or anomalies being discussed until consensus was achieved  
110 and no new codes were identified. This led to the development of a definitive coding  
111 framework and the entire dataset was coded accordingly (see Figure 1.).

112 A spreadsheet was generated and the data were 'charted' into the matrix. Charting  
113 involves summarizing data by category from each transcript so that coded data  
114 pertaining to individual interviews can be identified across the data set. Charting  
115 enables characteristics of and differences between the data to be identified, and an  
116 ability to map connections between categories to explore relationships and/or  
117 causality. Thus, framework analysis enabled a deep exploration of the data in a  
118 systematic and organised way and following repeated interrogation, reflection and  
119 synthesis, six themes emerged from the framework analysis. Relationships and  
120 influences between themes could be clearly identified in the data (Figure 2) with all  
121 themes influencing ongoing preferences for a VC service.

122

## 123 **Results**

124 Twelve families took part, which included thirteen parent and five child participants  
125 from eight outreach clinics (Table 1). The final sample included a range of ages and  
126 CKD stages representative of the regional paediatric nephrology population.

127

128

129 **Theme One: Logistics**

130 Seven families used a personal computer (PC), two used tablets and three used  
131 smartphones. Connection problems were raised in all but two interviews and usually  
132 lasted a few minutes but in one case, 25 minutes. Browser updates were often  
133 required to enable connection, needing telephone support from the dietitian. Once  
134 established, parents found the system simple, even when technologically  
135 inexperienced:

136 *'I was panicking, thinking oh, like, I don't do technology, I'm rubbish!.... I don't even*  
137 *know how to switch a computer on! When it was like... download an app...go to this*  
138 *email, I was thinking 'oh no', but actually it went really smoothly.'* (Natalie's mother)

139 Parents often perceived that their systems were out of date:

140 *'Well it was difficult to start with, it took me 25 minutes to actually get going, but that*  
141 *is technology for us, which is a bit of a shame. My computer is a bit slow so it's*  
142 *probably my fault anyway.'* (William's mother)

143 Most families did not report audio-visual issues; minor time-lags occurred in six VC,  
144 unrelated to geographical distance. Neither dietitians nor parents felt this affected  
145 their experience. Security concerns were negligible; parents felt they had been made  
146 aware of the risks of a webcam and microphone in their personal environment.  
147 However, it became evident that the dietitian wasn't always aware who else was  
148 present in the room at home, raising confidentiality concerns. One mother  
149 suggested:

150 *'You may need to consider conversations that parents might want to have with you,*  
151 *without their children overhearing.'* (Nicholas's mother)

152 Conversely, feelings of enhanced privacy were reported, compared to:

153 *'...corridor conversations in clinic.'* (Nicholas's mother)

154 *'..anyone walking in (referring to other staff entering the clinic room).'* (Thomas's  
155 mother)

156

157 **Theme Two: Understanding Information**

158 Drawing comparisons to face-to-face, phone and email conversations, parents and  
159 children valued being able to see the dietitian, especially if they had not met face-to-  
160 face. In screen-share mode diet sheets, growth charts and blood results could be  
161 viewed by all. Parents commented that in a face-to-face clinic, there is no time to  
162 process information on growth charts but screen-sharing, with discussion, enabled  
163 understanding of growth patterns, giving parents some relief and encouragement to  
164 continue dietary interventions:

165 *'It was really useful. I haven't seen my child's growth-chart for a long time. At one*  
166 *time she wasn't gaining any height or weight but (the dietitian) showed me the*  
167 *centiles and she's going up now. So, she is ok and this was nice to see.....we were*  
168 *thinking, "Well we are doing all this and she's not getting anywhere!" but now I can*  
169 *see that she is..'* (Ellie's mother)

170 Where children attend only at outreach clinics, specialist dietitians advise on email  
171 and by telephone. Screen-sharing of diets sheets enabled conversation directly with  
172 children rather than through a parent proxy by telephone. Children could generate  
173 their own ideas and questions:

174 *'I think on the phone, I might write it down and take it in, but my son was also able to*  
175 *look at it and say what he liked. We both looked at it at the same time I saw bits, but*  
176 *he was like... "ooh! I like that".... so that led on to other things ... you know it*  
177 *created more leads.'* (Thomas's mother).

178 Practical aspects were also raised by the same parent:

179 *'I just think, if I had something I could show you in the fridge, I could get it out and*  
180 *show you. You could tell me if its ok.'* (Thomas's mother)

181

### 182 **Theme three: Family Engagement**

183 Engagement with VC was good but influenced by the child's age. Pre-school children  
184 were not anticipated to have direct involvement and when one tried, the result was a  
185 chaotic VC, disengaging the parent. Dietitian interviews confirmed parents' reports  
186 that school-age children engaged positively. Nine year old William, who had not  
187 previously engaged, surprised his parents with eye contact and discussion:

188 *'He was really looking forward to doing it. He took the lead in it anyway... he loved it!'*  
189 (William's father)

190 Twelve year old Natalie regularly attended the specialist centre and lived 251  
191 kilometres away. For her, an important benefit was avoiding long journeys to protect  
192 leisure time:

193 *'It was very quick and easy. It didn't take time out of the day. We had pancakes and*  
194 *went to out for lunch. We went to the beach .....we didn't have to wake up at 5am to*  
195 *drive...I could have a lie in.'* (Natalie)

196 Increased motivation to engage was reported:

197 'You kind of felt he wanted to be there, not just because Mum had told him. He  
198 wanted to engage. ....he was a bit more positive, generally rapport was really good'.  
199 (Dietitian)

200 Several parents explained that anxiety over time and travel meant that they didn't  
201 always stay to see the specialist dietitian in clinic, being keen to leave to collect  
202 siblings or administer treatment such as feeds or dialysis.

203 *'It's just very time consuming. The clinics often run late as well and when your other*  
204 *children are at home being looked after by someone else, you just want to get*  
205 *home.'* (Ellie's mother)

206 An adolescent with communication difficulties was overwhelmingly in favour of the  
207 VC; his parent related this to the closeness of the screen. This family also praised  
208 the efficiency and confidentiality of the VC:

209 *'It was more efficient... because it was all there, all the information had been*  
210 *prepared beforehand. In clinic there is a lot of hanging around, there are*  
211 *conversations in the corridor, and you've got to go off, have bloods...It was*  
212 *timesaving.* (Nicholas's mother)

213

214

215 **Theme Four: Establishing Trust**



216 Despite half of the participants having never met the dietitian that delivered their VC,  
217 they described it as:

218 *'Personable and friendly'* (Amelia's mother)

219 *'More personal than a telephone call'* (Sid's mother)

220 Opinions varied as to whether a first-time meeting using VC was appropriate:

221 *'We have known this dietitian since he was born.... I wouldn't have wanted to do it if*  
222 *we had not met the dietitian before.'* (Nicholas's mother)

223 *'Oh god yeah!.... Yeah, definitely!..... I think it feels quite comfortable.'* (Natalie's  
224 mother)

225 And, demonstrating the trust in professional status regardless of prior meetings:

226 *'You are all professionals aren't you ..... I am quite easy going. I don't mind*  
227 *meeting people for the first time over the videoconference.'* (Ellie's mother)

228 Further inductive exploration found that a VC at home gave a sense of familiarity and  
229 intimacy, providing a more comfortable environment for children.

230

### 231 **Theme five: Willingness to change**

232 Willingness to change was identified in several conversations; older children  
233 contributed new mealtime ideas considering their diet restrictions. Parents  
234 acknowledged the benefit of direct conversation between the dietitian and the child,  
235 often with a sense of relief:

236 *'I think at a later date it would be really beneficial to have (the child) involved (in the*  
237 *VC) as well; you know, rather than Mummy just telling her what to eat, someone else*  
238 *could tell her.'* (Amelia's mother)

239 The findings of this theme strengthened the interpretation the themes 'Understanding  
240 Information' and 'Establishing Trust'; an openness to change was perceived after  
241 accessing specialist support, gaining new understanding, and building a rapport  
242 during the VC.

243

244 **Theme six: Preferences**

245 Where local dietetic face-to-face services were accessible, parents wanted this to  
246 continue. Due to the complexity of advice and service constraints, local services  
247 were only in place for three families, all who expressed a desire for a VC to  
248 supplement local dietetic care, rather than substitute. Parents valued a direct link to  
249 the specialists:

250 *'When we were in our local hospital, every time we had a concern or a query or*  
251 *anything.... they had to go and phone the renal ward to find out what the answer*  
252 *was..... it would be good to have a direct link, just to get some direct support*  
253 *really.'* (Robbie's mother)

254 All children reported a desire for future VCs. Younger children enjoyed the novelty of  
255 using the computer and older children enjoyed the familiarity of screen-based  
256 conversations. Convenience was important to parents as long as an appointment  
257 was pre-arranged. Most suggested email, or to a lesser degree, telephone, would  
258 complement the service well:

259 *'Email is easy as I can sit and do that later when the kids have gone to bed and I*  
260 *have peace and quiet. The videoconsultation is nice because you can see a proper*  
261 *person.....Timing is the key; it is a really good way of doing it but for us we would*  
262 *need to have a set appointment.'* (Robbie's mother)

263 *'I would be happy with video and emails, it's easy, y'know'. (Oscar's mother)*

264 Parents of children with severe CKD, who attend the specialist centre regularly still  
265 requested VC to reduce time spent there. They valued the likelihood of improved  
266 engagement and protected virtual time with the dietitian:

267 *'You know the time is your time- people aren't coming in and taking you away for*  
268 *other things.'* (Thomas's mother)

269

270

271

272

273 **Discussion**

274 This study demonstrates that using VC to support regional paediatric specialist  
275 dietetic care is feasible, acceptable and beneficial to those living with CKD.  
276 Convenience, efficiency and specialist dietetic access positively influenced  
277 engagement. Parents and older children described enhanced understanding when  
278 viewing on-screen information during the consultation. This led to a perceived  
279 enthusiasm for dietary change and preferences for ongoing VC as part of their  
280 dietetic care plan.

281 To our knowledge this is the first qualitative study of VC using home technology in  
282 the UK paediatric population. Familiar public VC platforms such as Skype have been  
283 internationally researched in healthcare<sup>(19, 20)</sup>, but security concerns exist<sup>(21, 22)</sup> and in  
284 the study location, its use was not permitted.

285 The lack of security and privacy concerns in this study may have been influenced by  
286 high trust levels in regular service users informed of potential risks. Similarly,  
287 concerns to privacy are not frequently voiced in other studies of VC within a patient's  
288 home<sup>(23-25)</sup>, however, relevant studies are set in neonatal situations where parent  
289 vulnerability may influence perspectives. Population differences mean these studies  
290 are not wholly comparable, but the current study also confirms that VC is not  
291 considered intrusive for this caseload. A minor concern was the possibility of  
292 sensitive information being overheard by children. Use of headphones could be  
293 recommended but is not a full solution; risks should be considered and consent to  
294 VC documented.

295 Where prior concerns over technological competence existed, parents experienced  
296 that VC software was straightforward to use. Doubts of capacity for technology may  
297 limit VC uptake<sup>(26)</sup>, but this is influenced by age and the current study supports  
298 research that younger adults find VC 'extremely easy' and superior to telephone  
299 support<sup>(27, 28)</sup>. Regular use can limit connection difficulties and improve user  
300 confidence<sup>(28)</sup> but consideration is required where only a few contacts are required  
301 annually. VC at home is less prevalent than facilitated clinic use and more evidence  
302 is needed to ensure families can use it without hands-on professional support<sup>(20, 29)</sup>.

303 It is likely that recent improvements in technology resulted in less abundant audio-  
304 visual difficulties than reported in the literature<sup>(24, 28)</sup>. Occasional dark images were  
305 rectified by guidance to sit in a well-lit area. 'Time-lag' was common in this study and  
306 others<sup>(20, 24)</sup> but users develop a 'pausing' style to overcome this<sup>(30)</sup>.

307 Screen-sharing contributed to improved understanding; of growth charts in particular.  
308 Growth retardation remains a major problem in CKD, with short-stature posing  
309 psychological and medical challenges<sup>(31)</sup>. Anecdotally, electronic growth charts  
310 appear difficult for a patient to view in clinic as the screen is in front of the  
311 professional, not the patient. In this study parents reported viewing information more  
312 clearly on their own devices, even on a small screen.

313 Good therapeutic trust and rapport is associated with improved adherence<sup>(32)</sup>, so  
314 virtual rapport must be understood. In this study, opinions were divided regarding the  
315 need for established face-to-face relationships before moving to VC. Age and  
316 technological confidence may additionally influence rapport; although positive virtual  
317 therapy alliances are described by adolescents, some parents prefer face-to-face  
318 consultations<sup>(33)</sup> and find a prior physical meeting preferable<sup>(33-35)</sup>.

319 The findings strongly support VC as a tool for improved engagement, particularly  
320 with older children and this is significant regarding self-care and transition.  
321 Developing evidence suggests that digital communication enables young people to  
322 take greater responsibility for their health and improves health professionals' access  
323 to young people<sup>(36, 37)</sup>. Talking to children through their parents can make children  
324 feel 'invisible'<sup>(33)</sup>. Gaining knowledge independently provides opportunities for self-  
325 care<sup>(38, 39)</sup>.

326 Risks of reduced engagement are acknowledged in this study. Interruptions in the  
327 home may be distracting<sup>(40)</sup>, but paediatric specialists are somewhat used to lively  
328 consultations, and visual images may offer more chance to anticipate an interruption  
329 compared to telephone. Statements show VC at home provided familiarity for  
330 children; studies agree the experience is 'as if sharing the same room'<sup>(41)</sup>. In line  
331 with other studies, parents described children as 'in their comfort-zone'<sup>(34)</sup>. These  
332 findings support research suggesting better therapeutic relationships are developed  
333 using VC compared to telephone<sup>(27, 42, 43)</sup>.

334 Regarding willingness for dietary change, parents believed the VC influenced new  
335 ideas and promoted enthusiasm for change. It is unknown if this will result in actual  
336 behaviour change in children, but evidence exists for adults<sup>(14)</sup>. Active engagement  
337 motivates adolescents to meet treatment goals<sup>(44)</sup> so success seems possible. This  
338 study also added evidence to the perception that VC's are enjoyable for children<sup>(34)</sup>  
339 and thus potentially 'motivating'<sup>(23)</sup>. Virtual access to the child's home environment  
340 can contextualise advice<sup>(34, 40)</sup>, making interventions more manageable.

341 Preferences for ongoing VC were influenced by its efficiency. Studies show that VC  
342 is associated with decreases in travel time and less disruption to education and  
343 employment <sup>(23, 35, 45)</sup>. The current study revealed parents appreciated a prepared  
344 and organised VC clinic in comparison to attending a multi-professional clinic at the  
345 specialist centre. These busy hospital clinics involve planning the movement of  
346 children around numerous multidisciplinary staff, with often frustrating waits for  
347 families. With VC, families seemed prepared and relaxed in their environment. This  
348 was reported by several parents in this study and is in line with other research<sup>(34, 46)</sup>.

349 Preferences were also influenced by access to specialist knowledge. Despite some  
350 having a trusted local dietitian, all families wanted a complimentary specialist VC.  
351 The paediatric CKD population is relatively small with significant variability in dietary  
352 needs. Dietitians working in general hospitals have little opportunity to develop renal  
353 expertise and are indeed not expected to. This supports UK recommendations that  
354 children in CKD stages 3-5D should have a specialist renal dietetic review at least  
355 annually<sup>(6)</sup>. Early dietetic advice supports prevention of bone mineral disorders<sup>(47)</sup>  
356 and optimises growth<sup>(48)</sup>. Although specialists provide training and lead care<sup>(6)</sup>, local  
357 teams rarely have capacity to prioritise these children<sup>(11)</sup>. If adequately resourced,  
358 VC could undoubtedly improve dietetic care, especially if supplementary to face-to-  
359 face care<sup>(34, 35, 41, 49)</sup>. More research is needed to determine if VC could be a sole  
360 communication method in earlier disease and if this jeopardises face-to-face  
361 services<sup>(24, 26, 34, 45, 50)</sup>. Quantitative research should investigate if VC developments  
362 can result in improved engagement with dietetic services and improved nutritional  
363 outcomes. This should not be restricted to children with renal disease and  
364 encompass all children with dietary related disease to enable a much larger sample.

365

366 Rigour and reflexivity

367 The researcher is a dietitian (ST), experienced in regional service challenges, so  
368 reflexive practices were used to ensure prior beliefs, values and predictions did not  
369 shape data interpretation. A second researcher (AS), who is not a dietitian nor has  
370 experiences with the nephrology service, assisted with developing the coding  
371 framework and analysis, adding further validity<sup>(15, 51)</sup>.

372 Limitations:

373 Due to timeframes, the study design included just one VC experience which may  
374 negatively bias perspectives, as technical difficulties are less likely to exist with  
375 established frequent use<sup>(28)</sup>. A second limitation was that a few families had  
376 established trust and rapport before the study as a consequence of usual care.

377 Conclusion:

378 This study presents promising evidence that videoconsultation can improve  
379 engagement with children and parents who may otherwise present barriers such as  
380 distance, time limitations, and motivation. Enhanced engagement, during an isolated  
381 VC, was demonstrated by adolescents in the study, but further research is required  
382 to determine if engagement with dietetic services will improve overall. The chosen  
383 VC system was secure and technologically feasible but families required telephone  
384 support during initial set-up. Screen-sharing of information generated practical  
385 discussion and was regarded superior to telephone calls. Children preferred VC,  
386 whilst parents felt VC was an efficient, trustworthy supplement to current dietetic  
387 care. VC complements NHS plans to improve quality and equity across networks<sup>(5)</sup>.  
388 Further research and evaluations are required to explore if dietary adherence and  
389 thus nutritional outcomes in paediatric CKD can be improved using a VC service.

390 References

- 391 1. Kitamura C, Zurawel-Balaura L, Wong R. How effective is video consultation in clinical oncology? A  
392 systematic review. *Curr Oncol*. 2010;17(3):17-27.
- 393 2. Department of Health (2012). The power of information: putting all of us in control of the health  
394 and care information we need. [https://www.gov.uk/government/publications/giving-people-](https://www.gov.uk/government/publications/giving-people-control-of-the-health-and-care-information-they-need)  
395 [control-of-the-health-and-care-information-they-need](https://www.gov.uk/government/publications/giving-people-control-of-the-health-and-care-information-they-need) (accessed 20.6.2018).
- 396 3. National Information Board (2014). Personalised Health and Care 2020: using data and technology  
397 to transform outcomes for patients and citizens – a framework for action

- 398 <https://www.gov.uk/government/publications/personalised-health-and-care-2020> (accessed  
399 20.6.2018).
- 400 4. Office for National Statistics (2017). National Population Predictions: 2016 Statistical Bulletin.  
401 [https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationproje  
402 ctions/bulletins/nationalpopulationprojections/2016basedstatisticalbulletin](https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2016basedstatisticalbulletin) (accessed 20.6.2018).
- 403 5. NHS England(2017). Sustainability and Transformation Partnerships.  
404 <http://www.england.nhs.uk/stps>(accessed 20.06.2018).
- 405 6. British Association of Paediatric Nephrology(2011). Improving the standard of care of children with  
406 kidney disease through paediatric nephrology networks: Royal College of Paediatrics and Child  
407 Health.<http://www.rcpch.ac.uk/networks>(accessed 12.12.2017).
- 408 7. Brown BB, Patel C, McInnes E et al. The effectiveness of clinical networks in improving quality of  
409 care and patient outcomes: a systematic review of quantitative and qualitative studies. *BMC Health  
410 Serv Res.* 2016;16(1):60.
- 411 8. Royal College of Paediatrics and Child Health(2012). Bringing networks to life - An RCPCH guide to  
412 implementing clinical networks.<http://www.rcpch.ac.uk/networks>(accessed 18.5.2017).
- 413 9. Furth SL . Growth and nutrition in children with chronic kidney disease. *Adv Chronic Kidney Dis.*  
414 2005;12(4):366-71.
- 415 10. Rees L, Shaw V. Nutrition in children with CRF and on dialysis. *Pediatr Nephrol.* 2007; 22(10):  
416 1689–1702
- 417 11. Trace S. Audit of dietetic contacts across the South West UK Network [presentation].  
418 International Paediatric Renal Dietitians Conference. Manchester, UK. November 2017
- 419 12. Hewitt H, Gafaranga J, McKinstry B. Comparison of face-to-face and telephone consultations in  
420 primary care: qualitative analysis. *Br Jour Gen Pr.*2010;60(574):e201.
- 421 13. OfCom(2015). Children and parents: media use and attitudes report 2015.  
422 [https://www.ofcom.org.uk/research-and-data/media-literacy-research/childrens/children-parents-  
423 nov-15](https://www.ofcom.org.uk/research-and-data/media-literacy-research/childrens/children-parents-nov-15) (accessed 21.2.2018).
- 424 14. Kelly JT, Reidlinger DP, Hoffmann TC et al. Telehealth methods to deliver dietary interventions in  
425 adults with chronic disease: a systematic review and meta-analysis. *Am J Clin Nutr.*  
426 2016;104(6):1693-1702
- 427 15. Patton MQ. Qualitative evaluation and research methods. 2nd ed. Newbury Park: Sage; 1990.
- 428 16. Denzin NK. The research act in sociology: Theoretical introduction to sociological methods.  
429 London: Butterworth; 1970.
- 430 17. Miles MB, Huberman AM. Qualitative data analysis: an expanded sourcebook. California: Sage;  
431 1994.
- 432 18. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A B, R.G,  
433 editor. *Analysing qualitative data.* London: Routledge; 1994. p. 173-94.
- 434 19. Fatehi F, Armfield N, Dimitrijevic M, et al. Clinical applications of videoconferencing: a scoping  
435 review of the literature for the period 2002–2012. *J Telemed Telecare.* 2014;20(7):377-83.
- 436 20. Armfield NR, Bradford M, Bradford NK. The clinical use of Skype—For which patients, with which  
437 problems and in which settings? A snapshot review of the literature. *Int J Med Inform.*  
438 2015;84(10):737-42.
- 439 21. Churcher J. On: Skype and privacy. *Int J Psychoanal.* 2012;93(4):1035-7.
- 440 22. Dupasquier B, Burschka S, McLaughlin K et al. Analysis of information leakage from encrypted  
441 Skype conversations. *Int J Inform Sec.* 2010;9(5):313-25.
- 442 23. Fairweather GC, Lincoln MA, Ramsden R. Speech-language pathology teletherapy in rural and  
443 remote educational settings: Decreasing service inequities. *Int J Speech Lang Pathol.* 2016;18(6):592-  
444 602.
- 445 24. Lindberg I, Christensson K, Öhring K. Parents’ experiences of using videoconferencing as a  
446 support in early discharge after childbirth. *Midwifery.* 2009;25(4):357-65.
- 447 25. Lindberg B. Access to videoconferencing in providing support to parents of preterm infants:  
448 Ascertaining parental views. *J Neonatal Nurs.* 2013;19(5):259-65.

- 449 26.Sanders C, Rogers A, Bowen R et al. Exploring barriers to participation and adoption of telehealth  
450 and telecare within the Whole System Demonstrator trial: a qualitative study. *BMC Health Serv Res.*  
451 2012;12:220.
- 452 27.Pols J. Wonderful Webcams: About Active Gazes and Invisible Technologies. *Science, Technology,*  
453 *& Human Values.* 2011;36(4):451-73.
- 454 28.McCrossan B, Morgan G, Grant B et al. A randomised trial of a remote home support programme  
455 for infants with major congenital heart disease. *Heart.* 2012;98(20):1523.
- 456 29.Armfield NR, Gray LC, Smith AC. Clinical use of Skype: a review of the evidence base. *J Telemed*  
457 *Telecare.* 2012;18(3):125-7.
- 458 30.Hibbert D, Mair FS, May CR, Boland A, O'Connor J, Capewell S, et al. Health professionals'  
459 responses to the introduction of a home telehealth service. *J Telemed Telecare.* 2004;10(4):226-30.
- 460 31.AI-Uzri A, Matheson M, Gipson DS et al. The impact of short stature on health-related quality of  
461 life in children with chronic kidney disease. *J Pediatr.* 2013;163(3):736-41.e1.
- 462 32.Horvath AO, Symonds BD. Relation Between Working Alliance and Outcome in Psychotherapy: A  
463 Meta-Analysis. *J Couns Psychol.* 1991;38(2):139-49.
- 464 33.Anderson REE, Spence SH, Donovan CL et al. Working alliance in online cognitive behavior  
465 therapy for anxiety disorders in youth: comparison with clinic delivery and its role in predicting  
466 outcome. *J Med Internet Res* 2012;14(3):e88.
- 467 34.Gardner K, Bundy A, Dew A. Perspectives of rural carers on benefits and barriers of receiving  
468 occupational therapy via Information and Communication Technologies. *Aust Occup Ther J*  
469 2016;63(2):117-22.
- 470 35.Zilliagus EM, Meiser B, Lobb EA, Kirk J, Warwick L, Tucker K. Women's Experience of Telehealth  
471 Cancer Genetic Counseling. *J Genet Couns.* 2010;19(5):463-72.
- 472 36.Armoiry X, Sturt J, Phelps EE et al. Digital Clinical Communication for Families and Caregivers of  
473 Children or Young People With Short- or Long-Term Conditions: Rapid Review. *J Med Internet Res.*  
474 2018;20(1):e5.
- 475 37.Chi J, Demiris G. Systematic review of telehealth tools and interventions to support family  
476 caregivers. *J Telemed Telecare* 2015;21(1):37.
- 477 38.Sawyer SM, Drew S, Yeo MS et al. Adolescents with a chronic condition: challenges living,  
478 challenges treating. *Lancet* 2007;28;369(9571):1481-1489
- 479 39.Dunhill A, Elliott B, Shaw A. Effective communication and engagement with children and young  
480 people, their families and carers. Exeter:Learning Matters; 2009.
- 481 40. Rayner M, Dimovski A, Muscara F et al. Participating From the Comfort of Your Living Room:  
482 Feasibility of a Group Videoconferencing Intervention to Reduce Distress in Parents of Children With  
483 a Serious Illness or Injury. *Child Fam Behav Ther.* 2016;38(3):209-24.
- 484 41.Solli H, Hvalvik S, Bjørk IT, Hellesø R. Characteristics of the relationship that develops from nurse-  
485 caregiver communication during telecare. *J Clin Nurs.* 2015;24(13-14):1995-2004.
- 486 42.Trief PM, Sandberg J, Morin PC, Shea S, Brittain R, Banks Feldhousen E, et al. Diabetes  
487 Management Assisted by Telemedicine: Patient Perspectives. *Telemed J E Health.* 2008;14(8):647-  
488 55.
- 489 43.Salisbury C, Thomas C, O'Cathain A, Rogers A, Pope C, Yardley L, et al. Telehealth in CHronic  
490 disease: mixed-methods study to develop the TECH conceptual model for intervention design and  
491 evaluation. *BMJ Open.* 2015;5(2).
- 492 44.Tong A, Wong G, Hodson E et al. Adolescent views on transition in diabetes and nephrology. *Eur J*  
493 *Pediatr.* 2013;172(3):293-304.
- 494 45.Greenberg N, Boydell K, Volpe T. Pediatric Telepsychiatry in Ontario: Caregiver and Service  
495 Provider Perspectives. *J Behav Health Serv Res.* 2006;33(1):105-11.
- 496 46.Sevean P, Dampier S, Spadoni M et al. Patients and families experiences with video telehealth in  
497 rural/remote communities in Northern Canada. *J Clin Nurs. Nurs.* 2009;18(18):2573-9.
- 498 47.Bacchetta J, Harambat J, Cochat P, et al. The consequences of chronic kidney disease on bone  
499 metabolism and growth in children. *Nephrol Dial Transplant.* 2012;27(8):3063-71



500 48.Salas P, Pinto V, Rodriguez J et al. Growth Retardation in Children with Kidney Disease. Int J  
501 Endocrinol. 2013;2013:970946  
502 49.Lindberg B, Nilsson C, Zotterman D et al.Using information and communication technology in  
503 home care for communication between patients, family members, and healthcare professionals: a  
504 systematic review. Int J Telemed Appl. 2013;2013:461829.  
505 50.Shulver W, Killington M, Morris C et al. 'Well, if the kids can do it, I can do it': older rehabilitation  
506 patients' experiences of telerehabilitation. Health Expect. 2017 Feb;20(1):120-129.  
507 51.Creswell JW. 30 Essential Skills for the Qualitative Researcher: Sage;Thousand Oaks;2016.

508

509

510

511

512

513

514

515

516

517

518

519

520

521

522

523

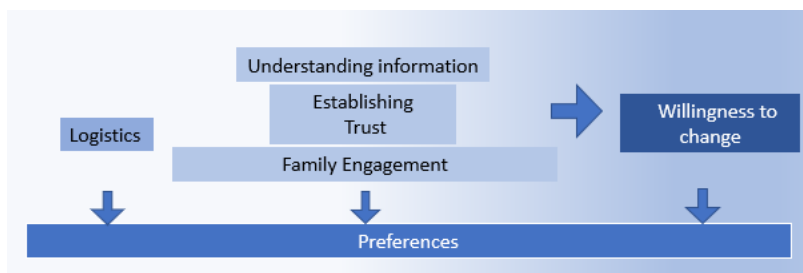
524

Theme	Codes	Definition	When to use	Example text
Willingness to change	Embracing new perspectives/idea's	New understanding supporting dietary/behavioural change	When statements imply new knowledge or understanding gained will lead to positive dietary actions	'A picnic...that's some before. To be hones w .....its nice to try again we don't want him on
	Agreeable to dietary change/ maintenance			
Logistics	Operating difficulties	Any technological issue disrupting the VC or preventing it from starting. Any problem with attending appointments	When perspectives on connection difficulties, sound, visual quality are raised. Operating difficulties. Concerns regarding security/privacy.	'I was panicking, think technology, I'm rubbish switch a computer on smoothly' 'It took 25 that's technology for slow.' 'You may need that parents might w their children overhea
	Technical issues with VC			
	Privacy/ security of VC			
Family Engagement	Engagement of participants and others	Describes family support and willingness to use VC to consult with dietitians and benefits or difficulties with this	When family members or children comment about ability to engage due to convenience/ease of access/time commitment/timing of appointment and the benefit/disadvantage of this to family life	'It's the school holiday centre) literally takes got to have an appoint we've been to a soft p we have been to the t that (the child) was at consultation, ... he act computer..... He stayed whole consultation, m and was answering at
	Attendance to VC fits around family life			
	Barriers to engagement			
	Facilitators of engagement			

525

526 Figure 1. Excerpt from the coding frame

527



528

529

530 Figure 2. Themes and their relationships

531