

Integrating Healthcare Education for Best Practice – A Question of which Health Professionals Between Paediatric and adult Chronic Kidney Disease (CKD) Patients – Topic Tagging and what is ‘Deemed’ Clinically Relevant Context – A Qualitative Perspective

Muhammad SN^{1*}, Orzechowska K^{2,3}, Gardener J³, Gardner V^{3,6}, Christine H⁴, Carson A⁵ and McGraw A⁶

¹Academic Scientist University of the West of England (UWE), Dept. of Health and Applied Sciences-Bristol UK

²Coventry University (CU), Dept. of Health and Life Sciences – Coventry UK

³Research Intern, the Renal Patient Support Group (RPSG) – Bristol UK

^{3,6}Chief Administrator, Founder the Renal Patient Support Group (RPSG) – Bristol UK

³Chief Administrator, Founder the Renal Patient Support Group (RPSG) - Bristol UK

⁴Chief Administrator, Founder Kidney Disease and Renal Support (KDARs) for Kids – North East Lancashire UK

⁵University of the West of Scotland (UWS) - Dumfries UK School of Health and Life Sciences

⁶Board of Directors Quality Insights Renal Network 5 – Virginia USA

ABSTRACT

Education and information seeking is pinnacle for patients with Long-Term Conditions (LTCs) like Chronic Kidney Disease (CKD) to take ownership of health and disease and navigate healthcare between health sectors. Patient and Public Involvement (PPI) are key to help understand gaps in health education.

Aims/ Objectives: 1) Involving patients between two support groups to help understand which topics and subjects are pertinent to CKD patients; 2) Involving patients to understand whether, retrospectively there has been an educational neglect in healthcare; and 3) To understand how healthcare and education for CKD patients could be more integrated.

Methods: Two PPI workshops were implemented (May and June 2019) after reviewing NIHR INVOLVE best practice guidelines. Fourteen (14) topic tags were applied over 1-month (March and April 2020) between the Renal Patient Support Group (RPSG) (est.2009) and the Kidney Disease and Renal Support (KDARs) (est.2014) for Kids platforms.

Ethics: Group disclaimers encouraged informed consent. GDPR (2018) guidelines were implemented to ensure best practice surrounding confidentiality and data protection.

Results: Thematic Analysis was used to highlight findings, according to over-arching themes having used Nvivo-12 software to code and help understand where there are healthcare educational inefficiencies. Five themes were identified through this study including 1) Using Different Mediums to Collect Qualitative Data and Understanding Healthcare; 2) Reliability and Validity of using the Internet to Collect Data; 3) Healthcare, Patient and Public Involvement and Maintaining Confidentiality through Online Methods to collect Qualitative Data; 4) Advantages, Disadvantages and Limitations to Online Data Collection and Peer Support Groups and 5) Using Qualitative Methodology to Understand Educational Needs for CKD Patients.

Discussion: Wider Allied Health Professionals (AHPs) could increasingly find themselves taking on roles, particularly where involvement is increasingly dependent bridging educational gaps and ‘alleviating misinformation’ through technology and ‘online spaces’.

Conclusion: This is the first UK retrospective study that examines educational gaps between online paediatric and adult CKD patients close to two decades (16 years), and highlights where further PPI-focused research would help understand where healthcare requires investment.

*Corresponding author

Muhammad SN, Academic Scientist University of the West of England (UWE), Dept. of Health and Applied Sciences-Bristol UK.

Email: shahid2.muhammad@live.uwe.ac.uk

Received: May 24, 2021; **Accepted:** May 28, 2021; **Published:** June 04, 2021

Keywords: Topic Tagging, Education, Chronic Kidney Disease, Adults, Paediatrics, Healthcare, Qualitative Research

Introduction

The proliferation of cheap and easy access to information and communication technology (ICT) over the past twenty years has created opportunities for research data to be collected via several media unavailable to previous generations of researchers [1]. The move to collect quantitative data using the World Wide Web was a relatively small step building on already established data entry systems. However, the use of on-line methods to collect qualitative data required a more significant shift in mind set to take advantage of the benefits offered.

Research data may be collected to highlight or outline a specific issue, or to substantiate and validate past and present research across age groups and diverse backgrounds. When using qualitative methods the researcher is the instrument and thus requires specific skills. Qualitative research often uses open-ended data collection methods e.g. direct observation of participants is common in experimental and qualitative research. There has been a growing interest in qualitative research methods in health and social care, often associated with Allied Health Professional (AHP) research. However, the emphasis on Evidence Based Medicine (EBM) accompanied by recognition of the importance of quality of life has prompted health care professionals of all disciplines to acknowledge the value of qualitative methods [2-5].

EBM requires the integration of individual clinical expertise with the best available external clinical evidence from research combining evidence from qualitative and quantitative research creates an opportunity for improving the way care is provided. The findings of qualitative research can complement quantitative studies offering insights and explanations relating to individual (or cohort) experiences, attitudes and beliefs in order to inform and develop better health care strategies Table 1 summarizes some of the key differences between qualitative and quantitative data collection approaches [6-9].

Chronic Kidney Disease (CKD)

Chronic Kidney Disease (CKD) is regarded as a public health problem globally. This Long-Term Condition (LTC) affects 10 – 16% of the general adult population in fast and slow developing countries. 5% of UK population suffer from stages CKD 3-to-5. The characterization of CKD at all stages is an important part of its management and allows the initiation of appropriate treatments with the aim of slow progression of kidney disease. CKD in children and adults is characterized by kidney damage or a decrease in glomerular filtration rate (or GFR) [10-15].

Providing up-to-date, accurate health information is pinnacle for patients to take ownership. The most recent definition for CKD describes kidney damage, a glomerular filtration rate of less than 60 mL/min per 1.73m² for 3 months or more recommended by Kidney Disease Quality Outcome Initiative (K/DOQI) [16].

In a U.S pilot investigation focusing on pre-dialysis education, several modalities of engagement and dissemination for education were evaluated. This included face to face education and online sessions and the endpoint was patient’s ability to select Renal Replacement Therapy (RRT) modality right for them. Three assessment tools were utilized to compare groups: including CKD knowledge, literacy, and quality of life. Education sessions were auctioned over five hours, and over three sessions. The study was undertaken over a three-year duration, wherein 240

consented to take part. It was recognised that education is required to support CKD patients have a smarter understanding of disease and treatment options. Patients wished they had been educated earlier irrespective of face to face or online modality [17].

Aims and Objectives

The changes in technology and the way care is delivered to patients will change the nature of roles for Allied Healthcare Professionals (AHPs) across CKD care. For example, Healthcare Scientists could have more educational and advice focused roles and supporting interpretation of test results where traditionally they are behind scenes’ in healthcare delivery. Technology also prompts change in relationship between areas of kidney care and healthcare professional involvement across health sectors [18-19].

The aims and objectives of this UK study include the following 1) To understand which topics and subjects are pertinent to CKD patients; 2) To understand whether, retrospectively there has been an educational neglect as part of healthcare delivery; and 3) To understand how healthcare and education for CKD patients could be more integrated. The aims will be achieved through topic tagging and identify threads and discussions close to two decades (16-years) between two peer support groups.

Methodology

The research team created a topic tagging activity wherein topics between two social media platforms, The Renal Patient Support Group (RPSG) and Kidney Disease and Renal Support (KDARs) for Kids having understood aims and remit of support groups. Tags were created against fourteen (14) different topics having extensively investigated over 1-month (March and April 2020) most popular key terms. Topics were tagged for 2-weeks per social media platform (i.e. 2-weeks RPSG, online adult renal population) and 2-weeks through KDARs, (online paediatric and young kidney population).

Topic tagging retrospectively will help understanding of what areas of healthcare are popular, and where patients between the two groups would find health professional involvement further supportive. Thematic Analysis was used to highlight findings, according to over-arching themes having used NVIVO-12 software to code and help understand where there are healthcare educational inefficiencies and identify what information needs still need to be met in the care for both paediatric and adult CKD patients.

Patient and Public Involvement (PPI)

More research is now highlighting how PPI is important to help understand gaps across healthcare. To this end, several authors have informed that to understand how best practice should be implemented. In this light, it is crucial that research has PPI work stream or ‘taskforce’, to help focus research and bring wider transparency. Additionally, it is imperative that any research methodology implemented is streamlined and based on potential participant group’s ability and capacity to get involved and contribute. This is also where it has been highlighted, that if researcher chooses online methodology to collect data, maintaining confidentiality is an overall deciding factor for participants who would otherwise not get involved. Whilst there is growing literature, Frameworks and Guidelines are yet to be published surrounding PPI in healthcare research [20-25].

The involvement of patients in decision about healthcare, planning and service provision has been introduced in several countries, including the UK, Canada, Holland, and Australia [26]. The public involvement and support are needed to promote innovation and

research; the research needs to reflect public interest and values. PPI is a key element in social and healthcare research in the United Kingdom [21, 25]. Patients should be a key part of the solution to establish beneficial health research.

PPI Workshop Implementation

PPI is an important mechanism; involving patients and carers in this work has led streamline focus and research rigour. NIHR INVOLVE best practice guidelines were followed prior PPI implementation (NIHR 2020). This research was co-developed between patients and researchers between two social media platforms wherein founders and administrators were able to highlight gaps surrounding aims and objectives through to study implementation. As part of this work, 13 team members (7xRPSG and 6xKDARs) attended two high street community workshops, Bristol in May and June 2019. Prior topic tagging activity, founders of both paediatric and adult renal social media platforms highlighted an understanding of how members use groups for sharing of experiences and understanding surrounding CKD. The evaluation and feedback helped the research team understand patients view surrounding access to healthcare education and information to focus this study. Feedback and context can be identified in Tables 5 and 6, supplement 3.

Topic Tagging - Development and Implementation

Topic tags were then co-created wherein, a research intern worked with founders to understand what areas of kidney health and care is popular using search facility via Facebook in these closed support groups. The team organised a co-production meeting wherein it was discussed and decided that given that that both groups have international membership and global reach, it would be important to ensure that topics and tags applied to general renal population, and not specific to paediatrics or adult population. This would help gain maximum number of tagged topics between two groups. This work aimed to tag as many topics according to designated topics (or themes) over 1-month duration between two groups. Table 2 provides main topics that were identified and tagged, respectively.

Ethics

All members between two groups were informed to refer to group disclaimers and that topics would be tagged. Administration teams between paediatric and adult kidney social media platforms ‘pinned’ an announcement at the top of respected groups, so that members would know 1) topics will be tagged to help identify experiences relating to themes and subject entities and 2) to highlight how tagging activity is being conducted to identify discussions relevant to health focuses and scenarios, more swiftly and 3) overall highlight how two kidney care platforms help searching out information to on-going aspects surrounding care and support.

As part of this activity, members between both groups were informed topic tagging and confidentiality will remain in group. Group disclaimers also prompted informed consent. Consideration for the need for ethics approval was made and the Department of Health guidance was consulted (Governance arrangements for research ethics committees 2012). Ethics committee approval was not required for this work; however, guidelines of General Data Protection Regulation (2018) were followed (refer below).

General Data Protection Regulation (GDPR) (2018)

Primarily the RPSG and KDARs are both closed Facebook support groups and both platforms are for patients and carers in CKD. RPSG and KDARs are covered under Facebook’s data privacy and protection policy. The General Data Protection Regulation (GDPR) creates consistent data protection rules across the EU. The GDPR has been in effect as of 25th May (2018) and applies to organisations based in the EU, as well as to companies around the world who provide or offer goods or services, and who process data from or about people in the EU. In keeping with GDPR, the research team have not reported any personal identifiable data (PID) (i.e. names, dates of birth, addresses and/ or locations) of participants. The GDPR and data protection guidelines were adhered to and applied throughout, respectively.

Results

The RPSG has over 8000 adult CKD patients and KDARs has over 1500 paediatrics and young patients (refer supplements 1 and 2). Between the two international groups, 2,560 threads tagged against 14 topics. Results here inform that patients between both adult and paediatric cohorts still require additional support across several areas of kidney care, and this retrospective trend analysis provides snapshot qualitative data of topics and context in relating to evidence-base from two renal online cohorts over 16-years. Topic Tags and Qualitative Data (RPSG) – Adult Population displayed in Table 3 and Topic Tags and Qualitative Data (KDARs) – Paediatric/ Young population are displayed in Table 4. Four main themes were identified through this study including 1) Using Different Mediums to Collect Qualitative Data and Understanding Healthcare; 2) Reliability and Validity of using the Internet to Collect Data; 3) Healthcare, Patient and Public Involvement and Maintaining Confidentiality through Online Methods to collect Qualitative Data; 4) Advantages, Disadvantages and Limitations to Online Data Collection and Peer Support Groups and 5) Using Qualitative Methodology to Understand Educational Needs for CKD Patients. In addition, this study informs that social media groups between adult and paediatric cohorts discussions are not just ‘clinically relevant’ but also form pinnacle understanding of where the gaps in education have been for patients near two decades.

Table 1: Summary of Main Topics Developed and Tagged between Paediatric and Adult Kidney Support Groups

Topics Developed and Tagged
1. Lab Tests and Biomarkers
2. Biopsy and Surgery
3. Diet and Nutrition
4. Renal Replacement Therapy (RRT)
5. Psychology and Related
6. Medication and Pharmacy
7. Lifestyle
8. Primary Care (GP)
9. Wellness and Wellbeing
10. Nursing
11. Exercise
12. Educational and Interactive
13. Peer Support
14. Covid-19 and Infections

Table 2: Topic Tags and Qualitative Data (RPSG) – Adult Population

Topics Tagged and Themes	Year Patient Posted	Patient Context	Context relating Citation and Evidence-Base
Lab Tests and Biomarkers	2011	“My husband’s today’s blood report reads creatinine 8, urea 113. Last report was creatinine at 7 and before that 4. He undergoes dialysis weekly twice. I do not understand why the creatinine and urea level is still at peak, or this is normal for dialysis patients”.	Nisha R, Srinivasa Kannan SR, Thanga Mariappan K, Jagatha P (2017). Biochemical evaluation of creatinine and urea in patients with renal failure undergoing hemodialysis”. J Clin Path Lab Med: 1(2)
Biopsy and Surgery	2014	easy...done in a doctor’s office, with just local anesthesia. I assume it’s more involved for kidney biopsies?” “I posted a few weeks ago about my acute renal failure and I’m pleased to say my eGFR hasn’t gone down for the last month after dropping from near normal to 28 in a couple of months. But because it has not improved in the last month either, so I have now got to have a biopsy. Does it hurt? Are there any after-effects? Anything else I should know? Thanks”	Dhaun N, Bellamy CO, Cattran DC, Kluth DC (2014). Utility of renal biopsy in the clinical management of renal disease. Kidney International 85(5), 1039-1048
Diet and Nutrition	2018	went on a low carb diet and he (Physician) told me to stop immediately or at least balance since low carb diet means high protein, high protein makes the kidneys to work hard which is not good for a transplant”.	Ko GJ, Obi Y, Tortoricci AR, Kalantar-Zadeh K (2018) “Dietary Protein Intake and Chronic Kidney Disease”. Curr Opin Clin Nutr Metab Care.: 20(1): 77-85
Renal Replacement Therapy (RRT)	2013	“...Had a transplant in April and so far, my bloods have been perfect. Docs did a routine biopsy last wed and there’s definite rejection. I had a steroid drip today and I have two more. Anyone gone through this or know the possibilities? Does this mean I’m going to keep rejecting?”	Ndemera H, Bhengu B (2017). Factors Contributing to Kidney Allograft Loss and Associated Consequences among Post Kidney Transplantation Patients”. Health Sci J, 11:3
Psychology and Related	2016	“I survived the kidney dialysis for 5yrs. I got a transplant in April 2012; it was said to be a sleepy kidney to start. It took a while to get going. Extra dialysis, meds and loads of fluid. It works now plus on loads of meds still; I have lost quite a bit of weight since then. But my weight is a bit up and down at moment. The main problem I seem to be having is I have been getting bad depression and anxious since i had the transplant. I was fine on dialysis; it was like my second home. can anyone offer me some advice on what to do to cope. But no more meds”.	Goh ZS, Griva K (2018) Anxiety and depression in patients with end-stage renal disease: impact and management challenges - a narrative review”. Int J Nephrol Renovasc Dis.: 11, 93-102

Medication and Pharmacy	2016	“Does this happen to anyone else, ever since my Consultant has put up the dose of Sodium Bicarbonate from a gram twice a day to 2 grams twice a day, I wake up with sore feet. They feel like I have been walking for miles”. “I was taking 500mg of sodium bicarb until my consultant stopped it altogether without explaining i was simply given a note at dialysis. I have started getting leg and arm cramps could this be a low sodium symptom? Thanks”	Witham MS et al. (2015). Does oral sodium bicarbonate therapy improve function and quality of life in older patients with chronic kidney disease and low-grade acidosis (the BiCARB trial)? Study protocol for a randomized controlled trial. <i>Trials</i>
Lifestyle	2017	“...Recently my left kidney was removed due to cancer contained in it so I need no further treatment. My problem is that my right kidney is not enjoying its new role and my potassium, sodium and creatinine level is only 31. I am 83 with chronic heart disease and take Warfarin, Furosemide and BP meds which make my problems worse. I live in London and badly need on adjusting my lifestyle and eating habits. I have been told to drink a lot of water! I hope you will not mind me asking questions!	Rysz J, Franczyk B, Cialkowska-Rysz A, Gluba-Brzozka A (2017). The Effect of Diet on the Survival of Patients with Chronic Kidney Disease”. <i>Nutrients</i>
Primary Care (GP)	2014	“Is anyone else out there having issues with receiving the correct amount of medication? I had my transplant 5yrs ago and all the sudden my GP has reduced the amount of tac I am taking. My consultant hasn’t authorized it”. “Does anyone just go to their GP for bloods? I feel going to my clinic is a waste of time”. “shows how much GP secretary knows about renal failure, just received a letter asking me to drop in a urine sample, so they can check my kidney function”.	Allen AS, Forman JP, Orav EJ, Bates D, Denker BM, Sequist TD (2011). Primary Care Management of Chronic Kidney Disease. <i>J Gen Intern Med</i> . 26(4), 386-392
Wellness and Wellbeing	2019	“Has anyone else had trouble telling the ppl they care about, their thoughts, their worries... I hate the thought of sharing these problems... loved ones don’t deserve the thoughts we have, the agonizing over future treatments. Trying to understand, why me? behind it all. Life really sucks at times”.	Subramanian L, Quinn M, Zhao J, Lachance L, Zee J, Tentori (2017). Coping with kidney disease - qualitative findings from the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) study. <i>BMC Nephrol</i> . 18(1), 119
Nursing	2015	“...I am stage 4 CRF with small kidneys I have been suffering with severe bone pain everywhere and insomnia my PTH is 33 despite a high dose of Alfacalcidol 3 a day, my renal	Malaki M, Mortazavi FS, Moazemi S, Shoaran M (2012). Insomnia and limb pain in hemodialysis patients: What is the share of restless leg syndrome? <i>Saudi Journal of Kidney Disease and Transplantation</i> 23(1), 15-20
Exercise	2011	“ I am really chuffed with my clearance this month they are the best they are since diagnosed with kidney failure. My dietician reckons that it is down to me going on exercise bike while I dialyze, just wondering whether anyone else go on an exercise bike and whether it helps with their clearance.”	Johansen KL (2007). Exercise in the End Stage Renal Disease Population. <i>JASN</i> 18(6): 1845-1854
Peer Support	2012	“I am wondering if people from this group date that have kidney failure and are on dialysis. I am single and I find very hard to date because my illness; it’s not that I can’t get dates but I find it hard to share my story about my illness with men that I just meet or fear of rejection because of my illness. Anyone have any advice for me about dating, relationship and dialysis?”	Bailey PK, Hamilton AJ, Clissold RL, Inward CD, Caskey FJ, Ben-Shlomo Y, Owen-Smith A (2018) Young adults’ perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies. <i>BMJ Open</i>
Covid-19 and Infections	2020	“...this is going to sound ridiculous but given what’s going on in the world I had to ask. I’m 2 years post tx and I have to say I’m a little concerned about the Coronavirus, have any of you had any info from your hospital to find out what might happen?”	Kliger AS, Silberzweig J (2020). Mitigating Risk of COVID-19 in Dialysis Facilities. <i>CJASN</i> 15(5), 707-709
Electronic Patient Records (EPRs)	2012	“I have just checked on Renal Patient View. All my blood tests from MRI from Transplant clinic, on there so know I can have a look on there and see what my blood is doing. Just a short question? Any idea what levels the Tac levels should be as it doesn’t show what levels they are on RPV”.	Navaneethan S, Jolly SE, Sharp J et al. (2013). Electronic health records: a new tool to combat chronic kidney disease? <i>Clinical nephrology</i>

Table 4: Topic Tags and Qualitative Data (KDARs) – Paediatrics and Young People Online Population

Topics Tagged	Year Patient Posted	Patient Context	Context relating Citation and Evidence-Base
Lab Tests and Biomarkers	2018	Children with underlying structural changes in the kidney may not have changes in serum creatinine due to the underlying ‘renal reserve’ – the capacity of nephrons to maintain GFR by hyperfiltration and compensatory. In children with CKD, a prognostic biomarker may allow us to identify patients at high risk of CKD progression. Prognostic biomarkers may be useful to enhance enrollment in paediatric CKD clinical trials and improve the efficiency of trial design. hypertrophy until substantial injury has occurred. Proteinuria and serum creatinine only explain 32% of the variability of measured GFR decline among children in the Chronic Kidney Disease in Children (CKiD) study.	Greenberg JH, Kakajiwala A, Parikh CR, Furth S (2018). Emerging Biomarkers of Chronic Kidney Disease in Children’. <i>Pediatr Nephrol</i> . 33(6), 925-933
Biopsy and Surgery	2018	“So, we’re 4 weeks post-transplant and on our 4th admission. Damn creatinine’s sneaking up again and they are not 100% why. Second biopsy tomorrow see if this sheds any information	Birk PE (2012). Surveillance biopsies in children post - kidney transplant. <i>Pediatr Nephrol</i> . 27(5), 753-760
Diet and Nutrition	2017	Consideration include calories, protein, sodium, calcium, potassium, and iron. The assessment provides starting point and allows frequent monitoring nutritional goals to meet the changing needs of the child with different stages of CKD. Summarizing the nutritional management is a challenge that requires sequential assessment. Renal dietitian plays a vital role in the CKD management. It is a challenge to achieve the balance between calorie, protein, and electrolyte needs.	Nguyen L, Levitt R, Mak RH (2016). Practical Nutrition Management of Children with Chronic Kidney Disease. <i>Clinical Medical Insights</i>
Renal Replacement Therapy (RRT)	2018	“Ok so (patient) heading for a transplant from her daddy. No date organized yet and she’s feeling grotty. She may need a bit of dialysis until date arranged. Anyone else had this? Did dialysis improve the symptoms please? Also did they have PD or HD?	Masood A, Musarrat R, Mazahir S (2016). Dialysis Modality Preferences and Quality of Life of Adolescents with Renal Failure”. <i>International Journal of Medical Research and Health Sciences</i> : 5(4), 182-189
Psychology and Related	2019	“How do your children manage day to day, I’m not just talking about the physical impact that this journey has on them but the psychological issues which come with it. I understand from previous conversations that there is definitely a lack of support for our children when it comes to their mental health, do you think that this journey has an impact on your children as regards to their mental health? Do you think there is anything we can do to make things better?	Assadi F (2013). Psychological impact of chronic kidney disease among children and adolescents: Not rare and not benign’. <i>J Nephropathol</i> . 2(1), 1-3
Medication and Pharmacy	2020	“(Patient) was changed from Sytron to Ferrous sulfate 5mg and losartan 12.5mg to 25mg. He had his first dose of the higher losartan last night. School rang to say he had had a big nose-bleed, the I had to collect him as he was throwing up and I’ve noticed there’s blood on his pillow that definitely wasn’t there last night”. “Archie’s had a rock belly for a couple of days he was prescribed Movicol when he had his last bladder assessment as bowel was blocked anyways”. “Anyone who’s child has taken or is taking losartan potassium, did they/do they have any issues with pain in their legs? My daughter started taking it a couple of weeks ago and has been complaining of pain in her legs for the past few days, tonight she was in really bad pain and could not bear weight at all.	Huque SS, Rahman H (2014). Prescription of Drugs in Children with Impaired Renal Function’. <i>Bangladesh J Child</i>
Lifestyle	2018	“Are there any beans that suffer with C. diff? (Patient) first got it when he was quiet small but for the last few weeks he’s been having accidents all the time finally at my wits end I sent a sample off as a last resort it’s come back as active C. diff again. We avoid antibiotics as much as possible.”	McKenna AM, Keating LE, Vigneux A, Stevens S, Williams A, Geary DF (2006). Quality of life in children with chronic kidney disease - patient and caregiver assessments. <i>Nephrology Dialysis Transplantation</i> 21(7), 1899-1905

Primary Care (GP)	2017	“Bit of a random question but does anyone else never see their GP? I have taken Isaac once when he was about 3 months old and they have told us they won’t see him because they don’t have enough specific training so have given him open access at our children’s ward”.	White CT, Trnka P, Matsell DG (2007). Selected Primary Care Issues and Comorbidities in Children Who Are on Maintenance Dialysis: A Review for the Pediatric Nephrologist”. <i>CJASN</i> : 2(4), 847-857
Wellness and Wellbeing	2016	“(Patient) was born with PUV. This week has been an extremely hard week for him, but he is getting stronger with every hour”. “Anyone else experienced both HD and PD? Did you notice any difference in sickness between the two methods? And general wellness?”	Clave S et al. (2019). Quality of life in adolescents with chronic kidney disease who initiate haemodialysis treatment’. <i>BMC Nephrology</i> (online)
Nursing	2018	“Yesterday I posted about (patient) and his pipe supra pubic catheter...today I bite the bullet and decided to hold him down to get it changed! That did not go to plan	Neyhart CD, McCoy L, Rodegast B, Gilet CA, Roberts C, Downes K (2010). A New Nursing Model for the Care of Patients with Chronic Kidney Disease: The UNC Kidney Center Nephrology Nursing Initiative. <i>Nephrology Nursing Journal</i> 37(2), 121-131
Exercise	2017	““Can our kiddies do sports? Some people tell me yes some say not contact sports. Shay wanted to go karate with his brother, but I wasn’t too sure he also wants to do football?”	Clapp EL, Bevington A, Smith AC (2011). Exercise for children with chronic kidney disease and stage renal disease’. <i>Pediatric Nephrology</i> 27: 165-172
Peer Support	2017	“Let’s talk MRSA... who’s had any experience with it? (Patient) last set of swabs have come back positive for it! First time ever in her 9 years has this ever happened!”	Cuervo G, Camoes M, Shaw E et al. (2015). Methicillin-resistant <i>Staphylococcus aureus</i> (MRSA) catheter-related bacteraemia in haemodialysis patients
Covid-19 and Infections	2020	“Has anyone that’s been shielding their little one still had to attend hospital check/ bloods? We are meant to be going tomorrow and I’m super nervous as we haven’t been out	Watanabe T (2013). Renal complications of seasonal and pandemic influenza A virus infections. <i>European Journal</i>
Electronic Patient Records (EPRs)	2016	“I’ve noticed on people’s posts that you seem to know all the detailed results of your children’s tests – GFR, reactive protein, C3 levels, haemolytic complement etc. - I have not even heard of some of these terms!... I have never seen any actual test results from anything, including biopsy. So, my question is how do you all know all the results in such details? Do you get to see test results?”	Wang L, McGregor T, Jones DP et al. (2017). Electronic health record - based predictive models for acute kidney injury screening in pediatric inpatients”. <i>Pediatric RESEARCH</i> 82(3), 465-473.

Table 5: Workshop, May 2019 – High Street Nailsea - Bristol

Event Expectations	On Scale of 0-10 (0 being the worst and 10 being the best) have your expectations been met?	Does Language in Health Literacy Need to be Better		Is it Important for Patients to Understand Health Information		Can we contact you in future surrounding research	
		Yes	No	Yes	No	Yes	No
Network with different organisations and colleagues	5	12	1	13	0	12	1
Learn More about Kidney Care	9	9		9		9	
Learn about The Work of the RPSG	8	8		8		8	
Learn about Renal Subjects	10	10		10		10	
Learn from Others	10	10		10		10	
Keen to Meet Renal Patients	9	9		9		9	
Learning	10	10		10		10	

More about Health	10	10	10	10
To Learn	10	10	10	10
Aspects of Kidney Disease	9.5	9.5	9.5	9.5
Find new Links	10	10	10	10
Network	10	10	10	10
Collaborate	10	10	10	10
Professional Development	5	5	5	5
Interact and be Involved	9	9	9	9

PPI Evaluation and Feedback from Workshops, May and June 2019

Table 6: Workshop, June 2019 – High Street Nailsea – Bristol

How important was this event in relating to healthcare	Not Relevant 0	Somewhat Relevant 3	Relevant 9
How was the level of learning for the event	Too Simple 0	About Right 3	Too Complicated 9
How satisfied were you with the venue	Not Satisfied 0	About Right 9	Very Satisfied 3
What other subjects would you like to see covered	Nutrition Renal Care Needs with Public Health Polycystic Kidney Disease (PKD) Organ Donation/ Transplantation Diseases of the Liver Wider Health Professionals in Community		

This workshop helped understand what additional educational support through online spaces and social media would help CKD Patients.

Supplement 1: The Renal Patient Support Group (RPSG)

Patients and carers often have various questions relating to kidney care following routine clinical outpatient appointments. Owing to lack of opportunities to share real-life experiences with fellow peers via face-to-face communication, the intention of the RPSG founders was to provide an online support group as part of kidney care received at the North Bristol NHS Trust in Bristol, South-West England UK. The RPSG was formally founded in (2009) to help raise CKD awareness on a wider scale, for the adult renal population and provides support from ages 18 plus. The group has grown exponentially and now has over 8700 members internationally. The RPSG has been a support group for ALL who live with this long-term condition. Patients and carers are using the RPSG all around the world because involvement and engagement activities through the social media platform provide a wider opportunity for discussions about how patients, professionals and researchers could be working in partnership to find answers and improve disease and lives of patients with this long-term condition. Being involved also provides potential to become an innovative model for shared decision-making. The RPSG membership has proved that those using the group now have an increasing understanding of CKD, care plans and related disease-processes. The RPSG is highly research active, building on evidence-base to better the care and lives of patients. Whilst the RPSG does not provide formal medical advice; it is a support group for patients, siblings, carers, guardians, and families to share real-life experiences and everyday challenges. Over 10 years, RPSG have an international administration and research team, and this helps keep group live and active, 7-days a week, 24 hours a day. The RPSG welcomes everyone to join.

Supplement 2: Kidney Disease and Renal Support (KDARs) for Kids

The Kidney Disease and Renal Support (or KDARs) for Kids is a group founded in Lincolnshire, North East UK, (2014) and was initiated for patients, parents, guardians and carers of babies, toddlers and young people who are living with CKD and renal disease. The social media platform supports paediatrics and young people from ages 0-18 years. KDARs was inspired by the founder’s own personal experiences when daughter suffered with AKI, secondary to antepartum haemorrhage during new-born period; the daughter of founder was later diagnosed with CKD stage 3B. The KDARs team offers ‘online space’ for families to communicate, share experiences and stories, offer supportive advice, especially when areas of health become challenging and where face to face communication is not always possible. The group has grown exponentially and now has over 1600 members internationally. Confidentiality is paramount in KDARs, and what is raised, shared, and discussed remains within the closed platform. Paediatrics and young people, families, siblings, parents, and guardians require a safe and secure place to share understanding without the anxiety of potentially feeling comprised elsewhere. The lack of support for paediatric renal patients and families is overwhelmingly obvious. The KDARs team is bridging a gap that requires more established educational and support pathways built into paediatrics and young people’s kidney care, especially in a minority renal health population. Safeguarding, confidentiality, and the security of KDARs members and families is extremely pertinent to objectives and mission of the group. Anyone who now wishes to join KDARs have a set of questions to answer before being accepted. The KDARs membership encompasses a strong administration team who have offered time to support and keep the

platform running smoothly on a 24-hour basis. Over 6 years, KDARs have admin involved from UK and USA, and this helps keep the group live and active, 7-days a week, 24 hours a day.

Theme 1

Using Different Mediums to Collect Qualitative Data

The internet and online methodologies allow considerable scope for investigators to both collect data through online platforms but also understand gaps in patient care and education across a wide range of health conditions [28-40]. Understanding educational needs across health conditions and diverse populations is challenging [41-44]. Equally using different data collection modalities to understand gaps across health spheres is demanding.

One study involving year 7-and year 10 pupils (n=76) from diverse cultural and ethnic backgrounds attending four schools in two UK cities that used traditional paper and pencil and face to face focus groups to explore heart health associated beliefs. The authors highlight difficulty of recruiting participants from black and minority ethnic populations. The team inform that a small sampling frame limited stratification of the study in terms of gender, and randomized selection of participants. This study provides some insight into health beliefs and behaviours of African and African Caribbean groups, and authors believe that use of the World Wide Web potentially allows access and recruitment of larger number of participants, perhaps attracting younger people from diverse backgrounds to participate in qualitative research. One team implemented online methods to collect data to understand support networks used by African American breast cancer support patients [36, 37].

A U.S study involving culturally diverse populations focused on two specific areas of enquiry. 1) The Internet as a modality to collect data, and 2) Explore how the Internet can be used as an educational tool. Attention was drawn to the difficulty of including and representing the experiences of multicultural populations from low-income and working-class communities who are less likely to have access to the Internet, and when they do are likely to use it searching for information about jobs, housing, and entertainment. The team were able to identify that those who are more likely to use the Internet to retrieve educational insights and implement decisions are more likely to be educated and have higher income, and that black and minority ethnic populations, people with disabilities, and many elderly people are likely to be excluded from participating through online research [39].

Other factors that may impact in participation via Online include age differences in Internet usage and the limited availability or high cost of high-speed connection. Limited access often results in limited familiarity with internet technology. There can also be language-related communication difficulties particularly when involving individuals from diverse ethnic minority backgrounds; for example, the translation of terms like baseline data, empowerment, or LTC can be complex and may not necessarily carry the same meaning that are assigned in English [39].

A UK study implemented qualitative methodology to explore the meaning/ definition of what it means to have Myalgic Encephalomyelitis (ME), also known to as Chronic Fatigue Syndrome. The investigation used several of mediums to collect experiences of having ME. Interviews were conducted with 56 individuals, 49 members of internet support groups (38 chat line, 11 personal) and 7 members of two face-to-face support groups. Internet respondents were recruited through a message posted on a web-based support group. The purpose of the research was discussed with participants, they were assured that all data would be confidential, and were informed that they could withdraw from study at any time. Internet data were collected either as part of a non-synchronous (not ‘real time’) web-based support group chat line, or via one-to-one e-mail. The authors conclude that there were practical advantages using the internet for research to collect data from individuals who suffer debilitating fatigue, amongst other health complexities. Moreover, by using computer-aided communication, access could be available to groups over a wide geographic area, some of whom may were housebound and otherwise were unable to participate [34].

An Australian team conducted a systematic search across several databases including Medline, CINAHL, Embase, Psych lit implementing keywords ‘focus group’, ‘cultural sensitivity’, ‘transcultural nursing’, ‘transcultural care’, ‘cultural diversity’ and ‘ethnic groups’ in early 2006. The teams aimed to understand online methodology and young people involvement. The review reported that bilingual healthcare workers and interpreters not only facilitate pragmatic elements of online involvement and methodologies for young people, but are also active to engage with community groups. The authors highlight that online

focus groups may be one of the more advanced research tools available for obtaining data from young people and that focus groups are otherwise more appealing to people from culturally and linguistically diverse backgrounds [35].

Another U.S study investigates feasibility and comparability of findings from face-to-face versus online focus groups [41]. Twelve people with colon cancer took part in Face-to-Face or On-Line Focus groups focusing on issues of lifestyle (nutrition and exercise), cancer screening, and treatment. Throughout the study a project coordinator could be contacted by e-mail and telephone, to answer additional questions about protocol and confidentiality. Findings indicated that Internet-mediated (Instant Messaging) can be more accessible than traditional face-face focus groups for ill or LTC participants. Because Instant Messaging does not require face-to-face interactions, it also provides participants with anonymity, encouraging more comfort ability about disclosing sensitive information. The authors inform there are circumstances wherein such facilitation provides a feasible alternative to traditional face-to-face groups or one to one physical interviews [41].

Theme 2

Reliability and Authenticity of using Internet to Collect Data

Conducting research surrounding challenging questions is arduous, so how does one study a particular subgroup without compromising the validity of the data, especially when employing non-traditional sampling methods? [45]. both surveys and interviews can be highly structured, but it has become more common practice for interviews to become more open-ended, allowing participants to provide detailed answers. It is important that whatever data

collection method; the design and purpose is reliable and valid for the population for which they will be used [46]. Concurrent with or following the iterative process, external validation, or transferability of the analysis is required. This may involve triangulation, i.e. involving two or more sources of information [9].

There is now a wide selection of mediums to create webpages and use the internet to collect data, involving interest groups and population. A webpage can contain formatted text, links to other websites, pictures, graphics, animations, and other media such as sounds or video. By using a variety of techniques, different internet users can be reached. However, there is no guarantee that any particular method of recruitment will yield a representative sample of a particular population [30, 47].

To ensure the reliability of qualitative research investigators are advised to adhere to the philosophy or analytic method used for data collection. The investigator needs to consider whether internet data collection allows a process to remain true to philosophy, as adopting a specific analytic method brings with it, differentiations between rigour and robustness. It is possible that authenticity and validity of online data collection is only as good as the team or investigator ensuring integrity of research question and methodology. Depending on the nature of a study web-based data collection can be advantageous, for example collecting data from international cohorts, exploring rare conditions, or sensitive issues. Larger online investigations tend to have greater power than traditional studies, however this may be offset by greater technical challenges (hardware, systems, and browsers) and demographic diversity in web respondents [48-51].

One Japanese study explores issues such as sampling, design, data collection and management, and the ethics of web-based research, collecting data relating to involuntary celibacy (Kanzaki, et al. 2004). The team retrospectively focused on advantages and disadvantages of using the Internet in sexuality studies and drew on research examples. The authors claimed that Internet broadens scope in comparison to research methods. However, the team also acknowledged further comparisons with data derived from previous studies was required to determine the reliability of current investigation [38].

A study conducted by a U.S team sought to explore internet as a means of data collection for sexuality research. Benefits reported included larger, more representative recruitment and participation, however, risks to validity were identified such as lying and sabotage in the context of how ‘having sex’ is defined by gay, lesbian and bisexual college students. The investigation informed that the validation of online data collection should involve a comparison of internet and traditional techniques to examine sample biases. For example, data analysis of possible correlations between demographics of respondents and identify general trends after adjusting for differences [5].

There are many advantages of collecting data using an online sample. However, reliability and authenticity of using Internet requires structure. It is also important to bear in mind that using traditional methods also have weaknesses. For example, using traditional methods may not elicit sufficient information for sensitive or personal topics that may be considered deviant, such as drug use or sexual misconduct, as participants will not want to talk about sensitive topics ‘openly’ in either face to face interview settings or amongst strangers. Using either a traditional or online group approaches can generally be overcome by an experienced facilitator. Though online methods are reliable and authentic,

more research using online methodologies are still required in the UK before it will be possible to conclude that internet-based data holds external validity [52-54]. Just over a decade on, in the UK online methods to collect mixed-method data are also becoming common-place and common practice in research.

Theme 3 Healthcare, Maintaining Confidentiality through Online Methods to Collect Qualitative Data and PPI

Informed consent, privacy, and confidentiality are basic ethical tenets of any scientific research involving patients and/ or members of the public. When considering potential hazards to group participants or a community, privacy issues are especially quintessential. Much will depend on the nature of data to be collected, how it will be reported, how vulnerable the community, or sensitive the topic is, and the degree to which a researcher interacts with participants members [55-57].

The internet also holds various pitfalls for investigators, who can easily and unintentionally violate the privacy of individuals. Participants should therefore always be approached to give explicit consent to be quoted verbatim, and researchers are advised to contact participants in advance. Several studies highlight this focus in addition to ethical and confidentiality during research practices [29, 58, 41, 59, 33, 35].

One U.S team of investigators explored attitudes of teenagers and parents toward the use of a patient information portal. This investigation was conducted in two phases. In the first, the team conducted four focus groups: two with teenagers and two with parents. In the second, the team initiated two online bulletin boards, one for parents and one for teenagers. Initially letters were sent to parents inviting either the parent or the teenager to participate in the study. Where applicable, the teenager’s willingness to participate was established. Interested participants were contacted by a research assistant who explained the study and reviewed the informed consent. Participants were randomly assigned to either an electronic bulletin board group or an in-person focus group. Those in bulletin board group were asked to login at regular intervals and respond to questions and responses from other participants. Participants in the focus groups were asked to attend a two-hour meeting with five to eight other participants. Videotapes of the focus groups and transcripts from the bulletin board groups were independently analysed by team and the focus group/ bulletin board facilitator aimed identify themes and develop conclusions. Findings revealed that there was considerable support among teenagers and parents via patient portal and general issues relating confidentiality [60].

One UK team explores use of internet-based focus group approaches to be an effective way of engaging young adults with appearance-related concerns associated with having chronic skin conditions. The authors describe process of hosting and moderating synchronous online focus groups with the young people, highlighting some of the ethical, pragmatic, and retention challenges that researchers face using online methods. The team inform that the ethical issues might be no more hazardous than those associated with conventional methods, and suggest that many of the ethical questions posed by the rapidly developing virtual environment can be resolved by examining reactions to past research and by refining the definitions of concepts used in ethical discussions. Data was captured and stored on a faculty drive and only accessible by primary investigators and an IT technician supporting the project in the same way as data would be managed in a study using traditional methods [29].

Face-to-face group discussion provides a rich context in which participants respond to each other as well as the interviewer, and many features of everyday conversation are present. E-mail texts, however, lacks certain features of oral communication such as pauses, turn-taking and self-repair [52]. These areas have been highlighted by several authors, retrospectively [61-67].

Theme 4

Advantages, Disadvantages and Limitations to Online Data Collection and Peer Support Groups

Whilst peer support groups, online forums, and social media platforms prompts various advantages for opportunities engagement and interaction, literacy, and language of patients between cohorts varies, and is also dissimilar to health professionals. When sharing evidence-based literature or context, unless it is information that has been ‘diluted’, patients can feel anxious when they review posts, discussions, and threads, and professionals do not comprehend this understanding. There will be a cohort of patients that are more ‘susceptible’ to anxiety than others when identifying health information and support [68-70].

One U.S study explored the lived experience of pregnant women confined to home bed rest following a diagnosis of preterm labour using a virtual focus group to collect qualitative data. In this study written informed consent was obtained from all participants via mail. Participants were informed that they were welcome to contact other women in the study via personal e-mail, outside the context of the virtual focus group, if the contact was of mutual consent. The virtual focus group process generated detailed qualitative data. Three major categories and seven subcategories regarding the lived experience of home bed rest were identified: 1) The effect of bed rest on participants’ lives, 2) the effect of bed rest on relationships with others, and 3) the virtual focus group as an online peer support group. The authors highlight that the virtual discussions are a useful tool for both collecting qualitative data and mediating the challenges and isolation of home bed rest. In addition, use of the virtual focus group enabled nurses to embrace technology via Internet to study and connect with this patient group as well as other isolated and understudied cohorts [66].

Collecting data online allows synchronous communication and reduces time and cost in terms of venues and travelling. It also offers opportunity to understand LTC groups and wider healthcare conditions [71]. However, there is potential for technical errors both before and during the discussions. For example, a participant may lose connection. In most cases, they are able to log back in and continue [29]. Internet access has become more readily available, so computer access for participants is becoming less of an issue [41]. In some rural areas, inadequate telecommunication services increase Internet ‘drop out rates’ but again, with developing technology, this problem is reducing. Whatever method is used adequate planning and clear explanations of decisions made during the conduct of the study can significantly enhance the validity and reliability of a project [52].

Data collection via the internet through online platforms is still relatively novel in the UK, however investigations have highlighted advantages, disadvantages, and limitations. Patients relying solely on peer support groups for educational support can be problematic because it potentially lead to misinformation without appropriate health professional involvement [72-77].

Theme 5

Using Qualitative Methodology to Understand Educational Needs for CKD Patients Biomarkers

Relating lab tests and biomarkers, experiences being shared through RPSG revealed adult patients have not always understand the significance of investigations or results. For example, in adults, increased levels of keratinise and urea are a complication in patients with renal failure before haemodialysis. At the same time significant differences in levels of serum urea before and after haemodialysis have been observed. In children with CKD, proteinuria and serum creatinine only helps explain 32% variability of measured GFR decline [77-78]. More clarity surrounding CKD investigations, tests and parameters are required.

Biopsy

There is variation in understanding of surgery, including biopsy. Experiences being shared through RPSG revealed adult patients did not always understand principle of having a biopsy. Renal biopsy is safe procedure when carried out by using standard techniques. It can be used as an adjunct with other tests, and is considered as ‘diagnostic cross talk’, in the case of antibody-mediated rejection. Renal biopsy can be beneficial for patients who have not responded and manage immunosuppression treatment. Sharing experiences revealed children have more robust immunological complications; they are at higher risk for transplant rejection. Post-surgery. For example, the most reported advance event is macroscopic haematuria. Management includes various dosing immunosuppression protocols, and this is not always understood [79-80].

Diet and Nutrition

Sharing experiences revealed adults are potentially informed kidneys have crucial role in breakdown and excretion of protein metabolites. However, education gap surrounds definition of high protein and renal complications, and how this has influence on intraglomerular pressure leading to higher GFR and increased renal blood flow [81]. Experiences being shared in KDARs revealed, it is a challenge to achieve the appropriate nutritional balance. Evaluation of children with CKD includes height, weight, body mass index and head circumference [82]. Assessment provides starting point and allows monitoring nutritional goals to meet the changing needs of the child. Different perspectives relating diet and nutrition between two groups and not all patients have access to a renal dietician.

Renal Replacement Therapy (RRT)

Sharing experiences revealed adults patients have concerns relating to different forms of RRT but more specifically surrounding education post-transplant. Ineffective management of post-transplant patients can result in graft loss. Medical care of patients on RRT have improved outcomes of transplantation [83]. Experiences being shared in KDARs revealed general information needs focusing on RRT. Due to effects of RRT, kidney failure has an impact on growth and endocrine system. In this group, experience highlight burden of CKD, life expectancy and quality of life [84]. Different perspectives relating RRT between two groups and need for wider AHP involvement.

Psychology and Related

Sharing experiences revealed adults patients have concerns surrounding Psychology and relating issues. Patients on HD have been shown to have higher symptoms of depression and anxiety than that on PD. It can be associated with procedural aspects of HD treatment such as spending long hours in medical environments and need to travel to dialysis centres. However, dialysis unit may prompt peer support among patients, and routine with staff can be beneficial in strengthening mental health and wellbeing

[85]. Experiences being shared in KDARs revealed interventions should involve information and education needs focusing on psychology and strengthening mental health. For example, children/ young people with CKD and families could be prompted on the importance of potential benefits of routine psychological evaluations addressing different needs [86]. Understanding reveals Psychology services and professional access varies nationally between two groups.

Medication and Pharmacy

Adult dosing guidelines prompt conversion into pediatric dosed and adapt to patient’s renal function. The drug metabolism, absorption, and excretion are different in children than adults. Most of the studies on drug dosage in patients with renal failure are performed in adults. Experiences being shared through RPSG revealed adult patients have concerns relating to Medication and Pharmacy. Chronic acidosis has been associated with muscle weakness – this leads to fatigue and falls, weight loss and increased bone reabsorption. Sodium Bicarbonate is a common prescription in RRT patients, however can lead to increased blood pressure and fluid overload [87]. Such context might not be provided during existing consultation scenarios. Experiences being shared in KDARs revealed, understanding is not always transparent as to why medication is adjusted according to creatinine clearance or glomerular filtration rate [88]. Where drug prescribing between and pediatric adult patients is concerned, clinical teams tend to consider multiple factors to drug dosing. Renal Pharmacist access varies nationally and thus misinformation is an issue.

Lifestyle

Experiences being shared through RPSG revealed adult patients have concerns relating to Lifestyle education. Renal disease surrounds several guidelines relating best practice around CKD management, and lifestyle modifications. The effect of high salt intake increases the GFR and albumin excretion [89]. Paediatric patients with renal disease require lifestyle modifications and monitored renal team. Experiences being shared in KDARs revealed, adapting lifestyle changes are ongoing challenges. Quality of life can be affected across several spheres including physical and cardiovascular complications, neuron-development disorders, and psychological problems. Contextualising for some patients is an ongoing battle. Group consultations where patients have access to appropriate educational support and professionals would help prompt smarter care.

Primary Care (GP)

Experiences being shared through RPSG revealed adult patients have concerns relating to Primary Care and healthcare access – there is a ‘mixed picture. Relating, one study informs GP did not appear to recognize the underlying presence of CKD. Integrated care through primary care should be an important component [90]. Experiences being shared in KDARs revealed nephrology team provides care in areas that have an impact on surround kidney, but not always able to help with family medical, social or economic stresses (which is where Primary Care is effective) [91]. Education through Primary Care involving wider AHPs could be effective for CKD patients.

Wellness and Wellbeing

Experiences being shared through RPSG revealed adult patients have concerns relating to Wellness and Wellbeing. Patients want to take better care of themselves and develop confidence on rely on family to cope with chronic condition. One investigation informs suggest that patients adapt to current position by developing coping strategies [92]. Experiences being shared in KDARs revealed that

more education is required surrounding Wellness and wellbeing and impact of disease and its treatment [93]. Education focusing self-care and self-awareness is now being prompted because of experiences shared through peer support, but access to support information needs is missing.

Nursing

Experiences being shared through RPSG revealed adult patients want more focus relating to nursing care. Patients have various potential co-morbidities including limb pain. Limb pain may be associated with burning sensation, or itching, and in one study, 91% patients suffered from this [94]. This study shows association between insomnia and limb pain in dialysis patients and how areas surrounding renal nursing could be more involved for adult patients. Experiences being shared in KDARs revealed that nurses could optimize patient care through improved communication, and developing strategies to address education barriers [95].

Exercise

Experiences being shared through RPSG revealed adult patients have concerns relating to Exercise. The lack of data on outcomes of physical activities on survival is perhaps just one reason that physical activity has not been introduced into the routine care of dialysis patients. The performance activity assessment is a first step in introducing dialysis patients in exercise program [96]. Experiences being shared in KDARs revealed that more education is required surrounding physical activity. Children/ young people and families require additional educational and motivational strategies in the implementation of an exercise programme. Additionally, it would perhaps be useful for children/ young people to have further understanding relating importance of exercise in relation to disease management [97]. This is an area that is now gaining momentum, but more could be done if professionals are available through online educational support.

Peer Support

Whilst both groups provide peer support in unique ways, unfortunately alone experiences and understanding being shared can lead to misinformation. Experiences being shared through RPSG revealed adult patients have concerns relating to Peer Support. Young and older adults feel that CKD impacts on identity and capacity to form relationships. CKD has been described as putting life ‘on hold’ [98]. Children/ young people and families require additional educational support and it was identified in once example; an understanding of infection control was important. In this context, vascular catheter is the most frequent area wherein bacteria can enter bloodstream. For paediatrics/ young people on PD/ HD patients – bacteraemia is problematic. Peer support is effective, but alone it is ‘just sharing experience’. Educational support would help prompt patients to be more involved in decisive care and actions.

Covid-19 and Infections

Experiences being shared through RPSG revealed adult patients have concerns relating to Covid-19 and Infections. There was lot of discussion surrounding this issue over the one-month topic tagging was taking place. Patients understood those on HD or transplanted, with symptoms of infection must be diagnosed, and those without symptoms should isolate and stay [99]. There was concern over little information or education they had been provided. Experiences being shared in KDARs revealed that more education is/ was required relating to whether allowed outside. There has been some evidence that viral injury to the kidney could alter immune response following virus infection [100]. Therefore, education surrounding infections is a key focus for paediatric/

young people and families, especially owing to terms such as ‘isolation and ‘shielding’.

Electronic Patient Records (EPRs)

Experiences being shared through RPSG revealed adult patients have concerns relating EPRs use reducing ownership of health. CKD management often requires coordination of care between physicians and health professionals across several specialties and services across allied health care. Effective EPR usage does help in exchange of information between health professionals [101]. However, different systems are used and thus there currently exists a lack of integration leading to gaps in healthcare structure. Experiences being shared in KDARs revealed that more understanding of how to use EPRs and how to access facility through healthcare provider is important. EPRs could be incorporated into clinical practice to alert providers of increased CKD risk and prompt effective implementation of health actions [102]. Education surrounding EPRs is still key and this could be provided through interactive online educational sessions.

Discussion

Retrospectively, methodologies for data collection have become more diverse and the way patients are encouraged to get involved in research is also becoming of wider intrigue. However, over two decades on, two important questions still need to be answered. 1) In the UK, is primary care ready to support patients via technology and e-health as highlighted by and 2) is there a role for wider AHPs to be involved in education provision for CKD patients in primary care? To facilitate patient engagement, this step should be accompanied by strategies to support patients interpret and ascertain education provision around disease trajectory. This would also build patient-professional communication [103-111]. Security and reliable connectivity maintained by the NHS is important – this would allow faster transfer of information, so that patient care is better integrated between NHS services, ultimately providing education and prompt shared-decision making.

Conclusion

Patients between the two support group platforms have educational needs, and thus access to wider healthcare professionals online or otherwise would be important to support best practice in future. Wider AHP groups may increasingly find themselves taking on roles, particularly where involvement is increasingly dependent bridging educational gaps and ‘alleviating misinformation’ through technology and ‘online spaces’. Kidney Care and Nomenclature is also continuously evolving, and thus it must be appreciated that patients should be armed with appropriate context and information so that they are able to have engaging communication and discussions with health professionals/ service providers [5]. To this end, it is now time that patients have wider access to different professionals to help bridge areas ‘educational advice and support’ [112-116].

Limitations

Whilst topic tagging has allowed a good understanding of where gaps in healthcare education for CKD patients could be bridged, qualitative data presented only provides a snapshot. Topic tagging for 1-month per social media platform, or more could have offered opportunity to identify more experiences between adult and paediatric support groups and thus helped conduct more in-depth analysis.

Summary

It is careless to presume that educational needs of CKD paediatric and adult patients, is only treatment related. Patients require education on diets, laboratory investigations, and fluid restrictions.

CKD patients require education and resources on across several aspects of healthcare, and adjusting to ‘new normal’, whilst navigating (and during) the many areas of this LTC. Patients and families will also require educational support surrounding guidance on self -care. Access to wider health professionals through technology can provide patients with educational support highlighting resources and evidence-base.

This UK retrospective snapshot study examined use of online methodologies to collect data and educational gaps between two social media peer support groups that have provided a platform for patients near two decades. Co-developing educational modules involving patients and professionals would prompt quality of joined up care in meeting information needs and addressing potential healthcare disparities. Online educational support would open access to wider AHP collaborations to support CKD patients, adults, and paediatrics. Whilst there is some novel educational projects and initiatives taking place, the UK is otherwise, behind in this effort.

PPI-focus had a positive impact on healthcare users. Those involved in co-creating research felt empowered, valued, listened to and positive about health experiences. Involvement also helped increase knowledge surrounding condition and developed life skills. A PPI focus has been advantageous for all involved; it increased understanding of evidence-based working and novel insights into collaborative efforts, thus allowing patients and research team to meet mutual goals and objectives.

Recommendations

- Researchers are encouraged to build opportunities for PPI-focused practices so thus to increase best practice and evidence-based healthcare
- Prospectively, online Multidisciplinary Team (MDT) and Group Consultations should be envisaged wherein education is also made part of follow up, involving wider health professionals. This would help integrate care and increase patient report outcome measures
- In the UK, patients and professionals should be proactively co-developing initiatives including joint Telehealth educational consultations. Such initiative should complement healthcare and peer support involving ‘expert patients’ to help provide supplementary care

What this work adds

- There are several ways to ensure robust data collection – experimenting and implementing different online methodologies can widen recruitment and participation
- This study highlights educational gaps in ‘technological age’ for adult and paediatric CKD patients
- This study informs that in addition to online and peer support groups and social media platforms, there should be efforts to prompt educational support digitally, including webinars, podcasts, and other online medium to help bridge gaps to prompt informed decision-making
- Fourteen topics created and tagged is enough to begin creating educational modules to both complement clinical practice and integrate education into CKD care pathway.

Acknowledgements

The lead and co-authors would like to acknowledge the following colleagues, patients and professionals who kindly provided time, insights and additional understanding co-creating context of this research.

References

- Ahmad F, Hudak PL, Bercovitz K, Hollenberg E, Levinson W, et al. (2006) Are physicians ready for patients with Internet-based health information? *J.Med.Internet.Res*, 8: e22.
- Bernhardt JM, Felter EM (2004) Online pediatric information seeking among mothers of young children: results from a qualitative study using focus groups. *J.Med.Internet.Res*, 6 (1) e7.
- Strickland OL, Moloney MF, Dietrich AS, Myerburg S, Cotsonis GA, Johnson RV, et al. (2003) Measurement issues related to data collection on the World Wide Web. *ANS Adv. Nurs.Sci*, 26: 246-256.
- Ahern NR, (2005) Using the Internet to conduct research. *Nurse Res*, 13: 55-70.
- Bliven BD, Kaufman SE, Spertus JA (2001) Electronic collection of health-related quality of life data: validity, time benefits, and patient preference. *Qual.Life Res*, 10: 15-22.
- Sackett DL, Rosenberg WM, Gray JA, Haynes RB, Richardson WS, et al. (1996) Evidence based medicine: what it is and what it isn't. *BMJ*, 312: 71-72.
- Sackett DL (1997) Evidence-based medicine and treatment choices. *Lancet*, 349: 570-573.
- Barbour RS (2000) The role of qualitative research in broadening the 'evidence base' for clinical practice. *J.Eval. Clin.Pract*, 6: 155-163.
- Huston P, Rowan M (1998) Qualitative studies. Their role in medical research. *Can.Fam.Physician*, 44: 2453-2458.
- Chadban SJ, Briganti EM, Kerr PG, et al. (2003) Prevalence of kidney damage in Australian adults: The AusDiab kidney study. *J Am Soc Nephrol* 14: 131–138.
- Hallan SI, Coresh J, Astor BC et al. (2006) International comparison of the relationship of chronic kidney disease prevalence and ESRD risk. *J Am Soc Nephrol* 17: 2275–2284.
- Coresh J, Astor BC, Greene T, Eknoyan G, Levey AS, et al. (2003) "Prevalence of chronic kidney disease and decreased kidney function in the adult US population: Third National Health and Nutrition Examination Survey". *Am J Kidney Dis*. 41: 1–12.
- Lysaght MJ (2002) Maintenance dialysis population dynamics: current trends and long-term implications". *J Am Soc Nephrol* 13: 37–40.
- National Kidney Foundation (2002) K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *Am J Kidney Dis*;39(2 Suppl 1):S1-S266.
- Lamb EJ, Levey AS, Stevens PE (2013) The kidney disease improving global outcomes (KDIGO) guideline update for chronic kidney disease: Evolution not revolution', *Clinical Chemistry* 59: 462–465.
- Easom AM, Shukla AM, Rotaru D, Ounpraseuth S, Shah SV, Arthur JM Singh M, et al. (2019) Home run—results of a chronic kidney disease Telemedicine Patient Education Study. *Clinical Kidney Journal*, p-1–6.
- Botsis T, Hartvigsen G (2008) "Current status and future perspectives in telecare for elderly people suffering from chronic diseases". *Journal of Telemedicine & Telecare* 14: 195–203.
- Collister D, Pyne L, Cunningham J, Donald M, Molnar A, Beaulieu M, Levin A Brimble, KS, et al. (2019) "Multidisciplinary Chronic Kidney Disease Clinic Practices: A Scoping Review", *Canadian Journal of Kidney Health and Disease*, v-6.
- Pollard K, Donskoy A, Moule P, Donald C, Lima M, Rice C, et al. (2015) "Developing and evaluating guidelines for patient and public involvement (PPI) in research", *International Journal of Health Care Quality Assurance*, 28: 141-155.
- Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R, et al. (2014) A Systematic Review of the Impact of Patient and Public Involvement on Service Users, Researchers and Communities, *The Patient - Patient-Centered Outcomes Research*, 7: 387-395.
- Crocker JC, Ricci-Cabello I, Parker A, Hirst JA, Chant A, Petit-Zeman S, Evans D, Rees S, et al. (2018) Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis", *BMJ (Clinical research ed.)*, 363: 4738.
- Daykin N, Evans D, Petsoulas C Sayers A (2007) Evaluating the impact of patient and public involvement initiatives on UK health services: a systematic review", *Evidence & Policy: A Journal of Research, Debate and Practice*, 3: 47-65.
- Kovacs Burns K, Bellows M, Eigenseher C, Gallivan J (2014) Practical' resources to support patient and family engagement in healthcare decisions: a scoping review", *BMC health services research*, 14: 175-175.
- Public Engagement – A Practical Guide (2017) (available at <https://senseaboutscience.org/activities/public-engagement-guide/>) (accessed June 2020)
- Baggott R (2005) A funny thing happened on the way to the forum? Reforming patient and public involvement in the NHS in England. *Public Administration* 83: 533-551.
- Aitken M, Tully MP, Porteous C et al. (2019) Consensus Statement on Public Involvement and Engagement with Data Intensive Health Research. *IJPDS* 4: 1-6.
- Atreja A, Mehta N, Miller D, Moore S, Nichols K, Miller H, Harris CM, et al. (2005) One size does not fit all: using qualitative methods to inform the development of an Internet portal for multiple sclerosis patients. *AMIA.Annu.Symp. Proc* 16-20.
- Adair CE, Marcoux G, Williams A, Reimer M (2006) The Internet as a source of data to support the development of a quality-of-life measure for eating disorders. *Qual.Health Res*, 16: 538-546.
- Birnbaum MH (2004) Human research and data collection via the internet. *Annu.Rev.Psychol*, 55: 803-832.
- Burgess EO, Donnelly D, Dillard J, Davis R (2001) Surfing for sex: Studying involuntary celibacy using the Internet. *Sexuality & Culture: An Interdisciplinary Quarterly*, 5: 5-30.
- Cantrell MA, Lupinacci P (2007) Methodological issues in online data collection. *J.Adv.Nurs*, 60: 544-549.
- Carolan M (2007) Health literacy and the information needs and dilemmas of first-time mothers over 35 years. *J.Clin. Nurs*, 16: 1162-1172.
- Guise J, Widdicombe S, McKinlay A (2007) 'What is it like to have ME?': the discursive construction of ME in computer-mediated communication and face-to-face interaction. *Health (London)*, 11: 87-108.
- Halcomb EJ, Gholizadeh L, DiGiacomo M, Phillips J, Davidson PM, et al. (2007) Literature review: considerations in undertaking focus group research with culturally and linguistically diverse groups. *J.Clin.Nurs.*, 16: 1000-1011.
- Higginbottom GM (2000) Heart health-associated health beliefs and behaviours of adolescents of African and African Caribbean descent in two cities in the United Kingdom. *J.Adv. Nurs*, 32: 1234-124.
- Henderson PD, Fogel J (2003) Support networks used by African American breast cancer support group participants. *ABNF.J*, 14: 95-98.
- Kanzaki H, Makimoto K, Takemura T, Ashida N (2004) Development of web-based qualitative and quantitative data collection systems: study on daily symptoms and coping

- strategies among Japanese rheumatoid arthritis patients. *Nurs. Health Sci*, 6: 229-236.
38. Suarez-Balcazar Y, Balcazar FE, Taylor-Ritzler T (2009) Using the Internet to conduct research with culturally diverse populations: challenges and opportunities. *Cultur.Divers. Ethnic.Minor.Psychol*, 15: 96-104.
39. Vandebosch H, Van CK (2008) Defining cyberbullying: a qualitative research into the perceptions of youngsters. *Cyberpsychol.Behav*, 11: 499-503.
40. Atkinson NL, Billing AS, Desmond SM, Gold RS, Tournas-Hardt A (2007) Assessment of the nutrition and physical activity education needs of low-income, rural mothers: can technology play a role? *J.Community Health*, 32: 245-267.
41. Kenny A (2002) Online learning: enhancing nurse education? *J.Adv.Nurs*, 38: 127-135.
42. Kettles AM, Kiger AM, Philip K, Caldow J (2008) An evaluation of a Mental Health Act educational resource. *J.Psychiatr.Ment.Health Nurs*, 15: 662-669.
43. Reynolds DJ, Stiles WB (2007) Online data collection for psychotherapy process research. *Cyberpsychol.Behav*, 10: 92-99.
44. Henderson PD, Fogel J (2003) Support networks used by African American breast cancer support group participants. *ABNF.J*, 14: 95-98
45. Koch NS, Emrey JA (2001) The internet and opinion measurement: Surveying marginalized populations. *Social Science Quarterly*, 82: 131-138.
46. Morgan GA, Harmon RJ (2001) Data collection techniques. *J.Am.Acad.Child Adolesc.Psychiatry*, 40: 973-976.
47. Birnbaum MH (2004) Human research and data collection via the internet. *Annu.Rev.Psychol*, 55: 803-832
48. Fox FE, Morris M, Rumsey N (2007) Doing synchronous online focus groups with young people: methodological reflections. *Qual.Health Res*, 17: 539-547.
49. Moloney MF, Dietrich AS, Strickland O, Myerburg S (2003) Using Internet discussion boards as virtual focus groups. *ANS Adv.Nurs.Sci*, 26: 274-286.
50. Granello DH, Wheaton JE (2004) Online Data Collection: Strategies for Research. *Journal of Counseling and Development*, 82: 387-393.
51. Kelly MA, Oldham J (1997) The Internet and randomised controlled trials. *Int.J.Med.Inform.*, 47: 91-99.
52. Lakeman R (1997) Using the Internet for data collection in nursing research. *Comput.Nurs.*, 15: 269-275.
53. Haven J, Burns A, Britten P, Davis C (2006) Developing the consumer interface for the MyPyramid Food Guidance System. *J.Nutr.Educ.Behav*, 38: S124-S135.
54. Freeman K, O'Dell C, Meola C (2003) Childhood brain tumors: children's and siblings' concerns regarding the diagnosis and phase of illness. *J.Pediatr.Oncol.Nurs*, 20: 133-140.
55. Glenton C, Nilsen ES, Carlsen B (2006) Lay perceptions of evidence-based information--a qualitative evaluation of a website for back pain sufferers. *BMC.Health Serv.Res*, 6-34.
56. Eysenbach G, Till JE (2001) Ethical issues in qualitative research on internet communities. *BMJ*, 323: 1103-1105.
57. Eysenbach G, Kohler C (2002) How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. *BMJ*, 324: 573-577.
58. Eysenbach G, Wyatt J (2002) Using the Internet for surveys and health research. *J.Med.Internet.Res*, 4-E13.
59. Alvarez MC, Cuenca, AM, Noronha DP, Schor N (2007) Reproductive health: a contribution to the evaluation of a virtual library]. *Cad.Saude Publica* 23: 2317-2326.
60. Brownlow C, O'Dell L (2009) Representations of autism: implications for community healthcare practice. *Community Pract*, 82: 18-21.
61. Bergman DA, Brown NL, Wilson S (2008) Teen use of a patient portal: a qualitative study of parent and teen attitudes. *Perspect.Health Inf.Manag*, 5-13.
62. Im EO, Chee W (2003) Issues in Internet research. *Nurs. Outlook*, 51: 6-12.
63. Rolfe G (2006) Validity, trustworthiness and rigour: quality and the idea of qualitative research. *J.Adv.Nurs.*, 53: 304-310.
64. Estellat C, Tubach F, Costa Y, Hoffmann I, Mantz J, Ravaud P, et al. (2008) Data capture by digital pen in clinical trials: a qualitative and quantitative study. *Contemp.Clin.Trials*, 29: 314-323.
65. Gosling AS, Westbrook JI, Coiera EW (2003) Variation in the use of online clinical evidence: a qualitative analysis. *Int.J.Med.Inform*, 69: 1-16.
66. Graham RJ, Pemstein DM, Palfrey JS (2008) Included but isolated: early intervention programmes provision for children and families with chronic respiratory support needs. *Child Care Health Dev*, 34: 373-379.
67. Ilic D, Maloney S, Green S (2005) Guiding users to quality information about osteoarthritis on the Internet: a pilot study. *Telemed.J.E.Health*, 11: 703-706.
68. Long JD, Armstrong ML, Amos E, Shriver B, Roman-Shriver C, Feng D, Harrison L, Luker, S, Nash A, Blevins MW, et al. (2006) Pilot using World Wide Web to prevent diabetes in adolescents. *Clin.Nurs.Res*, 15: 67-79.
69. Armstrong N, Powell J (2009) Patient perspectives on health advice posted on Internet discussion boards: a qualitative study. *Health Expect*, 12: 313-320.
70. Berendsen AJ, de Jong GM, Meyboom-de JB, Dekker JH, Schuling J, et al. (2009) Transition of care: experiences and preferences of patients across the primary/secondary interface - a qualitative study. *BMC.Health Serv.Res*, 9-62.
71. Armstrong N, Hearnshaw H, Powell J, Dale J (2007) Stakeholder perspectives on the development of a virtual clinic for diabetes care: qualitative study. *J.Med.Internet. Res*, v-9.
72. Winkelman WJ, Leonard KJ, Rossos PG (2005) Patient-perceived usefulness of online electronic medical records: employing grounded theory in the development of information and communication technologies for use by patients living with chronic illness. *J.Am.Med.Inform.Assoc.*, 12: 306-314.
73. Bryce CL, Zickmund S, Hess R, McTigue KM, Olshansky E, Fitzgerald K, Fischer G, et al. (2008) Value versus user fees: perspectives of patients before and after using a web-based portal for management of diabetes. *Telemed.J.E.Health*, 14: 1035-1043.
74. Dosanjh S, Matta JM, Bhandari M (2009) The final straw: a qualitative study to explore patient decisions to undergo total hip arthroplasty. *Arch.Orthop.Trauma Surg.*, 129: 719-727.
75. Xie B (2009) Older adults' health information wants in the internet age: implications for patient-provider relationships. *J.Health Commun*, 14: 510-524.
76. Hanusaik N, O'Loughlin J, Ryan A, Edwards AC, West R, Harvey D, Cameron R (2003) The G8 Heart Health Projects Database: Testing the compatibility of an Internet-based resource with health promotion planning processes. *Health Promot.Pract.*, 4: 413-421.
77. Kerr C, Murray E, Stevenson F, Gore C, Nazareth I (2006) Internet interventions for long-term conditions: patient and caregiver quality criteria. *J.Med.Internet.Res*, 8: e13.
78. Nisha R, Srinivasa Kannan SR, Thanga Mariappan K, Jagatha P (2017) Biochemical evaluation of creatinine and urea in

- patients with renal failure undergoing hemodialysis. *J Clin Path Lab Med*: v-1.
79. Greenberg JH, Kakajiwala A, Parikh CR, Furth S (2018) Emerging Biomarkers of Chronic Kidney Disease in Children’. *Pediatr Nephrol*. 33: 925-933.
 80. Dhaun N, Bellamy CO, Cattran DC, Kluth DC (2014) Utility of renal biopsy in the clinical management of renal disease. *Kidney International* 85: 1039-1048.
 81. Birk PE (2012) Surveillance biopsies in children post - kidney transplant. *Pediatr Nephrol*. 27: 753-760
 82. Ko GJ, Obi Y, Tortoricci AR, Kalantar-Zadeh K (2018) Dietary Protein Intake and Chronic Kidney Disease. *Curr Opin Clin Nutr Metab Care*, 20: 77-85.
 83. Nguyen L, Levitt R, Mak RH (2016) Practical Nutrition Management of Children with Chronic Kidney Disease. *Clinical Medical Insights*.
 84. Ndemera H, Bhengu B (2017) Factors Contributing to Kidney Allograft Loss and Associated Consequences among Post Kidney Transplantation Patients”. *Health Sci J-11*:3.
 85. Masood A, Musarrat R, Mazahir S (2016) Dialysis Modality Preferences and Quality of Life of Adolescents with Renal Failure”. *International Journal of Medical Research and Health Sciences*: 5: 182-189.
 86. Goh ZS, Griva K (2018) Anxiety and depression in patients with end-stage renal disease: impact and management challenges - a narrative review”. *Int J Nephrol Renovasc Dis* 11: 93-102.
 87. Assadi F (2013) Psychological impact of chronic kidney disease among children and adolescents: Not rare and not benign’. *J Nephrothol* 2: 1-3.
 88. Witham MS et al. (2015) Does oral sodium bicarbonate therapy improve function and quality of life in older patients with chronic kidney disease and low-grade acidosis (the BiCARB trial)? Study protocol for a randomized controlled trial. *Trials*
 89. Huque SS, Rahman H (2014) Prescription of Drugs in Children with Impaired Renal Function’. *Bangladesh J Child*
 90. Rysz J, Franczyk B, Cialkowska-Rysz A, Gluba-Brzozka A (2017). The Effect of Diet on the Survival of Patients with Chronic Kidney Disease. *Nutrients*.
 91. Allen AS, Forman JP, Orav EJ, Bates D, Denker BM, Sequist TD, et al. (2011) Primary Care Management of Chronic Kidney Disease. *J Gen Intern Med*. 26: 386-392.
 92. White CT, Trnka P, Matsell DG (2007) Selected Primary Care Issues and Comorbidities in Children Who Are on Maintenance Dialysis: A Review for the Pediatric Nephrologist”. *CJASN* 2: 847-857.
 93. Subramanian L, Quinn M, Zhao J, Lachance L, Zee J, Tentori (2017) Coping with kidney disease - qualitative findings from the Empowering Patients on Choices for Renal Replacement Therapy (EPOCH-RRT) study. *BMC Nephrol* 18-119.
 94. Clave S et al. (2019) Quality of life in adolescents with chronic kidney disease who initiate haemodialysis treatment’. *BMC Nephrology* (online)
 95. Malaki M, Mortazavi FS, Moazemi S, Shoaran M (2012) Insomnia and limb pain in hemodialysis patients: What is the share of restless leg syndrome? *Saudi Journal of Kidney Disease and Transplantation* 23: 15-20.
 96. Neyhart CD, McCoy L, Rodegast B, Gilet CA, Roberts C, Downes K (2010) A New Nursing Model for the Care of Patients with Chronic Kidney Disease: The UNC Kidney Center Nephrology Nursing Initiative. *Nephrology Nursing Journal* 37: 121-131.
 97. Johansen KL (2007) Exercise in the End Stage Renal Disease Population. *JASN* 18: 1845-1854.
 98. Clapp EL, Bevington A, Smith AC (2011) Exercise for children with chronic kidney disease and stage renal disease’. *Pediatric Nephrology* 27: 165-172.
 99. Bailey PK, Hamilton AJ, Clissold RL, Inward CD, Caskey FJ, Ben-Shlomo Y, Owen-Smith A, et al. (2018) Young adults’ perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies. *BMJ Open*, 8- e019926.
 100. Kliger AS, Silberzweig J (2020) Mitigating Risk of COVID-19 in Dialysis Facilities”. *CJASN* 15: 707-709.
 101. Watanabe T (2013) Renal complications of seasonal and pandemic influenza A virus infections. *European Journal*
 102. Navaneethan S, Jolly SE, Sharp J et al. (2013) Electronic health records: a new tool to combat chronic kidney disease? *Clinical nephrology*.
 103. Wang L, McGregor T, Jones DP, et al. (2017) Electronic health record - based predictive models for acute kidney injury screening in pediatric inpatients”. *Pediatric RESEARCH* 82: 465-473.
 104. Murray DM, Fisher JD (2002) The Internet: A virtually untapped tool for research. *Journal of Technology in Human Services*, 19: 5-18.
 105. Pope C, Mays N (1995) Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*, 311: 42-45.
 106. Rhodes SD, Bowie DA, Hergenrath KC (2003) Collecting behavioural data using the world wide web: considerations for researchers. *J.Epidemiol.Community Health* 57: 68-73.
 107. Rozmovits L, Ziebland S (2004) What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient.Educ.Couns*, 53: 57-64.
 108. Skinner H, Biscope S, Poland B, Goldberg E (2003) How adolescents use technology for health information: implications for health professionals from focus group studies. *J.Med.Internet.Res*, 5-e32.
 109. Steele R, Mummery KW, Dwyer T (2007) Development and process evaluation of an internet-based physical activity behaviour change program. *Patient.Educ.Couns.*, 67: 127-136.
 110. Van dM, V van Stel HF, Detmar SB, Otten W, Sterk PJ, Sont JK (2007) Internet-based self-management offers an opportunity to achieve better asthma control in adolescents. *Chest*, 132: 112-119.
 111. Mannan R, Murphy J, Jones M (2006) Is primary care ready to embrace e-health? A qualitative study of staff in a London primary care trust. *Inform.Prim.Care*, 14: 121-131.
 112. Stevenson FA, Kerr C, Murray E, Nazareth I (2007) Information from the Internet and the doctor-patient relationship: the patient perspective--a qualitative study. *BMC.Fam.Pract*, 8-47.
 113. NIHR INVOLVE (2020) How to Involve People in Research (<https://www.invo.org.uk/find-out-more/how-to-involve-people/>) (accessed June 2020)
 114. Adler CL, Zarchin YR (2002) The “virtual focus group”: using the Internet to reach pregnant women on home bed rest. *J.Obstet.Gynecol.Neonatal Nurs*, 31: 418-427.
 115. McKenna AM, Keating LE, Vigneux A, Stevens S, Williams A, Geary DF (2006) Quality of life in children with chronic kidney disease - patient and caregiver assessments. *Nephrology Dialysis Transplantation* 21: 1899-1905.
 116. Cuervo G, Camoes M, Shaw E, et al. (2015) Methicillin-resistant *Staphylococcus aureus* (MRSA) catheter- related bacteraemia in haemodialysis patients

Copyright: ©2021 Muhammad SN, et al. This is an open-access article distributed under the terms of the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original author and source are credited.