Educational Support Surrounding Chronic Kidney Disease: Qualitative Enquiry

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ABSTRACT

Objective: An estimated 15 million patients in England have at least 1 long-term condition, with the prevalence of chronic kidney disease rising. Understanding educational support can help navigate between health sectors.
Methodology: This research used Qualitative Methodology, and an Inductive Content Analysis (ICA) approach which is particularly effective in linking theory, or framework. Two workshops took place in May and June (2019) wherein topic tagging activities were co-developed between the Renal Patient Support Group (RPSG) and the Kidney Disease and Renal Support Groups (KDARs) for Kids platforms. 19 participants between 4 cohorts, that included 6 General Practitioner (GPs), 4 Healthcare Scientists (HS), 3 Nephrologists/ Clinicians (N/Cs), and 6 CKD Patients (CKDPs) were recruited and participated in telephone interviews. Topic guides were developed for participant cohorts with several themes to collect data through one-to-one telephone interviews. NViVo-12 software provided opportunity to code and glean insight to develop overall conclusions
Results: Nine main themes and several sub-themes were identified when coding for health professionals, and 9 main themes and several sub-themes identified when coding qualitative data for chronic kidney disease patients.
Conclusion: There needs to be a coordinated effort between patients and professionals, to understand how chronic kidney disease education should be more integrated at point of care, and in line with public health.
Keywords: Education, qualitative research, nephrology, PPI

INTRODUCTION

Chronic kidney disease (CKD) is a slow decline in general health with malnourishment and wasting related to decreased appetite and progressive metabolic disturbance.[1] However, patients are living longer and more awareness through local solutions and community, and social media platforms have supported to inform and deliver health improvements for CKD patients,[2,3] and in those patients who are suspect/high risk for end-stage kidney disease (ESKD).[4,5] The inclusion of service users is growing but it has not been evaluated or contextualized around educational provision and use of Social Media platforms.[6,7]

Aims and Objectives

The aims and objectives of this work include the following to understand how healthcare and education for CKD patients encourage patients take ownership of healthcare. The objectives of this research are as follows: (1) to describe how CKD patients are managed in between healthcare sectors with a view to capture and analyze qualitative data from the perspectives of

patients and professionals and (2) to understand options for obtaining advice and educational support through an online platform.

Research Question

This UK study seeks to understand Educational Support surrounding CKD and explore Patient and allied health professional (AHP) Perspectives.

Chronic Kidney Disease and the Role of Education

There is evidence to suggest that more health promotion in the community can also support some of the educational complexities relating to health and disease.[7,8] A need is found to educate the educators in surrounding the long-term condition (LTC) model and through a population health approach.[9,6,10,11] It has been perceived educators integrate aspects of LTCs well yet found prevention and early detection is at the 'hard end'.[12,13]

There is now an increasing body of research focusing on linking education, health literacy, peer support, and education.[14-16] Therefore, it is now more transparent that integration of point of care is becoming more important to patients with LTCs where, especially healthcare has become more remote.[17,18] This, however, also presents an opportunity for AHPs, to be involved in supporting areas of healthcare, and education through 'online spaces', which is also where patients share understanding and lived experiences aligned to important clinical and pathology questions.[18-21]

METHODOLOGY

The Research Scientist Investigator (RSI) involved in this research played the role of facilitator, thus adjusting use of topic

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MAIN POINTS

- Educating healthcare professionals surrounding the importance of the patient role and how to be more interactive with patient care still requires integrative practice.
- Targeting the attitudes and behavior of providers through potential solutions is important so that the relationship between the patient and the provider is balanced and smarter.
- Patients/carers still want more face-to-face understanding of test results, and between the 2 social media platform initiatives (i.e., RPSG and KDARs), there has been implementation of pilot patient and AHP webinars to deliver educational support through media such as Facebook, YouTube, and Instagram.
- Smarter working will help in meeting challenges on educational needs to support CKD patients. This will also reduce fatigue, increase streamlining healthcare services, to reduce existing impacts.
- Ultimately, by joined up efforts between AHPs and CKD patients, the aim between the 2 social media platforms is to equip patients with education and knowledge to ensure they have a strong basis for shared decision-making throughout kidney care.

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guides to effectively involve participants involved. At times this required the RSI to also play a slightly more professional role, providing background of research to fulfill inclusion and exclusion criteria, so thus to help inform the sequence of activities. The justification for using a qualitative methodology design is that it tends to help answer multi-faceted questions.[22] Similar methodologies have also been used to help answer questions relating to healthcare education.[17,23]

Through co-development, the RSI also organized 2 high street community workshops in Bristol City, England UK (May 2019 and June 2019). Aligned to Patient and Public Involvement (PPI), which was an important mechanism; involving patients led to achieving rigor throughout this research. As part of this investigation, 13 team members, 7 admin members from the RPSG and 6 from the Kidney Disease and Renal Support Group (KDARs) for Kids attended the workshops. Basic evaluation and feedback provided an understanding of patients' perspectives surrounding access to healthcare education to focus aims and objectives surrounding this research. The workshops were co-developed between patients, researcher, and co-founders of the 2 social media platforms.

Following workshops, a topic tagging activity was implemented between the 2 platforms. In following workshops, a third Renal Workshop Event also took place in collaboration between the RPSG and KDARs, October 2019 wherein topics between the 2 global social media platforms were co-developed having understood aims and remit of the RPSG and KDARs. Tags were co-developed against 14[14] different topics having investigated over 1-month (March and April 2020) most popular healthcare terminologies. Topics were tagged for 2-weeks per social media platform (i.e., 2-weeks through RPSG, online adult population and 2-weeks through KDARs, online pediatric renal population). Topic Tagging example was implemented following research outlined by refs (24-26). Table 1 highlights an overview surrounding Topic Tagging Activity.

Ethics Approval

This research proposal has undergone both academic and NHS Ethics approval process highlighting all aspects of research. General Data Protection Regulation (GDPR 2018) guidelines were implemented to ensure best practice surrounding confidentiality, data protection and compliancy. Information sheets and consent forms were produced to inform participants the intentions and outcomes. This research was appraised according to academic ethics committee, and NHS ethics prior to starting any data collection and all other aspects of this investigation. Ethics application had been granted via the University of West of England (UWE) ethics committee and by Greater Manchester South Research Ethics Committee (Project ID: 19/NW/0282), before recruiting patients and healthcare professionals. UWE ethics approval was granted on 21st May 2019 and NHS Ethics approval by favourable opinion was granted on 18th June 2019. The ethics processes covered a broad focus

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Table 1. PPI Topic Tagging Activity between RPSG and KDARs Social Media Platforms

Topics Developed and Tagged

1. Lab Tests and Biomarkers

2. Biopsy and Surgery

3. Diet and Nutrition

4. Renal Replacement Therapy (RRT)/Kidney Replacement Therapy (KRT)

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 1: The RPSG/KDARs assigned several tags having conducted baseline investigation to understand what topics and subject entities are important to CKD patients (pediatrics and adults) globally.
Table 1 summarizes PPI Topic Tagging Activity between RPSG and KDARs Social Media Support Groups. Education is identified as an essential tool wherein patients become more autonomous surrounding health and disease. The topic tags would serve as proposed over-arching themes wherein patients have questions, and where there is opportunity for educational support through advice giving, guidance surrounding clinical and non-clinical case scenarios. Depending on structure of advice, this is where online consultations could be encouraged, involving AHPs. Application Programming Interface (API) would encourage building a database outside of Facebook, and ultimately involving patients and AHPs knowing who/when to contact. Given the significant consequences to patients' health and the economic impact on healthcare systems, interventional updates could also be a way to integrate education and involving patients and AHPs. Educational Modules should encourage patients and professionals to support best practice with equality. The following links provide an overview surrounding the 2 workshops: Workshop event (1) Review—Renal Awareness Event Hosted by The Renal Patient Support Group at 65 High Street | NailseaTown.com and Workshop event (2) Review—Kidney Disease Awareness Event Hosted by The Renal Patient Support Group at 65 High Street | NailseaTown.com

including robustness of research design, research integrity and transparency to ensure confidentiality and anonymity surrounding data protection, security, and informed consent. Information sheets and consent forms were produced to inform potential participants the intentions and outcomes of research. All compulsory documentation such as Information Sheets, Consent Forms, Introductory research flyers were approved by university and NHS ethics approval.

Qualitative Data Integrity, Reflectivity, and Trustworthiness

Ethics applications and documentation were finalized to enable qualitative data collection and integrity. Inductive Content Analysis (ICA) was implemented owing to nature of the research question. To achieve robust research, a Checklist for Researchers Attempting to Improve the Trustworthiness of a Content Analysis Study as outlined in research by Refs. 22, 27, and 28 was applied. Using the checklist and evidence relating examples of best practice was of utmost importance. Several texts were followed to ensure underpinnings of qualitative data and ICA integrity, including Refs. 28-32. These references helped provide a basis and checklist for academic rigor.

In this research, RSI encouraged involvement and discussion implementing different topic guides, thus providing lived experiences to participants who met inclusion and exclusion criteria. Telephone interviews were used to save time, encourage trustworthiness having built initial repertoire with RPSG and KDARs moderators through social media and workshops. This was important so thus to encourage inclusion, and diversity of patients. A pre-interview discussion with participants fulfilled ethical obligations, ensuring that participants were informed on nature of research, and were clear on expectations.

Scheduled telephone interviews were conducted to ensure high number of participants and positive interview experiences. Guidance was sought from supervisory team, and several texts to gain understanding of process flow[33,34] to ensure academic rigor.[35,36] Interviews conducted were balanced with an informal requirement to respond to questions asked by RSI. Participants were informed they would receive a research summary following completion.

Data Protection, General Data Protection Regulation 2018, Privacy, and Storage

All data retrieved from telephone interviews will be stored using NVivo software during and after analysis. NVivo software will be installed on a password-protected computer in an office on university campus grounds. All information participants provided was confidential and used for the purposes of this study only used for the purposes to investigate research question. The data were collected and stored in accordance with the General Data Protection Regulation (GDPR 2018), and any unnecessary data were disposed of in a secure manner. Data (especially paper copies) were only accessed by those on the research team. All participant data have been collected outside the university site and housed on a secure server with firewall protection within university.

Topic Guides, Telephone Interviews, Schedules, and Support

Participants were informed of telephone interview schedules once organized. This information was outlined in a research recruitment flyer. Participant Information Sheets were made available either at recruitment site or through the RPSG and outlined how telephone interviews would take place. The RSI provided contact details to all participants, so they have opportunities to ask questions. At times, it was important to remind participants regarding schedules and this was achieved sending

an email or by telephone correspondence. Introductory letter/flyer was available to read with information sheets, topic guides and consent forms with research team details on all documentation.

Topic guides were used to provide a basic content and structure of semi-structured qualitative interviews. Scheduled telephone interviews were conducted to ensure data generated was high quality and participants had positive interview experiences. Guidance was sought from several texts to gain understanding of process and flow[33,34] and to ensure academic rigour[35,37] during (and following) interviews[35,36] and again, guidance was implemented via academic supervisory team. Interviews seeked to address the research question and objectives gaining perspectives across 4 cohorts whilst recognizing that everyone had a different understanding and experience. Participants were briefed prior interview recording and involved retrieving consent, and participants were informed about the nature of research, and expectations.

The RSI informed participants that interviews were to be recorded, and highlighted formality of the interview process, according to Refs. 33, 34, and 38. Telephone interviews were conducted in a private setting. To help reduce interview bias, participants were informed that it would be important to provide views in relation to LTCs according to literature and healthcare. The topic guide/s instrument included a closing discussion which reflected on themes—points raised during interviews provided an opening for participants to reflect on the interview content. Participants were provided RSI and academic supervisory team contact information; telephone interviews were implemented and audio-recorded after taking consent. Supplementary Information in this works highlights the topic guides implemented by way of qualitative enquiry across 4 cohorts.

Sites and Participant Identification
The Local Clinical Research Networks helped identify General Practitioners (GPs) and/or Nurse Practitioners (NPs) in South-West England. The Royal College for Physicians (RCGP) also helped identify GPs; The institute of Biomedical Sciences (IBMS) helped identify Biomedical Scientists with a Clinical Chemistry background. The Association for Clinical Biochemistry (ACB) helped identify Clinical and Consultant Scientists. The North Bristol NHS Trust (NBT) helped identify Renal Clinicians, and Chief Administrators for the RPSG helped identify CKD patients (CKD stages 3-5) for a single telephone interview.

Participant Approach
Before recruiting participants, the RSI approached participants to identify if were deemed suitable to be involved in this investigation through face to face and/or telephone communication. Contact details for participants were made available for participants to approach the RSI, so that they can retrieve more information about the research before making a formal decision of getting involved. The RSI, as part of the process, seeked informed consent after providing overview of the study.

Participant Recruitment
Prior recruiting, the RSI established whether a potential participant is suitable to be involved in this study through telephone or email communication. Potential participants will have the opportunity to ask questions about this study. The RSI also informed participants that this work will be used for research purposes only. Research Introductory Flyer, Information Sheets, Topic Guides, and Consent forms were made available prior recruitment. Quota sampling was used and allowed the RSI to ensure there is equal or a proportionate representation of participants depending on age, race, gender, and education.[39] This process also prevented a selection bias. A dedicated advertising section of the RPSG website was organized by the RPSG team once ethics applications had been granted via the University Ethics Committee and NHS Ethics to recruit patients and health

Table 2. Participants Recruited and Cohorts

Health Professionals—General Practitioners		
Generic Code	**ID**	**Gender**
AF	AF	Female
AH	AH	Male
MR	MR	Male
NW	NW	Female
OG	OG	Male
SW	SW	Male
Health Professionals: Healthcare Scientists		
Generic Code	**ID**	**Gender**
CE	CE	Female
FM	FM	Female
MC	MC	Male
PS	PS	Male
Health Professionals—Nephrologist/Clinic		
Generic Code	**ID**	**Gender**
NC1	DT	Male
NC2	FC	Male
NC3	KA	Female
Chronic Kidney Disease Patients		
Generic Code	**ID**	**Gender**
AM	AM	Male
AO	AO	Female
HA	HA	Male
MC1	MC1	Male
MK	MK	Male
NG	NG	Male

professionals. The webpage allowed the RSI to display research flyers, participant information sheets, topic guides and consent forms. The RPSG website details were made available to participants to complete online (available at RPSG for Advertising | The Renal Patient Support Group (RPSG). Table 2 highlights Participants Recruited and Cohorts.

Analysis

Inductive Content Analysis
Inductive content analysis (ICA) as a research method is a systematic and objective means of describing and quantifying phenomena.[40-42] Inductive content analysis is also known as a method of analyzing documents. Inductive content analysis allows an investigator to test theoretical issues to enhance understanding of the data. It is assumed that when classified into the categories, words, and phrases, ICA data creates meaning.[27]

Inductive Content Analysis Basis of Analysis
Interview data is initially presented thematically, and thereafter analysis involved an added layer implementing ICA to contextualize qualitative data collected. Inductive content analysis also helped understand context of relating Health Professionals, and CKD Patients. Since this research was multifaceted, a theoretical and coding framework with ICA phases helped highlight understanding surrounding CKD according to public health, and educational needs for patients to contextualize.[27]

Inductive Content Analysis Process of Analysis
Inductive content analysis was implemented in this research because there has been little or no prior knowledge contribution to research that seeks to answer question. What has been highlighted in literature is that where knowledge surrounding education is fragmented—ICA approach is recommended.[27,43] The categories are derived from data in ICA. Researchers are prompted to understand in some level of detail sampling considerations before selecting the unit of analysis.[27,43]

Inductive Content Analysis Applications
Inductive content analysis has notably been applied across several areas in health research investigations.[43] In broad context, ICA can be applied to also help understand and explain patterns and sequences of qualitative data. It thus helps investigators and audience to appreciate 'conditions' across data set.[27,30] Researchers implement ICA use to obliquely or unambiguously as an analysis tool to generate theoretical suggestions.[30]

Inductive Content Analysis Measurement of Error
Inductive content analysis is a tool to help assess both intricate and fragmented questions of a very specific type.[30] Investigations that seek to implement ICA or sub-categories thereof is where potential uncertainty can arise if against research question, hypothesis or condition being explored.

Measurement of error will be applied, implementing guideline summarized by Ref. 29 thus through preparation, organization, and reporting phases, respectively.

Justification For Inductive Content Analysis Approach
Having become acquainted with transcript data, NVivo-12 software allowed generating initial codes for ICA. NVivo-12 software provided opportunity to classify, sort, and arrange transcript context and thus allowing time to analyze data, glean insight, and overall develop conclusions.[32] Using the Coding Density facility on NVivo-12 software was particularly helpful because this supported tracking of analysis for ICA and semi-structured topic guides were developed to help prompt data collection across participant cohorts.

RESULTS

General Practitioners

Understanding of Chronic Kidney Disease and Perception of Kidney Healthcare
There are many people also who would not understand, despite leaflets, what the hell CKD is and what is good for them. Wider Health Professionals who have expertise where patients can visit, or contact would be more proactive. Relating CKD2, GPs code it according to what has been conveyed by healthcare scientists in the laboratory but because it does not have physical impact on patient—it only gets described as a 'problem' in patient notes and not much else (NW).

There are a significant number of patients who do not want to understand what CKD is and what lifestyle changes are required. *There are many people also who would not understand, despite leaflets, what is good for them.* A GP here, suggests (as others) that it might benefit to CKD patients that they have access to health professionals with specialist knowledge to help understand different disease stages, and at what point treatment needs to be escalated.[44-46]

Education in Healthcare Surrounding Long-Term Conditions
It's how bothered patients are and how much information do patients want. Having pre-printed information. I mean there's certain things, for diabetics—information leaflets, from the Diabetes Society….. Would be helpful to have similar for CKD Patients (OG). NHS does not 'make collaboration' easy. Community Education from MDT—not just CKD but other LTCs as well (MR).

One GP perceives that the level of patient engagement is key in terms of how much information they want.[12,47,48] It could be suggested that the level of patient engagement relates to many complexes, broader factors connected with individual circumstance, demographic factors, health literacy, family, and history.[49,50] A second GP informs a need for patients to be provided with information and need for wider education.[49,50]

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Education through Technology and Digital Healthcare
General concerns surrounding education—certainly, many hundreds of websites for patients and professionals to choose from via Google—overwhelming (MR).

Patient care necessitates understanding health education seeking behavior and modes of delivery to improve knowledge surrounding health and disease.[3,5,7] Understanding here reveals that large amounts of health education is available to CKD patients online however, there is a requirement for patients to be guidance on how to navigate context appropriately for it to be implemented.[16,17]

Future Roles of Allied Health Professionals
CKD2 and that whole pathway currently still lacking most of the time. Could be a decent 'channel' for those who visit GP-land to see wider healthcare professionals. Healthcare scientists could be involved here (NW). Smarter Algorithms and sharing information. MDT approach—everyone has a responsibility to contribute best practice. GPs focus on AKI (not so much CKD), Renal Consultants coming out and teaching GPs about CKD has probably been the most significant development in last decade (AH).

One GP suggests a need for a shared approach in care of CKD patients where specialists to educate non-specialist health professionals (GPs) on CKD. In context, GP states: '*Smarter Algorithms and sharing information. MDT approach—everyone has responsibility to contribute best practice*'.[47]

Screening and Kidney Biomarkers
Perception is unsubstantiated in primary care—the difficulty that comes is, what in terms of monitoring them, does patient's blood need re-check? Are there other underlying causes? (OG). No routine monitoring, but there are alerts on GP systems to prompt screening GPs can also look at renal urine/protein to provide some sort of indication relating stage and severity. Not so much for CKD—more for AKI (SW).

Understanding reveals that there is little consistency with regards to the monitoring of CKD patients in primary care, and GP suggests the need for clearer guidance on monitoring CKD patients, especially in relating to severity.[12]

Safety and Governance
If GPs know that there is a patient who has got CKD or is at risk of developing CKD, or on medicine which increases the risk of developing kidney insufficiency, they will 'play safe'. It really is about patient safety (SW).

A GP relates understanding patient safety and medication management; there is a need to be aware of patients who may be at risk of developing CKD due to medication use. Diagnoses and coding are key.[49,50]

Healthcare Scientists (Allied Health Professionals)

Education through Technology and Digital Healthcare
Health literacy is not always the problem. However, we're seeing more younger patients and there is a desire for information and wanting to make sense of why things are being done and what they mean. Signpost to patient.co.uk or NHS choices (FM). Digital access to a range of health professionals could work quite well, especially if only to provide additional education (MC). Short Video Clips drilling down basic Point of Care Testing (POCT) and educational information for CKD patients and the public would be helpful (MR).

As well as highlighting a need for easily accessible information on managing CKD available online, 1 healthcare scientist interviewed felt that patients also needed digital access to a range of health professionals. Another HS felt that visual online education should be available for patients through POCT.[14]

Future Roles of Allied Health Professionals
If a CKD patient was in an A&E setting and they were known in GP-land in that regard, it would be useful if an A&E clinician could get laboratory context directly from a summary care record (SCR) then absolutely—it would be useful for patients and professionals to have a smarter understanding from AHPs relating lab investigations and parameters (MC). Healthcare requires smarter links between health and social care. This could expand roles of 'traditional healthcare scientist' (AF).

Understanding informs the need for HPs and hospital clinicians to work more closely together in interpreting laboratory tests surrounding CKD and bringing health and social care provision closer together in supporting CKD patients. Allied health professional suggest there is need for improved digital access to test results for health professionals providing care for CKD patients.[11]

Nephrologists/Clinicians

Understanding of Chronic Kidney Disease and Perception of Kidney Healthcare
So, I suppose one thing about knowing about the numbers and understanding them is that if we're over reliant on the numbers then we might be falsely reassured for instance. I do not know whether that's an enormous gap, I suppose I think part of the understanding of the blood results is that it's part of a bigger thing, which is taking control of your illness and understanding its treatment and being a partner in your own care. So, I think it's an important part of that, but don't know whether understanding adequately is a big gap to be honest (DT).

Nephrologist's perception informs there should be a link between patient's level of understanding and taking ownership of health and self-managing care.[16-18]

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Education Through Technology and Digital Healthcare
Could look on the internet in various ways and they can use patient support as they often do, they can do all sorts of online exploring—those people who use online forums. Here the patients have access to fellow kidney patients, so they can. I think that's got a role in finding things out (DT).

Understanding highlights the importance of peer support for CKD patients, in terms of providing education and patient support.[14,16,17]

Health Literacy and Professionalism
Now, I suppose some people might argue that that information is given in such a raw form as to be too complicated to understand for many patients or that you might say that many patients might not have the ability to understand that information (DT).

Understanding informs the importance of acknowledging patient health literacy levels, and a need to provide education that is accessible to all.[13]

Future Roles of Allied Health Professionals
I mean we get a lot of phone calls from GPs and sometimes we feel that they don't all necessarily need to come through us but we're usually available, you know, the registrars are usually available at the end of the phone and that's where they go and sometimes you think, yes, they could potentially have other access that would be able to answer—I think that would be good actually, that would be brilliant (KA).

Nephrologists understanding inform a requirement for CKD patients to have specialist input in helping them interpret and understand medical context. Research has also several areas where future roles for professionals should develop best practice.[48]

Chronic Kidney Disease Patients

Understanding of Chronic Kidney Disease and Perception of Kidney Healthcare
People do not know, mistaken for diabetes. Fluid overload is a problem; it is because of the heart again because the heart needs to work. I've seen it for myself, a lot of people don't understand why. Mentioning kidney failure is not a good idea because the patient might not be aware what they are looking for and some patients will feel there is a certain way they feel, and they will take it as the norm (AO).

Patient informs what CKD is and why fluid retention occurs. The patient talks about how health professionals should communicate with patients around CKD and how patients may not understand certain medical terms.[50] Context highlights the importance and presence of condition.[50]

Appropriate Educational Support
So, they haven't necessarily got the time to be so one on one with your care. So, it's a lot more just like, "Here's what you need to know so go and look it up yourself. Kind of thing. If there was a level off, they'd give us like booklets. They'd talk to my mum and dad and explain to them what they could do to help, all that jazz (AM).

Patient suggests a need for health professionals (the patient does not give details of which type of health professional) to provide CKD patients with more targeted education to manage health. Understanding also reveals a need for health professionals to provide patients with a range of educational support, across healthcare conditions and sectors.[16,17]

Perception of Healthcare Professionals
I don't think I should go to my GP for check-ups that's the reason I've got a consultant but in my case my GP is excellent, again it's another person I can just book an appointment with and say actually I'm a bit unsure about this or I'm struggling a little bit with mental wellbeing, or I've got a little concern about my transplant and she'll talk to me about it. It just so happens that I've had the same GP since 1995 so she's got the knowledge. It is my big fear about moving away from Somerset what am I going to do about my GP but there you go. Especially as I've got mental health issues as well. So, I think the GP plays an important role (MC1).

It is important to understand multi-morbidities (including mental health issues) and where GPs should work together with patients and AHPs. Literature informs patient perception and need for specialist knowledge to manage CKD differs across regions.[47]

Digital Technology
I think the patients should receive the information they want in whichever way they're comfortable to receive it. So, for some of the older patients they may not be as comfortable with modern technology they might prefer a phone call or a face-to-face appointment or a letter. For other people who are a bit more up to date with technology they might like to go on to have a look at their results on the website and say oh I can see that I'm not happy with this result I better make a phone call. So, I think the patients' comfort and reassurance must be paramount (MC1).

Patient highlights a need to receive health education in a range of ways where appropriate—via face to face and verbal communication, via digital platforms online, or by phone or leaflet. Patient also highlights the importance of being able to receive test results online via a website such as Patient View. It is Important that patients are 'reassured' about kidney care.[12]

Education Through Technology and Digital Health Care
I think Patient View has made a massive improvement and a bit of an odd one I think social media. Now I hold those two on equal

level (MC1). *Something that's more accessible to patients in terms of technology. Patient View, it is more supportive because it gives you an immediate window into your health, how your renal function is doing, how your blood pressure, how your various levels of your blood are. What could it improve? It is there but, again, it's going back to this thing of learning how to use it. So, you can go into a particular blood result, for example, go into your iron result of your blood and then you can then click on that link and it'll tell you these are the norms that you'd be between* (NG).

Patient View has improved self-management of CKD and social media has its place. Technology is integrated into everyday lives. Access to social media also offers patients access to peer support, However, it must not be presumed that all LTC patients can interact and engage with aspects of technology, online spaces, or healthcare.[18] Primary care networks also offer a solution wherein multiple HPs could be involved to support health educational needs.[47] E-Learning/modules can offer a solution for educational support, and this could lead to with higher levels of literacy and educational attainment.[16,17,50]

Healthcare Communication

I'd just ask the nurse in dialysis but to be quite honest, I think the nurse would be reluctant. That's my experience, when you get results, they seem a bit, oh, they don't want to be running around. The problem is, when I was in the other unit, I had a good nurse because what she would do is, oh, your results are good, and that's it, she'll just tell me your results are good (AO). *If you have reassurances from health professionals and you always have access to them or you're in doubt, that education would prepare somebody, because you're better prepared because you have more information* (HA).

Understanding here reveals the importance of a patient being educated prior and following contact with health professionals. Access to health education can prepare a patient, encouraging shared decision making.[47,48]

Influences on Willingness to Take Ownership of Health

I think Patient View has made a massive improvement and a bit of an odd one I think social media. Now I hold those two on equal level. I could not pick a favourite, so I'll tell you why. In terms of Patient View, I can access my blood test and I do every time I have a check-up. A couple of days after my check-up I go through my blood test and make sure I'm happy with everything (MC1).

It is key to have links between patient accessing test results digitally following medical appointments. Patient View, for example is secondary care specific. Patient did not indicate whether access to health record should be between primary or secondary care or healthcare sector specific. By encouraging education

across health disciplines, this would reduce inequity, increase influence on taking ownership, and improve overall healthcare in CKD population.[12]

DISCUSSION

Whilst there was some overlap relating themes and ICA, this research has highlighted online spaces can be used inventively to help highlight how PPI can also play a role on developing educational support via healthcare systems.[24-26] All CKDPs were in between CKD4 and CKD5; telephone interviews were short, but allowed participants to put forward views and understanding, relating to educational needs, and patient care. Using an ICA approach has helped gain a rounded understanding of the research question, and healthcare requirements, specific to CKD suffers.

Access to AHPs through online spaces could also provide patients with educational support improving quality, experience, and evidence-based practices. Mentoring, training, and patients sharing experiences should be about inclusivity and empowerment.[47] Patients and families will also require educational support surrounding guidance on self-care. Access to AHPs through online space could also provide patients with educational support improving quality, experience, and evidence-based practices.[47]

By 2030 (if not before) AHPs can perhaps expect to be better integrated into pathways, working through online spaces and group consultations.[18] Having access to a network of AHPs prompts CKD patients to be more included in aspects of healthcare, thus increasing practical understanding of disease, treatments and overcoming educational barriers, and addressing possible healthcare inequalities. Peer to peer interactions can be used to educate and empower patients, but alone it is inadequate and imperfect. Whilst there is some novel educational projects and proposals taking place, joined up thinking would prompt a smarter working relationship across professions to drive an all-encompassing approach to CKD and wider LTC care pathways to convey better outcomes for patients' future.[18,20] There is scope for service development and initiatives relating patient care through online education and peer support, but there needs to be a coordinated effort between service users and providers, to understand how and where inclusion can be improved, including online and social media platforms for healthcare education provision.[6,18]

CONCLUSION

After documenting, interviews were critical in generating themes in preparation of ICA implementation. 19 telephone interviews between 4 cohorts were conducted with a requirement to respond This research informs that there is scope for educational service development and initiatives focusing on AHP involvement,[47] but there needs to be a coordinated effort between service users and providers.[6]

Point of Care Education could be integrated through online space (e.g., via the RPSG) and linked to EPRs. Educational support is thus required wherein there is access to AHPs prompting advice, guidance, and support through online spaces, aligned to traditional physical consultations.[20] This research informs that co-developed education modules could be delivered between patients and AHPs.[47] Education modules could be linked through social media platforms, integrating a proposed Education Pathway for CKD patients so that public health, and research meet practice excellence.

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INTERVIEW TOPIC GUIDE—PATIENT

About you?
1. How long have you been a patient?
2. What motivated you to join in this interview discussion?

Understanding CKD
1. Can you tell me a little about what it means to be diagnosed with CKD?
2. What steps were taken to provide you with a CKD diagnosis?

Appropriate Technology Support
1. How do you think patients with CKD should receive more information about their disease? Can you provide some examples?
2. Would you agree with the following: *Evidence indicates that accessing CKD laboratory and test results via online streams (e.g. Patient View) is supportive.* How do you think access to CKD laboratory tests and investigations information could be better supported?
3. What is your view on having more educational support surrounding CKD and laboratory test investigations through technology?

Educational Support on Laboratory Parameters
1. What other health professionals do you think CKD education could be provided by in primary care?
2. What do you think are some of the key problems on laboratory parameters, where more advice, education is needed? (i.e. creatinine, potassium, blood sugar, urea, sodium, KT/V)—All?
3. Tell me some more about the challenges you may encounter where understanding laboratory tests and results are concerned? What other ways do you think advice/ education around these could be improved?
4. What would be your view on advice/education around CKD laboratory investigations if this was made available for patients in CKD?
5. In your view, how would you feel if more advice/education from other healthcare professionals was made available to patients in primary care? (Scientists, Nurses, etc.)

Ongoing Care
1. What are the information needs of patients with CKD and which health professional?
2. Who should have responsibility for providing education of CKD laboratory test investigations in primary care?
3. Are there any national policies that patients' can get an understanding of their CKD laboratory investigations and test results?
4. What's been the biggest improvement surrounding CKD, from a patient perspective in past decade?

INTERVIEW TOPIC GUIDE: SCIENTISTS/ ALLIED HEALTH PROFESSIONALS

About you?
1. What type of healthcare scientist are you?
2. What motivated you to join in this interview discussion?

Understanding CKD
1. Can you tell me what some of the challenges might be for patients surrounding CKD?
2. What fundamental steps do you take to provide CKD care?

Appropriate Technology Support
1. How do you think patients with CKD should receive more information about their disease? Can you provide some examples?
2. Evidence indicates that accessing CKD laboratory and test results via online streams (e.g. Patient View) is supportive. How do you think CKD laboratory tests and investigations could be better supported?
3. What is your view on having more educational support surrounding CKD and laboratory test investigations through technology?

Educational Support on Laboratory Parameters
1. What other health professionals do you think CKD education could be provided by in primary care?
2. What do you think are some of the key problems on laboratory parameters, where more advice, education is needed? (i.e. creatinine, potassium, blood sugar, urea, sodium, KT/V—All?
3. Tell me some more about the challenges you may encounter when providing understanding of laboratory tests and results to health colleagues? What other ways do you think advice/ education around this could be improved?
4. What would be your view on advice/education around CKD laboratory investigations if this was made available for patients in CKD?

Ongoing Care
1. What are the information needs of patients with CKD and which health professional?
2. Are there any other health professionals that could be involved in prompting education for patients?
3. Who should have responsibility for providing education of CKD laboratory test investigations in primary care?
4. Are there any national policies that patients' can get an understanding of their CKD laboratory investigations and test results?
5. What's been the biggest improvement surrounding CKD, from a scientist/Allied Health Professional perspective in past decade?

INTERVIEW TOPIC GUIDE: NEPHROLOGISTS/ CLINICIANS

About you?
1. How long have you been a clinician?
2. What motivated you to join in this interview discussion?

Understanding CKD
1. Can you tell me what some of the challenges might be for patients surrounding CKD?
2. What fundamental steps do you take to provide CKD care?

Appropriate Technology Support
1. How do you think patients with CKD should receive more information about their disease? Can you provide some examples?
2. Evidence indicates that accessing CKD laboratory and test results via online streams (e.g. Patient View) is supportive. How do you think access to CKD laboratory tests and investigations information could be better supported?
3. What is your view on having more educational support surrounding CKD and laboratory test investigations through technology?

Educational Support on Laboratory Parameters
1. What are the information needs of patients with CKD and which health professional?
2. What do you think are some of the key problems on laboratory parameters, where more advice, education is needed? (i.e. creatinine, potassium, blood sugar, urea, sodium, KT/V)—All?
3. Tell me some more about the challenges you may face when providing understanding of laboratory tests and results? What other ways do you think advice/ education around these could be improved?
4. What would be your view on advice/ education around CKD laboratory investigations if this was made available for patients in CKD?

Ongoing Care
1. What other health professionals do you think CKD education could be provided by in primary care?
2. Are there any other health professionals that could be involved in prompting education for patients?
3. Who should have responsibility for providing education of CKD laboratory test investigations in primary care?
4. Are there any national policies that patients' can get an understanding of their CKD laboratory investigations and test results?
5. What's been the biggest improvement surrounding CKD, from a clinician perspective in past decade?

INTERVIEW TOPIC GUIDE: GENERAL PRACTITIONERS (GPS)

About you?
1. How long have you been a GP?
2. What motivated you to join in this interview discussion?

Understanding CKD
1. Can you tell me your challenges to diagnose CKD in primary care?
2. What steps do you take to diagnose CKD in primary care?

Appropriate Technology Support
1. How do you think patients with CKD should receive more information about their disease? Can you provide some examples?
2. Evidence indicates that accessing CKD laboratory and test results via online streams (e.g. Patient View) is supportive. How do you think CKD laboratory tests and investigations could be better supported?
3. What is your view on having more educational support surrounding CKD and laboratory test investigations through technology?

Educational Support on Laboratory Parameters
1. What are the information needs of patients with CKD and which health professional?
2. What do you think are some of the key problems on laboratory parameters, where more advice, education is needed? (i.e. creatinine, potassium, blood sugar, urea, sodium)—All?
3. Tell me some more about the challenges you may face when providing understanding laboratory tests and results? What other ways do you think advice/education around these could be improved?
4. What would be your view on advice/education around CKD laboratory investigations if this was made available for patients in CKD?

Ongoing Care
1. What other health professionals do you think CKD education could be provided by in primary care?
2. Are there any other health professionals that could be involved in prompting education for patients?
3. Who should have responsibility for providing education of CKD laboratory test investigations in primary care?
4. Are there any national policies that patients' can get an understanding of their CKD laboratory investigations and test results?
5. What's been the biggest improvement surrounding CKD, from a GP perspective in past decade?