

# Renal service users' and carers' collaboration to improve education and research in the UK: an update four years on

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Chamney, M. (2014). Renal service users' and carers' collaboration to improve education and research in the UK: an update four years on. *Renal Society of Australasia Journal*, 10(3), 102-105.

Submitted: April 2014, Accepted: April 2014

## Abstract

In 2010 an advisory group was formed of City University London academics, renal service users and carers to create the Kidney Research and Education Initiative. The main aim of the initiative was for renal service user and carer participation in all aspects of the group as well as becoming a centre of excellence for kidney care, education and research, with a specific focus on patient participation in research and teaching. Service users and carers can provide a wealth of knowledge and experience to the training of student nurses.

## Keywords

Service users and carers, renal, student nurse education, collaboration.

## Background

Academic institutions often involve service users and carers in curriculum planning and teaching activities and this is something the School of Health Sciences at City University curriculum development planning team decided was imperative when developing the latest undergraduate nursing curriculum in 2012. This pre-registration nursing programme has two routes, either BSc (Hons) Nursing or Post Graduate Diploma (PG Dip) in Nursing and each route has three pathways reflecting the three fields of nursing practice (Adult, Child and Mental Health). The Nursing and Midwifery Council (NMC) standards (2010) for pre-registration nurse education require nurse education providers to demonstrate how they involve service users and carers in the planning, delivery, teaching and evaluation of nursing curricula. Service users were involved on the panel during the approval process and continue to be involved with curriculum planning and its delivery, the strategic development of educational activities; recruitment of students, staff development, and the development of practice-based learning documentation and assessment strategies.

### Renal National Service Framework

Historically, in the UK, kidney patients have led the way in many improvements to the care of others within the renal community and it was a kidney patient who initiated a coordinated effort by the renal community which led to publication of the first Renal National Service Framework (NSF) in 2004. The Renal NSF provided a solid foundation of

principles from which the renal community could advocate for improved services and detailed the infrastructures required for a successful service, including coordinated structured support systems for renal service users. This was taken one step further with the publication of *Kidney Health: Delivering Excellence* (2012), where the renal community drew upon information gained from former NSF successes to articulate its aspirations for the future and provide the framework for a clear, long-term strategy to meet the needs of kidney patients.

### Relationship-centred care

Within the School of Health Sciences, service user and carer involvement is strengthened by a set of values incorporated into the latest nursing curriculum based on a commitment to relationship-centred care (RCC), where health professionals and students value and attend to the relationships that form the context of care, including those among and between service users and carers. RCC is hoped to address the public concerns over a suspected lack of care and compassion within some circles of nursing practice and foster service user engagement in decisions about their care. The curriculum is also based on the Six Senses Framework (Nolan *et al.*, 2006) where students are taught alongside the senses framework and should experience a sense of:

- Security — to feel safe
- Belonging — to feel part of things
- Continuity — to experience links and connection

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- Purpose — to have a goal(s) to aspire to
- Achievement — to make progress towards these goal
- Significance — to feel that you matter as a person (Nolan *et al.*, 2006, p. 25)

## Standards

The National Safety and Quality Health Service (NSQHS) Standards were developed by the Australian Commission on Safety and Quality in Health Care by discussion and partnership with a wide range of participants including health care professionals and patients. The primary aims of the *NSQHS Standards* are to protect the public from harm and to improve the quality of care provided by health service organisations. When nurses form partnerships with patients and carers, not only can a patient's experience of care be improved and their training can also be more effective (ACSQHC, 2012). These standards provide a useful basis to guide services, not only in Australia but also the UK, where the patient in this context is termed a 'service user'. This includes people who use, have used or have the potential to use health care services. The term 'carer' includes informal carers and parents/guardians of people who use health care services. The importance of involving service users and carers in the education of health and social care professionals has been well documented (Levin, 2004). City University has a long tradition of involving service users with long-term conditions and their carers in the teaching of student nurses in relation to renal care.

## User and carer involvement

Involvement of service users and carers in education can test well-established opinions of health professionals, educate students to embrace a more user-centred approach and produce nurses capable of delivering improved and more relevant outcomes for service users and their carers (Tew *et al.*, 2004). Primarily for education providers, particularly those working in higher education, there is the need to meet national requirements such as the NMC (2010) for involving service users and carers in nursing programmes of study in a consistent and meaningful way.

Involvement means different things to different people. Incorporating service user and carer involvement within student nurse education is about influencing their training and helping students develop the personal and professional skills necessary to become better registered nurses and contribute to the improvement of services in the future. Meeting service users and carers outside clinical environments helps students gain a clearer understanding of how conditions can affect people's daily lives (Terry, 2011). It also provides a focus for students to be made aware of the countless tools and systems available to service users and carers to help them manage their long-term condition better so students can then use these to incorporate into the care of people with kidney failure and their extended family and friends (Expert Patients Programme 2012).

The widespread involvement of service users involved in the education and evaluation of a range of health and social care professionals has led to increased monitoring and regulation of service user involvement in the education and training of health and social care professionals (Chambers & Hickey, 2012). This includes assurances that service users and carers are aware of what their role entails, the commitment to their time and also the monetary remuneration (Staley, 2013).

## Student nurse renal teaching

In 2010 the Kidney Research and Education Initiative (KREI) members began their involvement with teaching renal care to the pre-registration students in the second year of their programme. As well as involvement with teaching, they have also been involved in curriculum design and contributed to research grant applications (Chamney *et al.*, 2012). One of the KREI academic staff is now employed at Southbank University and has commenced teaching with the KREI service users and carers in 2014.

With this renal collaboration history in mind, in 2013 I decided to open this up further and introduce a programme manager's seminar series based on service user and carer perspectives that runs alongside the Long Term Conditions Module in year two of the nurse training for both BSc (Hons) Nursing and PG Dip Nursing students. The individual sessions include lived experiences of the individual with a long-term neurological condition, a renal condition, living with cancer, specialist support and management of an individual with dementia undertaken by a carer and showing videos of the individual suffering from dementia as she goes about her daily life.

The renal seminar is a mixture of information provided by the renal senior lecturer and a service user alongside photographs of the service user and his carer throughout their renal journey. Students ask interesting and sometimes extremely personal questions and particularly are keen to review his arterial venous fistula. These seminars have been positively evaluated and when the module runs again in late 2014, additional topics including tuberculosis will be added as tuberculosis is on the increase in the east end of London, where many nursing students undertake their clinical placement experience.

## Curriculum development

KREI service users and carers have been involved in exploring user experiences of care and presenting this to classes of students for the past three years and have also been involved in the development of patient blogs and websites. Service users and carers were crucial in the development of patient scenarios and provided case study material for the long-term conditions module. The service users involved believe strongly in sharing their knowledge and thoughts with the nursing students. It has been reported as providing cathartic effects resulting from their involvement, including enhanced confidence, self-esteem and feelings of empowerment (Morgan, 2009). Another reason that

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service users get involved is that they want to make a difference, to improve the services for themselves and other people and make a change, if possible (Beresford, 2013).

## Research

During the past four years, many firsts have occurred with the KREI. Service users and carers were involved in two research grant applications addressing methodological issues. A National Institute Health Research (NIHR) grant was successful: Dr Helen Noble, Queen's University, Belfast. This grant provided £513,000 to undertake the PACKS study exploring quality of life, decision making, costs and impact on carers in patients with advanced kidney disease managed without dialysis.

Service users are regularly involved in health research studies as collaborators and there are an increasing number of service user-led research projects. Results and findings from these studies can offer a good emphasis for teaching and learning activities. The KREI membership is awaiting the outcome of the second grant applications relating to "peer support of renal patients" and the outcome of this will be known in September 2014.

## Presentations

Members of KREI gave an oral presentation at the INVOLVE conference in 2010. INVOLVE is a national advisory group supporting public involvement in National Health Service (NHS), public health and social care research. The year 2014 saw an innovative seminar series commence at City University, "Exploring innovative approaches to involving patients, service users, carers and the public in health education and research". A renal service user and carer will present one of these seminar series with the renal senior lecturer to an audience of staff and students, not just from the School of Health Sciences but the University as a whole. A blog has been set up to promote and support the involvement of patients, service users, carers and local communities in all educational and research activities across the School of Health Sciences. It includes guidelines, suggestions, useful tips, resources, case studies, research and much more. <https://blogs.city.ac.uk/communityengagement/seminar-series/> [accessed 20 March 2014].

At the National British Renal Society conference a presentation was given by two members of the KREI titled "An evaluation of patient and carer involvement in a renal nursing education and research interest group". Four members of the KREI also ran a workshop on "Benefits of service user and carer involvement in renal care" at the International European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) conference.

## Publications

In 2012, three service users and two academics were involved in the publication of an article "Renal health care professionals,

patients and carers collaboration to improve education and research" (Chamney *et al.*, 2012) and the fourth edition of the *Renal Nursing* textbook for nurses (Thomas, 2014) included a chapter on "Patient and Carer Involvement in Renal Care", which four service users/carers of the KREI developed and are cited as the authors.

## Other initiatives

KREI members were involved in initiatives, such as the Renal Patient Support Group (RPSG) on Facebook and the Enhancing Care and Saving Lives of people with chronic kidney disease (CKD) (ENABLE) study, which aims to improve the management of people with CKD, where the patient and carer group is chaired by a KREI member and service user. <http://support.kidneyresearchuk.org/page.aspx?pid=341>

Two other KREI members are the service user and carer representatives on the Adult Programme Committee at City University chaired by the Adult Programme Manager, which involves senior members of the academic team and students to allow all parties to be aware of the latest curriculum developments as well as being involved in changes within the nursing programme.

## Evaluation

We had hoped to be able to evaluate the benefits of user involvement in a formalised way, but unfortunately due to constraints within KREI membership, including the deaths of two service users who had co-authored the previous KREI article (Chamney *et al.*, 2012), this was not able to occur prior to funding for this initiative ending. I am hopeful that the developments created during this time by a core group of people will continue into the future and that the development of KREI will influence renal education nationally. None of these things would have been possible without the formation of the KREI or the funding provided by the British Kidney Patient's Association (BKPA).

## Conclusion

The past four years have highlighted that service users and carers can provide a wealth of knowledge and experience to the training of student nurses, not only those in the nephrology speciality but for all areas of nursing as has been shown by the introduction of the programme manager's lecture series earlier this year.

"There is great potential to promote the learning of patient-centred practice, interprofessional collaboration, community involvement, shared decision making and how to support self-care" (Towle *et al.*, 2010 p. 64).

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