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Is There a Need for Healthcare Scientists and Educational Support Surrounding Chronic Kidney Disease (CKD) Laboratory Investigations and Tests? Summarizing Polls via a Patient Support Group Platform

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Abstract

Objective: Patient access to information support to supplement their understanding of laboratory and test parameters remains challenging because of medical and scientific terminology. These challenges have led to the exploration of new and efficient ways of approaching educational and information support for patients with long-term conditions (LTCs) such as chronic kidney disease (CKD). This study aims to explore the perspectives on educational support surrounding CKD laboratory investigations from a sample of the Renal Patient Support Group (RPSG).
Materials and Methods: The research team conducted five polls from January 2018 to July 2018 via the RPSGs "closed" social media platform to help understand the importance of healthcare scientist's educational support for laboratory tests and investigations. The target of this study was to seek 1,000 responses from 8,000 members of this social media platform.
Results: A total of 574 RPSG members participated in polls, representing a 7% response rate. Seventy-seven percent (mean: 23; SD: 5.48) of the respondents agreed that access to a healthcare scientist in primary care would be advantageous. When asked about what technology solutions are available via general practitioner (GP)/transplant unit, a portal allowing access to medical records and laboratory results scored highest with 26% (mean: 25.3; SD: 5.02) respondents selecting this choice. Assessing a remote healthcare scientist via a computer or application was selected by 33% (mean: 17.8; SD: 4.21) of the respondents. CKD patients get confused regarding laboratory investigations accessed by a mix of healthcare professionals. Healthcare scientists should educate patients about laboratory investigations.
Conclusions: The polls conducted added value to an important topic of healthcare scientist involvement in educating CKD patients about laboratory investigations. Currently, there is more scope for healthcare scientists to provide support to CKD patients with smarter education regarding laboratory investigations and parameters.
Keywords: Educational activities, statistics and numerical data, chronic kidney disease, data collection methods, biochemistry, nephrology

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INTRODUCTION

Patient access to information support to supplement understanding of laboratory and test parameters faces challenges because of medical and scientific terminology. Such terminology is "everyday language" for health professionals communicating with each other, but when professionals communicate with patients/carers, the medical jargon can become overwhelming. Such constraints give rise to gaps in appropriate advice, information, and education in several aspects of health and disease (1-4). These challenges have led to exploration of new and efficient ways of approaching educational and information support for patients with long-term conditions (LTCs) (5).

In addition, there has been a rise in support groups online via social media (e.g., Facebook and Blogs) where patients and carers are sharing experiences and understanding to help increase shared decision-making (6). It is against this background that there have been calls for the use of technology in healthcare to improve access to services, to enable better integration and to delivery of care swiftly (7, 8).

In the United Kingdom, healthcare service providers are being encouraged to use technology in several ways including moving away from paper to digital records and offering services via apps and web portals. The new digital offerings range from administrative tasks of patient registration (9), laboratory investigations and tests (10), booking appointments and repeat ordering of prescriptions (5) to provision of clinical services such as video consultations (11,12) and medication reviews (13-15). Similarly, patients are being exposed to and are engaging with a range of technologies including web portals, social media (e.g., the Renal Patient Support Group) (6), and apps to assess and manage their health risks (10, 16-18). This has perhaps become especially important and true for patients with LTCs such as chronic kidney disease (CKD).

What Is CKD?

CKD is an irreversible LTC in which a reduced renal function is evident and/or damaged kidneys are unable to/cannot filter blood as per normal physiology (19, 20-23). CKD is a major public health concern because there is a considerable overlap between CKD, diabetes, and cardiovascular disease; the risk of developing CKD increases with age and it costs UK £1.02 billion to prevent acute kidney injury (AKI) (24). There is a higher risk of dying from AKI than myocardial infarction, breast cancer, heart failure, and diabetes. Due to increasing prevalence and costs, there is a higher risk to develop CKD/end-stage renal disease (ESRD) as a result.

There are several risk factors that interact with the disease, and patients can also be affected by the socioeconomic status in addition to age, gender, ethnicity, proteinuria, hypertension, serum phosphate, parathyroid hormone levels, and bone metabolism (25). CKD/ESRD is continuation of receiving hemodialysis (or alternative renal replacement treatments) until receiving a kidney transplant (24, 26-32). Creatinine remains the gold-standard biomarker for renal function. The estimated glomerular filtration rate (eGFR) is a calculation that allows a general evaluation of creatinine in blood filtered over 24-hours (19-22, 33, 34). Table 1 summarizes the five stages of CKD.

The Healthcare Laboratory and New Models of Service

The increase in demand for healthcare has also led to year-on-year increase in the number of laboratory investigations and tests carried out by healthcare scientists. In addition to fulfilling NHS laboratory tests for CKD patients and other LTCs, healthcare scientists are also fulfilling requests that are not always necessary/warranted in primary care (i.e., potential over-requesting) (35, 36). Only healthcare scientists who perform laboratory investigations can provide specific education and guidance regarding laboratory trends and parameters, when to screen patients for specific disease states, and prompt reference for treatment and/ or referral, and thus shift the cost of healthcare from the NHS (10, 16-18). Technology has enabled a range of point-of-care testing (POCT) or near-patient testing (NPT) and diagnostic kits to be more accessible to patients, thereby improving screening and compliance, but for CKD patients, understanding disease pathways and test result relevance is still a challenge (37-42).

The understanding provided by an array of healthcare professionals relating to laboratory tests and investigations adds to this complexity; patients see several members of the multidisciplinary team (MDT) at varying times and can receive misinterpreted results (43-45). Although information technology and the exchange of laboratory results via electronic patient records (EPRs) have enabled health professionals to share models of care delivery, there are still missed opportunities in primary care to support best practice for the CKD population.

Main Points

- Patients with LTCs seek more background and understanding relating to health and well-being to take ownership of disease.
- Telehealth links for video consultations, imaging, and laboratory data could also enable Healthcare Scientists to be involved in discussions with patients and carers remotely (i.e., digital scientist).
- Patients/carers still want more face-to-face understanding of test results.
- Smarter working will help in meeting challenges on educational needs in primary care to support CKD patients. This will also reduce fatigue, increase streamlining and workflow of services, and reduce existing healthcare strains.
- There is now potentially more scope where Healthcare Scientists could support CKD patients with smarter education surrounding laboratory investigations and parameters.

Table 1. Stages of chronic kidney disease (CKD)*

CKD severity	CKD classification
Stage 1	Kidney damage with normal or raised GFR (greater than 90 mL/ min/1.73 m^2)
Stage 2	Kidney damage with normal or raised GFR (60-89 mL/ min/1.73 m^2)
Stage 3	Moderately impaired GFR (30-59 mL/ min/1.73 m^2)
Stage 4	Severely impaired GFR (15-29 mL/ min/1.73 m^2)
Stage 5	End-stage renal failure or GFR (less than 15 mL/ min/1.73 m^2)

CKD: chronic kidney disease; GFR: glomerular filtration rate
*Reproduced from (Chronic Kidney Disease 2012). CKD is classified in five stages, according to the level of kidney damage and the ability of the kidneys to filter blood. The glomerular filtration rate (GFR) measures the amount of blood that passes through the tiny filters in the kidneys, called glomeruli, each minute. As the disease progresses, the GFR falls. Stage 3 is divided into two parts –stages 3A and 3B (but classification for these two sub-divisions are not outlined here).

The key drivers for change to pathology and laboratory medicine services include following: (1) greater need for patient-focused services, (2) the need to embrace competitiveness and plurality of provision, (3) a requirement to reprofile the workforce to make it better suited to new technology and modern ways of working, (4) the need for the definition of core data to create a framework to measure efficiency and effectiveness, (5) recognition of the status of a core clinical service in relation to impact on the patient's journey leading to a requirement for laboratory services to be commissioned and delivered as part of an integrated healthcare system, and (6) the need for strong leadership (46-48).

Healthcare Scientists in the United Kingdom

Over the past decade, the healthcare science profession has been advocating an expansion in the role of the scientist from purely a laboratory diagnostic role to a more advice/educational focus providing understanding of tests and results (and their impact). CKD Patients often seek education and/ or understanding of laboratory tests and investigations to support recommendations regarding their disease pathway. Healthcare scientists have ability and capacity to extend their knowledge base surrounding diagnostics to provide baseline education of laboratory investigations for patients with LTCs (49-51).

Although it is to be appreciated that healthcare scientists do not train to have "clinical involvement" in patient care, they do have an "unused knowledge base." A real hunger in the NHS is to integrate diagnostics with the rest of medicine and to make crucial imaging available in a timely manner to the people tasked with saving lives. Information can no longer be confined in pathology or any of the "ologies" (13, 52, 50-57).

Given that most NHS laboratories have now become more automated, routine tasks are now undertaken by support staff and delegated to other workers (58). The knowledge and skill base healthcare scientists acquire through training become specialized or advanced in healthcare delivery that extends beyond the core, preregistration training for a given area of practice (58). Skillset required by the health workforce change, depending on the needs and demands –this includes diversification (50, 51, 59). Diversification can take several forms, including (1) the identification of new markets or new settings for the delivery of certain services, (2) new ways of providing existing services, (3) the introduction of new types of technology such as medication or new therapies, (4) the adoption of new language to describe existing treatment, and (5) new philosophies of care (58).

Literature Review

Healthcare scientists are involved in 80% of all clinical decisions in the prevention, diagnosis, and treatment of a wide range of LTCs by NHS (37-40, 60). There is a traditional sense that scientists have "always" been involved in the support of healthcare teams, providing test results in the pathology laboratory, and as part of secondary care (60). Understanding economics, and smarter working will allow better care of patients in the primary care (60). Currently, however, the evidence base for scientists involved in primary care is insubstantial. Healthcare sciences as a "hidden" service remains largely unchanged and cross-profession collaborative working is still questionable (60).

Although websites and apps, such as LabTests Online (established in 2014), provide patients with information on the purpose of the text and reason for their prescription by a healthcare provider, the time is now right for scientists to identify novel ways of working and collaborating in wider healthcare (61). The novel technology and/or POCT/NPT kits could prompt healthcare scientists to become more active in primary care environments to monitor suspected/high-risk patients for specific LTCs such as CKD. Scientists not only authorize, validate, and interpret results but also know how/why laboratory tests are important in wider healthcare (37). Scientists could provide baseline explanations on the objective of tests and the specific impact of results (37).

Healthcare Scientists have a unique role to play (37). Scientists need to be able to share scientific knowledge in terms that the layman can understand to help bridge gaps in public understanding relating to clinical scenarios, especially to capture Patient Reported Outcome Measures (PROMs) (37). There is wider evidence to suggest that more health promotion in the community can support the understanding of some of the complexities relating to laboratory investigations, health, and disease (10, 52, 17, 18).

In a mixed-method, triangulated research approach, three universities, two health departments, and two indigenous organizations collaborated to identify workforce capacity in remote communities through innovative education (62). A need was observed to educate the educators in the chronic care model and in using a population health approach (62). There should be more practical ways to alter the acute disease-based practice model that dominates in the health workforce toward an integrated, systematic, population-based approach. Study highlights that scientists have a wider role in the wider healthcare workforce (62).

In qualitative research, to learn what educators across the health professions involved in primary healthcare think about interprofessional collaboration, one of the challenges is ensuring clear definitions of providers' roles and expectations regarding shared care (63). Defining roles and responsibilities will enhance the positive elements of collaborative interprofessional care and reduce misunderstandings regarding protocols, procedures, responsibilities, and authority (63).

Collaborative patient-centered practice is designed to "promote" the active participation of each discipline in patient care (63). Collaborative working enhances mechanisms for continuous communication, optimizes staff participation in decision making within and across disciplines, and fosters respect for disciplinary contributions from all professionals (63). Unfortunately, in this study there is no participation from scientists.

A meta-analysis of 72 independent studies (incorporating 4,795 teams) across a range of industries highlighted that information sharing positively predicted the performance of the team (64). Areas where information sharing has been shown to be inadequate are the interface between contexts, such as interdepartmental transfers (64). However, to improve CKD care plans –the healthcare scientist's role could be expanded from a purely laboratory diagnostic validation role to educational thus enhancing smarter and collaborative working (64, 65).

The GP Forward Review (61) highlights how primary care could look in the future. Patients want the education, skills, and confidence to take more responsibility for their health and feel more in control of their outcomes. Channeling this growing patient appetite for services that help patients to help themselves unlocks both a better patient experience and a way to alleviate practice workload. This avenue could open doors to involving scientists more so on the front line, supporting care for patients with LTCs (61). The need for a healthcare scientist in primary care to support practice on the front line, providing education relating to disease trends, could become important owing to patients with LTCs being prompted to self-care (26). This will lift "technical" burden off GPs (43).

Aims

To explore the perspectives relating educational support surrounding CKD laboratory investigations and tests and scientist's role from a sample of the RPSG members. The research team conducted five polls from January 2018 to July 2018 to help understand healthcare communication, technology needs, and importance of healthcare scientist educational support for laboratory tests and investigations.

Objectives

The objectives of this exploratory study were to help answer the following:

1. Would you see a physician other than your own? (Poll 1)
2. How can health professionals better understand (appreciate) being in a chronic illness? (Poll 2)
3. What technology solutions are available via your GP/Transplant Department? (Poll 3)
4. If you had access to Healthcare Scientist in Primary Care/Community who could tell you all about your renal tests and investigations, would you access this service? (Poll 4)
5. How likely are you to use the following future technologies for educational support from a scientist? (Poll 5)

MATERIALS AND METHODS

Justification for Polls and Sample

Previous studies have used surveys/polls of CKD patients and general public; these are the studies that inspired poll implementation via the RPSG (66-69). It was decided between the research team to administer five short polls from January 2018 to July 2018 via the RPSGs "closed" Facebook/social media platform. Ethics committee approval was not required for this work; however, guidelines of the British Healthcare Business Intelligence Association (69) were followed.

This work aimed to obtain an initial perspective from a social media platform. The time frame for the collection of responses to the polls was limited to 6 months and therefore, a sample size calculation was not carried out; instead, a target of 1,000 responses was set. It was important to get representation from various ethnicities using the RPSG, and the polls were "pinned as announcements" over the planned duration. Table 2 summarizes polls, questions, and responses.

Polls Development and Implementation

An initial version of the polls was piloted, and amendments were made to question phrasing. The updated version of the polls (Table 2) was used to gain responses from RPSG members. Potential respondents were informed of the reason for the poll, the anonymity of the responses, and their ability to withdraw from the polls at any time. Table 2 also provides a background summary of respondents. Supplement 1 summarizes information about the RPSG, and Supplement 2 summarizes context relating to the polls.

Respondents were asked: (1) Would you see a physician other than your own? (2) How can health professionals better understand (appreciate) being in a chronic illness? (3) If you had access to a Healthcare Scientist in Primary Care/Community who could tell you all about your renal tests and investigations, would you access this service? (4) Technology Support and Usage –What Technology Solutions are available via GP and/or Transplant Dept. and (5) How likely are you to use the following future technologies for educational support from a scientist?

RPSG General Data Protection Regulation (2018)

Primarily the RPSG is a closed Facebook support group and this website is an educational/information portal for patients and carers in CKD. The RPSG is 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 from 25th May (2018) and applies to organizations based in the EU, as well as to companies around the world that provide or offer goods or services, and 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.

RESULTS

The team sought to obtain 1,000 responses from 8,000 members using the support group platform. A total of 574 RPSG members

Table 2. The Renal Patient Support Group (RPSG) polls*

Would you see a physician other than your own? (Poll 1)	**Number of Responses**	**%**
1. Yes	33	61
2. No	13	24
3. Will only see my physician	6	11
4. No preference	2	4
Poll 1 Total responses	54	100
How can health professionals understand (appreciate) being in a chronic illness? (Poll 2)	**Number of Responses**	**%**
1. Communicate more with patients	47	33
2. Learn through networks	30	21
3. More opportunities to ask questions	13	9
4. Encourage them to learn via patient-based events	11	8
5. Invite to kidney patient association (KPA) meetings	7	5
6. Give them time to understand	4	3
7. Listen to patients more	17	12
8. More empathy	9	6
9. Offer patient perspectives at lectures	5	3
Poll 2 Total responses	143	100
If you had access to a healthcare scientist in primary care/community who could tell you all about your renal tests and investigations, would you access this service? (Poll 3)	**Number of Responses**	**%**
1. Yes	53	77
2. No	12	17
3. May be	4	6
Poll 3 Total responses	69	100
Technology support and usage What technology solutions are available via you GP and/or transplant dept. (Poll 4)	**Number of Responses**	**%**
1. Portal allowing access to medical records and laboratory results	41	26
2. Online appointment booking/appointment reminders	34	22
3. Digital Patient Comms. (e.g., email, text messaging)	27	17
4. Repeat prescriptions	24	15
5. Remote patient consultations	11	7
6. Online educational material (e.g., videos, downloadable)	8	6
7. Person-centered education (e.g., labs, medication, diet, physical activity)	5	3
8. Patient-reported outcomes (e.g., paper or digital)	3	2
9. Smart pill boxes - digital medication reminders	2	1
10. Remote laboratory advice - education via a health care scientist	2	1
Poll 4 Total Responses	157	100

Table 2. The Renal Patient Support Group (RPSG) polls* (Continue)

How likely are you to use the following future technologies for educational support from a healthcare scientist? (Poll 5)	**Very Likely**	**Likely**	**Neither Likely nor Unlikely**	**Very Unlikely**	**Not Applicable**
1. To communicate with a health care scientist via a patient app on your mobile phone			15, 9.9%		
2. To receive text messages or communication regarding laboratory tests/investigations via a patient app on your phone (e.g., to support your educational needs).		40, 26%			
3. To access a remote healthcare scientist via a digital facility			10, 6.5%		
4. To access a remote health care scientist for education via a patient app on your mobile phone		38, 25%			
5. To access a remote health care scientist via a computer/ via a desktop app so you can access at home		48, 33%			
Poll 5 Total Responses				151	100
Your Background		**Your Age**			
White	80	18-20			12
White British	15	21-29			47
White Irish	7	30-39			105
Black	5	40-49			98
Black British	6	50-59			39
Asian	13	60 or over			63
Asian British	144	Rather not say			210
Chinese	1				
Other (please specify)	303				
Your Gender					
Female	91				
Male	88				
Other	2				
Prefer not to say	201				
(blank)	192	**Total No. of Respondents**			574

KPA: Kidney Patient Association
*Summarizes Results: Poll 1 - Would you see a Physician other than your own? Poll 2 - How can health professionals understand (appreciate) being in a chronic illness? Poll 3 - Health care Scientist Access in Primary Care and Chronic Kidney Disease (CKD) Poll 4 - Technology and Usage Poll 5 - How likely are you to use the following future technologies for educational support from a healthcare scientist?

participated in polls, representing a 7% response rate. Being an international support group, the respondents had demographics with varying ethnicity, age range, and sex representation (Table 2). These polls did not seek to collect data for level of education, employment, and relationship status.

Table 2 (poll 1) summarizes the number of respondents who polled yes to would you see a physician other than your own. Over 50% (mean: 5; SD: 4.42) respondents agreed and 4% (mean: 11; SD: 3.32) disagreed on whether they would be content seeing a renal consultant that they would not normally see. The results from this poll demonstrate that given "today's" technological advances and use of social media for information-sharing capacity to support informed decision-making, CKD patients would see another health professional who know more about their tests and impact of results. Figure 1 summarizes poll 1 data graphically.

When considering how can health professionals better understand (appreciate) the state of a patient with a chronic illness, communication with patients was deemed the most important element. The proportion of respondents who voted for more communication was 33% (mean: 13.2; SD: 5.59). This poll indicates that CKD patients want more communication with health professionals. The results from this poll also demonstrated that CKD patients want opportunities to ask questions (9% of respondents; mean: 2.8; SD: 3.77) and health professionals should listen to patients more often (12% of respondents; mean: 1.2; SD: 1.10). More opportunities to communicate about CKD laboratory tests and investigations

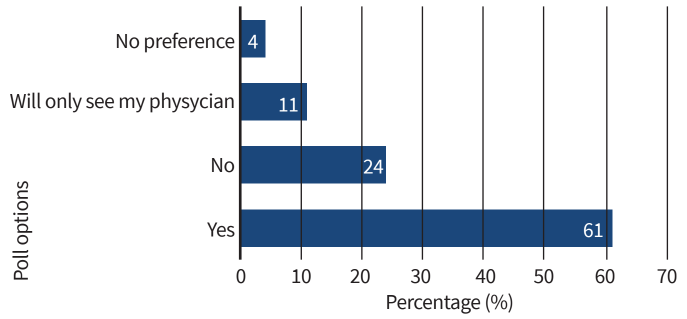

Figure 1. Would you see a health professional other than your own physician?*

*Summarizes Poll 1 Data

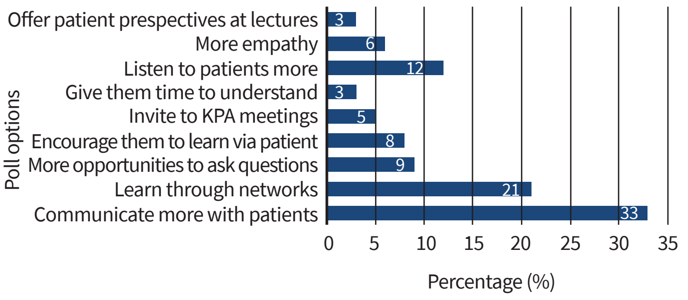

Figure 2. How can health professionals understand (appreciate) being in a chronic illness?*

*Summarizes Poll 2 Data

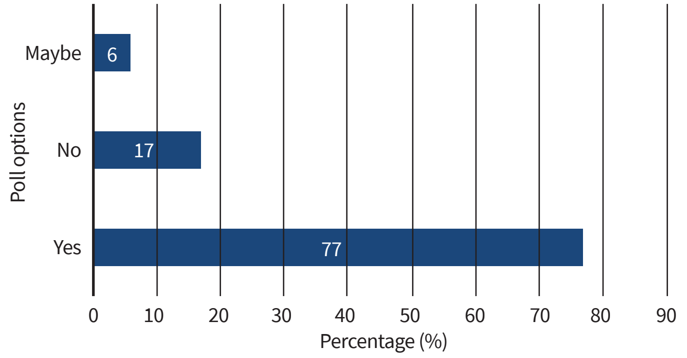

Figure 3. Healthcare scientist access in primary care and chronic kidney disease (CKD).*

*Summarizes Poll 3 Data

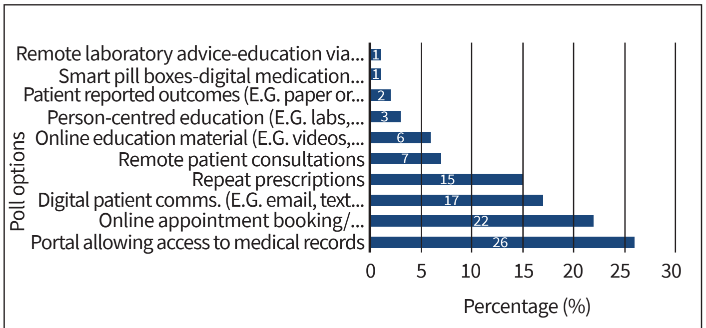

Figure 4. Technology and usage.*

*Summarizes Poll 4 Data

would also increase health literacy. Figure 2 summarizes poll 2 data graphically.

Similarly, when CKD patients were asked if they would access a system wherein a healthcare scientist in primary care/community could tell them about renal tests and investigations, 77% (mean: 23; SD: 5.48) of the respondents polled in yes and 17% (mean: 11; SD: 3.32) answered as no for this question. Given that patients are being prompted to self-care more and CKD being a clinical chemistry/laboratory LTC, patients want to gain more understanding of their tests and impact of results through a healthcare scientist since these are professionals who know about this disease intricately. Access to a healthcare scientist would be especially important for patients in CKD stages 3-5 where laboratory investigations are "frequent." Figure 3 highlights poll 3 data graphically.

When asked about technology and its usage (what technology solutions are available via your GP/Transplant unit), a portal allowing access to medical records and laboratory results scored high (26%; mean: 25.3; SD: 5.02), which demonstrates that 74% of patients do not have a portal allowing access to medical records. A total of 22% (mean: 18.3; SD: 4.28) of respondents checked lab results via GP and/or Transplant Department's Online Appointment Booking/Appointment Reminders, which means that 78% of patients do not have a portal allowing online appointment booking/appointment reminders via GP and/or Transplant Department. Digital Patient Comms. (e.g., email, text messaging) was used by 17% (mean: 11.3; SD: 3.36) of the respondents, indicating that 83% of patients do not have a portal allowing digital comms via GP and/or Transplant Department. Repeat Prescriptions was opted by 15% (mean: 8.3; SD: 2.88) of the respondents, which also demonstrates that 85% of patients do not have a portal allowing repeat prescriptions via GP and/or Transplant Dept. What is also interesting here is that Person-Centered Education (e.g., labs, medication, diet, physical activity) is low (3%; mean: 10.7; SD: 3.27), indicating that 97% of patients do not have access/receive person-centered education. Only 1% (mean: 13.7; SD: 3.70) agreed when asked about Remote Laboratory Advice –Education via a healthcare scientist, which highlights that 99% of patients do not have access/receive laboratory remote education via GP and/or Transplant Dept. This also reiterates that online apps and EPRs are not supportive because having access to test results without the education/knowledge behind them is not "complete care." Figure 4 highlights poll 4 data graphically.

Twenty-six percent (mean: 9.8; SD: 3.13) agreed when asked how likely you are to use the following future technologies for educational support from a scientist to receive text messages or communication regarding laboratory tests/ investigations via a patient app on your phone (e.g., to support your educational needs), 25% (mean: 7.8; SD: 2.79) agreed to access a remote healthcare scientist for education via a patient app on their mobile phone, and 33% (mean: 17.8; SD: 4.21) were likely to access a

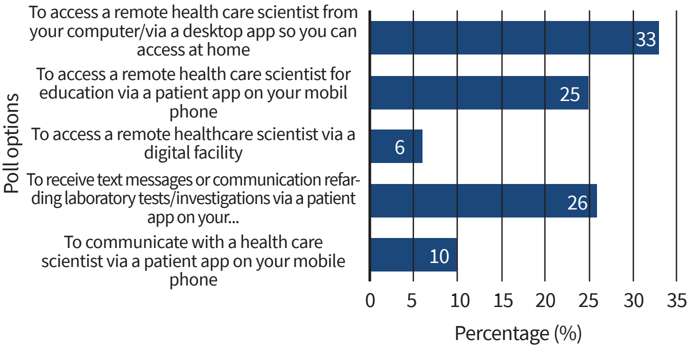

Figure 5. How likely are you to use the following future technologies for educational support from a healthcare scientist?*

*Summarizes Poll 5 Data

remote healthcare scientist through computer/app from home. For CKD patients it is important that a healthcare scientist (i.e. those who know more about the tests behind pathology scenarios) provides educational support surrounding laboratory investigations and impact of results. This is perhaps consistent with patients having access to results via EPRs but an added stage is needed whereby they have education to support interpretation of results. Figure 5 summarizes poll 5 data graphically.

EPRs and Technology

The use of Information Communication Technology (ICT) and shared decision making is important for most patients (70). There is also compelling evidence that patients who are active participants in managing their health and healthcare have better outcomes than patients who are passive recipients of care (70). The use of user-friendly ICT services is also important for knowledge and resource acquisition and for integrated care to enable better patient outcomes (70).

A significant proportion of patients with LTCs rely on the internet to make critical health decisions and often bring information retrieved from the internet into medical consultations, some of which relate to laboratory testing and disease trends (32, 68). Technology has allowed (1) at least one day faster service as results are received electronically and not by post, (2) reduced opportunity for errors introduced during data entry, (3) auditable sample trail –bar-coding used from end-to-end, (4) reduces ad-hoc enquiries because of electronic status checking and monitoring, (5) supports smarter commissioning decisions, and (6) could help break down the organizational and geographical barriers to collaboration (26).

In a review of systematic reviews, authors inform of how effective it is for health professionals to use handheld computers for clinical work (32). Scientists who are proactive tend to be at the forefront of accessing evidence-based practice guidelines surrounding test parameters, sensitivities, and diagnostics. This means that handheld computers improved patient documentation through more complete records with fewer documentation errors and improved the ease and efficiency of documentation (32).

EPRs access and its usage has increased and became part of the routine healthcare since 2013 and the introduction of Patient Online: The Road Map (65). Renal Patient View (now Patient View) has perhaps been a pioneering example for CKD patients, wherein it serves as an EPR management system for patients and carers. RPV/PV was established in 2004; this interface provides CKD patients access to live test results and information about their condition and treatment. It is available in most UK renal units with up to 75% of patient groups registered in some centers. One team analyzed patient use up to 4 years and investigated factors associated with more persistent use. At the time of the RPV census, 11,352 patients had been registered from 37 of the United Kingdom's 73 adult centers (70). All the different types of support are important components of the shared decision-making jigsaw needed to encourage self-care, but information provision alone is unlikely to be enough to motivate self-management and improve outcomes (71).

In a UK qualitative study, 100 patients from a randomized group viewed their online electronic records for the first time (72). Of the first 100, 65 of the respondents were women aged between 18 and 84 years (mean=52 years) and 35 of the respondents were men aged between 19 and 81 (mean=56 years). Many patients requested explanations of medical terms (42%), abbreviations and acronyms (13%), and information on tests or results (17%). Majority of patients have concerns about receiving new information; for example, test results or correspondence between health professionals. They were especially concerned if the information contained abnormal results or bad news (72). Again, this highlight where healthcare scientists are required (36, 45-47, 73, 74).

DISCUSSION

Evidence indicates a proportion of CKD patients access online health records intermittently but over extended periods (75). The patterns and timing of use indicate strong patient interest in detailed information such as recent test results and clinic letters (71). However, this does not immediately translate that patients know what results mean, thus health literacy is still an issue (76).

Patients with LTCs seek more background and understanding relating to health and well-being to take ownership of disease; they also tend to do this faster, via online means and otherwise (77), than some of the very health professionals who look after them. Telehealth links for video consultations, imaging, and laboratory data could also enable scientists to be involved in discussions with patients and carers remotely (i.e., digital scientist) via MDT meetings. This would be advantageous given the population is living longer (78).

While patient use of EPRs like PV has been evaluated in several studies, patients' continuing use of EPRs over longer terms have not been reported. Although certainly clinicians report that consultations with some patients have changed because of patients' access to EPRs, patients still have questions about tests and healthcare (13, 52-57, 79).

At present, eGFR guidance between primary and secondary teams is shared electronically. Guidance of who to screen and when is also shared electronically between healthcare sites. This can cause discrepancies between sites and laboratories; thus, renal results and care differ across sites and sectors (80-83). This can cause ongoing concerns to CKD patients. The understanding provided by a mix of healthcare professionals relating to laboratory tests and investigations can also be confusing because patients see many members of the MDT at varying times and can receive misinterpreted results (43, 44, 84-88).

Strengths and Limitations

Although the overall respondent rate was low, and polls received 164 responses (29%) from British RPSG members over the duration of implementation, this is the first exploration study via a support group and social media platform to inform how healthcare scientists could be more involved in educational support for CKD patients. This investigation also adds to previous work considering perception of the healthcare scientist supporting best practice (10, 16-18).

The data collected were limited by its sample size and duration. However, the RPSG is an international support group, and overall there was representation from all ethnic groups. The results cannot be extrapolated to the UK general population with confidence. However, the respondents to the polls showed a range of characteristics representative of an international general population.

Implications to Practice and Research

Educating healthcare professionals about the importance of the patient role and how to engage with patients is another key area of study. Evidence indicates that healthcare professionals using professional or expert language or *technical jargon* without patient having knowledge in the first instance will continue to act as a barrier to communicate (76). 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.

The polls conducted via the research team have added value to an important topic encasing scientist involvement in provision of education surrounding laboratory investigations and tests for patients in CKD. Greater use of skill-mix will be key if UK healthcare is to offer CKD patients' choice. The aim should be to equip patients with education and knowledge-base to ensure they have a strong basis for shared decision-making at all levels of their care (80-84).

CONCLUSION

Little is known about patients' understanding of results received via EPRs, and only having access may not guarantee that patients know how to use the information (36, 45, 46). Patients/carers still want more face-to-face understanding of test results (or at least have professionals be part of online support group discussions where they can get more rounded care) (47, 73, 74).

Scientists who have trained to acquire variable skills across practice (and across specialties) could perhaps apply education base to support patients with LTCs/ CKD in primary care; this will bring a much-needed healthcare professional asset into primary care. "Digital Scientists" or e-clinics with a healthcare scientist could be another progressive proposition. As technology develops, there will be more pathways for scientists to widen skillsets where education and knowledge sharing for CKD patients is concerned (62, 80-88).

Smarter working will help in meeting challenges on educational needs in primary care to support CKD patients. This will also reduce fatigue, increase streamlined flow of services, and reduce service strain (55). There is now potentially more scope where scientists could support CKD patients with *smarter* education surrounding laboratory investigations and parameters.

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Supplement 1. The Renal Patient Support Group (RPSG)

Patients and/carers often have various questions relating to kidney care following routine clinical outpatient appointments. because 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 South-West England UK. The RPSG was formally founded in 2009 to help raise chronic kidney disease (CKD) awareness on a wider scale. The group has grown exponentially and now has over 8,000 members globally. The RPSG has been a support group for ALL who live with this LTC. 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 LTC. 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. Although 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. The RPSG welcomes everyone to join.

Supplement 2. About the Polls

The RPSG is conducting this poll to see what the needs of the patients are relating to renal care and services, if there are any limitations to the current model of service provision and to help understand healthcare communication, technology needs, and importance of healthcare scientist educational support for laboratory tests and investigations.

Thank you for taking time and helping us to complete these polls about renal care needs. The information from these polls will be used to influence future developments to assist in future shaping of services for patients. All replies to these polls will be treated with the strictest confidence. There are only 31 questions, and these are short. Will only take 15 minutes.