

# An Overview of Health Inequalities – Kidney Care for All in Support of World Kidney Day (2022)

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#### Abstract

**Introduction:** In the UK, unfortunately, one of the main issues surrounding healthcare is that patients with chronic illnesses like Chronic Kidney Disease (CKD) are restricted to NHS healthcare services and approaching healthcare provider. Further complications can arise especially for those who have healthcare challenges and where misinformation can lead to fragility and health inequalities. Patient and Public Involvement (PPI) can help bridge issues surrounding health inequalities.

**Aims:** To identify 1) whether patients with CKD would like to approach health professionals and patients through online consultations and educational support, thus prompting collaborative efforts and 2) understand if/ whether CKD patients would welcome more integrative support from healthcare professionals through social media, wherein patients and professionals can bridge gaps across health inequalities.

**Methodology:** In support of World Kidney Day (2022), this article seeks to highlight how health inequality can be bridged through online spaces and integrative practices between patients and health professionals. **Discussion:** Patients are the intermediaries between primary and secondary healthcare services. CKD patients now have more opportunities to share lived experiences owing to the nature and implementation of social media platforms, like the Renal Patient Support Group (RPSG) and the Kidney Disease and Renal Support Group (KDARs) for Kids.

**Conclusion:** In addition to sharing experiences, this prompts patients to be more than mere recipients of healthcare; CKD patients become more empowered so that more informed decisions can be made. **Summary:** Educational intercessions are required generally to offset issues where there are inequalities but also to ensure excellence in health practice.

#### Introduction

It has been reported that patients with Long-Term Conditions (LTCs) account for around 50 % of GP appointments, 64 % of outpatient appointments and 70 % of hospital bed days (1). Around 70 % of total health and care expenditure in England is attributed to people with

LTCs (1). Education and consultations through online spaces where patients have access to peer support and Allied Health Professional (AHP) involvement would help prompt smarter care (2-4). Providing CKD patients education that is centred surrounding clinical and nonclinical scenarios is important owing to changes in health and disease over time (5; 6). Health Professionals are



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prompted to keep up to date with aspects that surround 'at risk patients' and consult nephrology guidance where most applicable (7; 8). A stance is now required where healthcare educational interventions constitute service equality and improvement.

Healthcare is best when there is a position to deliver the NHS Long Term Plan's aim for 'triple integration' of primary and specialist care, physical and mental health services, and especially if connectivity is 'unified' via the Health and Social Care Network (HSCN) (9) this can allow interconnectivity in healthcare that meets compliance (10; 9). HSCN should allow 'untapped' areas focusing on education provision surrounding disease trends through e-health (11; 12). HSCN provides the underlying network arrangements to help integrate and transform health and social care services by enabling care organisations to access and share information more reliably, flexibly, and efficiently (9).

Patients may also increasingly find themselves taking on roles, particularly where involvement is dependent on bridging educational gaps (13; 14) through technology and 'online spaces' (15; 16). Quality of education should also empower and support self-care (17). Patient and Public Involvement (PPI) can help bridge issues surrounding health inequalities. (18; 2).

#### Aims

Toidentify 1) whether patients with CKD would like to approach health professionals and patients through online consultations and educational support, thus prompting collaborative efforts and 2) understand if/ whether CKD patients would welcome more integrative support from healthcare professionals through social media, wherein patients and professionals can bridge gaps across health inequalities.

### Healthcare Complexity

An estimated 15 million people in England have at least one Long-Term Condition (LTC) with the prevalence of cancers, chronic kidney disease (CKD) and diabetes rising most quickly (19). It is predicted that the number of people with LTCs will remain relatively stable over the next six years, although the number of people with multiple LTCs (known as multi-morbidity) is set to rise from 1.9 million in 2008 to 2.9 million in 2018 (19). This consequently has an impact on health and lives (20). Already the 30% of the population with LTCs account for 70% of NHS spending (21). Reducing people's dependence on health professionals and increasing their sense of control and wellbeing is a more intelligent and effective way of working (22). Despite overwhelming evidence, people with an LTC or a disability face several challenges regarding discrimination and/ or ignorance; people may feel disenfranchised; have perceptions of helplessness and feelings of powerlessness against a backdrop of diminished health (23-25).

# Healthcare and the National Health Service (NHS)

First announced in 2003, the term *population health* was used to describe health outcomes surrounding disease trajectories across health conditions (19). Population health has now progressed to include identifying people at risk of LTCs, according to severity of illness, demographics, and broader bioinformatic parameters to identify risks in leveraging resources to improve healthcare and outcomes (19).

Healthcare education has diversified for patients with LTCs over the past two decades (19; 21). Patients with LTCs use the internet to access peer support groups via social media (21), and whilst this can be helpful, peer support alone does not over-ride the necessity for educational support (26; 27). It is in this context, patients either become more informed as decision-makers or misinformed around disease trajectory, leading to compromised quality of care (26; 27).

Technology has allowed patients with LTCs to access supplementary information relating to health and disease, including National Health Service (NHS) websites and portals, Patient-based organisations, and various other sources (28). The current concern is that despite technology advances, integration between information searching vs. knowledge implementation differs between age groups and across LTCs (29). Information available over the internet is vast and much of it can be daunting and lead to educational barriers.

Transparency is required to define the remit against which progress can be measured (30). The role of Clinical Commissioning Groups (CCGs) and NHS Commissioning Boards should relate healthcare back to patients and the public (31; 32). Evidence has underscored the importance of effective self-management and delivery of healthcare to LTCs (33; 34). Patients who are 'activated' (that is, who recognize that they have an



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important role in self-managing, have skills confidence) experience better health outcomes (35; 36). The government has a wide role in preventing ill-health, prompting the nation to live healthier lives, not just longer ones (37-41; 19). The problems, which appear in healthcare have risen from a lack of understanding about the multidimensional nature of patient and public involvement (17).

## Information and Communications Technology (ICT) and Shared Decision Making

Reducing people's dependence on health professionals and increasing sense of control and wellbeing is a more intelligent and effective way of developing joined up thinking between patients and all health professionals (18). There are a wide range of initiatives to support selfmanagement including information leaflets, online peer support, one to one counselling, group education sessions, use of social media with technology, and selfmanagement interventions. Initiatives can be categorised along a continuum, with passive information provision about people's condition and 'technical skills' at one end of the scale and initiatives that more actively seek to support self-management and increase self-efficacy at the other end of the continuum (18).

The use of Information and Communications Technology (ICT) and shared decision making is important for most patients because many want to be more involved than are in making decisions about their health care (19). There is also compelling evidence that patients who are active participants in managing their health and health care have better outcomes than patients who are passive recipients of care (19). The use of user-friendly ICT services is also important for knowledge and resource acquisition and for integrated care. User friendly ICT services allow the delivery of better understanding, enhancing care quality efficiencies across care providers, to enable better patient outcomes (20).

All types of support are important components of the shared decision-making jigsaw needed to encourage empowerment, but information provision alone is unlikely to be sufficient to motivate or improve healthcare outcomes (18).

### **Challenging Inequality**

The involvement of citizens in decision about health policy, planning and service provision have been

introduced in several countries, including the UK, Canada, Holland, and Australia (17). The public involvement and support are needed to promote innovation and research, the research needs to reflect public interest and values. In line with research and challenging aspects that encourage inequality, Patient and Public involvement (PPI) has become a key component healthcare and research in the United Kingdom (38). PPI gives healthcare service users the opportunity to be part of the solution to establish beneficial healthcare and tackling inequity through research and involvement. PPI is also an important mechanism for inducing necessary healthcare though research (31) and allows to improve the quality of health care (39). The essential changes are the belief that involving patients in healthcare leads to improving quality of healthcare through participation.

Several studies suggest that users of public healthcare with a history of chronic disorders can be involved in health services, and this can depend on adequate support (33). The study of Brett and collaborators reports evidence of the beneficial and challenging impacts of PPI on researchers and communities engaged in the research. PPI has positive impact on healthcare users, they feel empowered, valued, listened to and more positive about their experiences. The most important impact is that it has an increasing influence on users to possess more knowledge around their condition and develop life skills (30). The PPI is also beneficial for researchers, as it has positive impacts about gaining new insight into their work and gaining better understanding of the area under study (30). The involvement and engagement of patients and researchers need to be preceded by the development of guidelines for users integrated into a project, and the permission on transferring the expertise and skills between the academic, practice and service user communities (34).

PPI helps in the bridging gaps between healthcare professionals, scientists, and patients (31). The involving of patients in healthcare is an ethical requirement since patients pay for services so they should have an influence on healthcare together with health professionals and across sciences (35).

#### The Renal Patient Support Group (RPSG)

Patients and carers often have various questions relating to kidney care following routine clinical outpatient appointments. Owing to a 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 broader scale, for the adult renal population and provides support from ages 18 plus. The group has grown exponentially and now has over 9000 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 diseaseprocesses. The RPSG is highly research active, building on evidence-based treatment 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 a decade, the RPSG has an international administration and research team, and this helps keep group live and proactive, 7days a week, 24 hours a day. The RPSG welcomes everyone to join.

# The 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 newborn 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 2000 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 7 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.

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#### Discussion

Initiatives such as 'integrated care pathways', 'patientcentred care' and 'shared decision-making' are examples of attempts to align clinical, managerial, and service user interests, and to improve coordination of care for patients with LTCs (42). Concern about fragmentation typically focuses on a lack of service coordination for individual patients and, particularly, the structural and cultural isolation of generalist from specialist medicine, or adult social care from health care, which often results in patients experiencing discontinuity of care when they are transferred from home to hospital, or vice versa (42). The UK healthcare system should not ignore the evidence (22).

'Integrated care' is a term that reflects a concern to improve patient experience and achieve greater efficiency and value from health delivery. The aim is to address fragmentation in patient services, and enable better coordinated and more continuous care, frequently for an ageing population which has increasing incidence of chronic disease (42).

#### Conclusion

Patients are the intermediaries between primary and secondary healthcare services. CKD patients now have more opportunities to share lived experiences owing to the nature and implementation of social media platforms, like the Renal Patient Support Group (RPSG). In addition to sharing experiences, this prompts patients to be more than mere recipients of healthcare; CKD patients become



more empowered so that more informed decisions can be made.

Patients should be armed with appropriate education, so they are able to have 'level-up' communication and discussions with service providers (43-45). Health professionals associate younger people wanting access to technology. There is scope for service development and initiatives relating patient care through advice, education, and peer support, but there needs to be coordinated effort. Service providers should focus attention to how online spaces and technology can improve CKD education provision. Healthcare challenges have led CKD patients to explore new and more effective ways of approaching medical practice with integrated educational support.

#### Summary

Educational intercessions are required generally to offset issues where there are inequalities but also to ensure excellence in health practice. Patients would welcome health professional involvement through online platforms. The above notwithstanding, future research should look to encourage development of a novel framework to help streamline educational support and highlight what CKD education in healthcare could look like with healthcare professional involvement to bridge health inequalities through the RPSG and KDARs.

Any health education provided will also require documenting and transfer of information, connectivity of any future technologies or links between Electronic Patient Records (EPRs). Knowledge provision would need to be fast, reliable and General Data Protection Regulation (GDPR) compliant.

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Shahid N. Muhammad is an Author, Specialist Biomedical scientist, HCPC Scientist, Chartered Scientist, writer, presenter, co-founder, lecturer, supervisor, researcher, blogger, contributor. And Advancing Healthcare Awards (2018) and (2022) Finalist. Shahid is a Specialist Biomedical Scientist and member of the Healthcare Professions Council (HCPC). Shahid is a Fellow for the Institute of Biomedical Sciences (FIBMS) and a Chartered Scientist with the Science Council (CSci). Shahid has built experience in laboratory and health practice surrounding pathology. Shahid has been involved in the development of key practices through several working groups/ panels and was a member for the NHSBT Paediatric Kidney Advisory Group (PKAG-sub-committee 2009-2011). It was in (2009), Shahid co-founded the Renal Patient Support Group (RPSG). Shahid was a member of the

British Association of Paediatric Nephrology (BAPN) (2011-2014). Shahid was involved in the development of the BAPN; Nephrology Networks Guide (2012) and was also a member of the Kidney Research Education Initiative (KREI) (2010-2013), and has supported development of frameworks, and healthcare initiatives. Shahid developed research between (2010-2013) with the University of the West of Scotland (UWS) surrounding Paediatric Nephrology and between (2017-2021) developed research Adult Nephrology under the University of the West of England (UWE). Shahid is currently an Academic and Scientist at Coventry University, England UK. Shahid has formed several key publications, and presented work locally, regionally, in various European countries, virtually and internationally.

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