Renal health care professionals’, patients’ and carers’ collaboration to improve education and research

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Introduction
The Kidney Research and Education Initiative (KREI) was established in 2010 by lecturers and researchers at the School of Health Sciences at City University London, who all have local, national and international profiles in the kidney research, education and practice fields. The reasons for setting up KREI were twofold: firstly, to consolidate the existing expertise in kidney care among staff in the School of Health Sciences and formalise their cross-school working relationships; and, secondly, to enhance the research and education activities in kidney care and facilitate the dissemination of new knowledge to improve patient care (Noble et al., 2010). Following an initial brainstorming session, it was mutually agreed that a core value of the KREI should be to have patient and carer participation in all aspects of KREI activities. Accordingly, it was agreed that the main aim of the initiative would be to become a centre of excellence for kidney care education and research with a particular focus on patient and carer involvement.

To our knowledge this is the first initiative of its kind internationally to promote patient and carer involvement in renal education and research. Patients and carers are involved in many different teaching and learning activities for health professionals, including curriculum planning and development of nursing programmes, classroom teaching, e-learning and the assessment of students (Lathlean et al., 2006; Masters et al., 2002; Simpson et al., 2008; Stickley et al., 2010; Terry, 2011). Research on the involvement of patients in education has demonstrated that it can challenge well-established perceptions and attitudes of health professionals (Katan & Prager, 1986), educate students to use less jargon and adopt a more user-centred approach (Wood & Wilson-Barnett, 1999) and ultimately produce practitioners capable of delivering improved and more relevant outcomes for patients and their carers (Tew et al., 2004).

In terms of research, there is a long history of patient and carer involvement in nursing and health care research (Morrow et al., 2012) with some health fields further advanced in involvement, for example mental health (Rose et al., 2011; Telford & Faulkner, 2004) and cancer research (Cotterell et al., 2008; McCormick et al., 2004). A recent review by Staley (2009), identified 89 published research studies that actively involved the public in health and social care research internationally. This review identified a number of impacts of public involvement in research, including: improving the research design and relevancy of research questions; helping researchers develop

Abstract
The Kidney Research and Education Initiative (KREI) was established to develop collaborative working for renal education and research between renal patients, carers, lecturers, researchers and practitioners at City University London. This article will describe the background to KREI and considers the motivation for its establishment in addition to outlining the achievements to date and plans for the future. Narratives from patient and carer members of the KREI are presented, in which KREI members reflect upon their experiences of being involved in the initiative. This paper addresses the benefits and challenges of patient and carer involvement and also outline the initiative’s future plans.

Keywords
Patient and carer involvement, renal, education, research.
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ethically acceptable research; improving recruitment and response rates; enhancing the collection and analysis of data; and enhancing dissemination of findings in an accessible way to the general public. It is widely acknowledged that patient and carer involvement in research is not without its challenges; for example: ensuring that any involvement is meaningful and not simply tokenistic; researchers needing to give up/share power in the research process; researchers accepting that the research will often take a slower pace; and ensuring there are adequate resources, in terms of people and money, for additional training and support required for the patient and carer researchers (Staley, 2009; Trivedi & Wykes, 2002; Wright et al., 2006; Wyatt et al., 2008).

KREI – the story so far

Once it had been decided that patient and carer participation would be an integral part of the KREI, a patient representative from a national kidney patient organisation was invited to join KREI to help develop the initiative. In particular, the patient representative helped the group to think about terms of reference for the KREI and a recruitment strategy for patient and carer members. It was decided to hold a launch event, to promote the new initiative locally and nationally and to showcase the kidney research and education being undertaken at City University London. Accordingly, patient representatives from local (London and the south–east region) Kidney Patient Associations and national groups (the British Kidney Patient Association and Kidney Alliance) were invited to attend, as well as academic staff from City University London and clinicians from local health care organisations. In addition, clinicians from local renal units were asked to inform patients attending their service about the initiative and invite any interested individuals to attend. The launch event was held in October 2010 and was attended by 40 delegates, including patients, carers, clinicians, lecturers and researchers. Presentations and workshops were given about current kidney care projects at the University and there was a keynote presentation from the Chair of the Kidney Alliance about the importance of patient and carer involvement.

Following the launch of the KREI, an advisory group was established in February 2011, composed of kidney patients, carers, lecturers and researchers. The main recruitment criteria for patients and carers to join the advisory group were the experience of kidney disease (either personally or as a carer), and an interest in kidney research and education. There was no formal assessment of people’s qualifications; instead an invitation to participate was based on people’s experiences as kidney patients and carers and interest in being involved. It was deemed important to recruit members with different experiences of kidney disease and treatment, such as haemodialysis and transplantation. It was also considered relevant to recruit people who represent both local and national organisations as well as other individuals not involved in patient associations. The patient and carer members of the advisory group were mainly recruited from the launch event according to the criteria outlined above.

A key factor that has enabled the KREI to establish an advisory group and support its activities has been the obtaining of dedicated funding. The twice-yearly meetings are funded by a grant from the British Kidney Patients Association (see acknowledgements). This funding is used to reimburse the patients and carers for their time and expenses, and also pay for lunch and beverages. Providing payment for the patients and carers is an important way of recognising and valuing their expertise and contribution to the initiative, with the amount of payment in accordance with national guidance (INVOLVE, 2010). A further way of acknowledging the contribution made by the patients and carers is that they have all been made Honorary Lecturers in the School of Health Sciences, with a contract and access to University buildings and facilities, such as the library.

At our first advisory meeting, the members contributed to the development of the overall aims and the terms of reference of the initiative. In summary, the aims of the KREI are to:

- Work in collaboration with kidney patient groups, professional organisations and other stakeholders in the UK and internationally.
- Involve patients and carers in the development and delivery of education.
- Undertake high-quality kidney care research.
- Involve patients and carers in the planning, designing, conducting and dissemination of research.
- Support academic staff and local clinicians in kidney care research activities.
- Support the dissemination of research findings and implementation into clinical practice.
- Act as a resource for kidney care quality improvement initiatives.

Current activities of KREI

During the first 12 months of the KREI, the patients and carers have been involved in undergraduate nurse teaching sessions relating to kidney disease, contributed to a new nursing curriculum and actively participated in the development of two new research proposals, led by researchers from City University London. In this section some of the KREI members discuss their experiences of this involvement. (Please note that pseudonyms have been used to replace the real names of members, at their request.)

Reviewing and improving teaching sessions

KREI members attended an undergraduate renal teaching session and made recommendations regarding how to refocus the session around patients’ experiences of living with kidney disease. Following this feedback, several KREI members have participated in subsequent teaching sessions, which included a question and answer session between the nursing students and patients and carers about their experiences. It is hoped that this new component to the teaching will put a “real face” to the
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illness and its consequences and has the potential to enhance patient-centred practice, inter-professional collaboration and shared decision making (Towle et al., 2010).

Here is a quotation from one of the KREI members, reflecting on her experience of observing the teaching session:

I attended an interesting teaching session in June 2011 which involved year 2 student nurses. It allowed renal patients and carers to observe what was taught, how the lectures were conducted and see what was learnt. Patient and carer participation was encouraged and it was felt the student nurses required supplement and enhancement of examples of first-hand experiences from renal patients and carers. An evaluation was carried out following the session where we provided feedback with regards to the format/structure of future renal care lectures. Future sessions will hopefully encourage motivation and interest of renal care in student nurses. (Anne)

The next step is for the KREI to evaluate the impact of the patients’ and carers’ involvement in teaching on students’ knowledge of kidney disease and understanding of the patient and carer perspective (see discussion section).

Curriculum development

The University is currently developing a new nursing pre-registration curriculum, which will commence in September 2012. Members of the KREI have been involved in the development of the new curriculum. One KREI member expresses her thoughts and hopes for how patient and carer involvement can improve the preparation of nursing students:

The University can through this initiative identify particular areas on which to focus, and times of high stress for patients – and include this in their unique training. For example:

• Breaking bad news to people, something many struggle with.

• Encouraging people to look after themselves. Writing this from our viewpoint.

• Lack of communication and lack of information and frequent misconceptions.

• Simple things such as where dialysis patients sit – which may seem insignificant to a health care practitioner but is really quite important to someone on dialysis 3 times a week. (Marie)

Involvement in research

Two staff members of the KREI have recently developed research proposals in the field of kidney care and KREI members have been actively involved in contributing to the design of the respective studies and commented on draft proposals. Members of KREI are co-applicants on these projects and, if funded, will be involved in the studies at all stages of the research process.

Anne describes her experience of being involved in the development of the research projects:

Being a member of the KREI has also given us the opportunity to get involved in the exciting proposed research projects. Research in renal care is the way forward if changes to renal care education and awareness of the concept of continuity of care are to be made (Anne)

Patients’ and carers’ experiences of involvement

What does this all really mean to the patients and carers? How do they feel about the process, the experience and the impact of their involvement? The KREI members were asked to describe their experiences so far of being involved in the research and education activities at City University London. Four main themes emerged: “providing a voice to patients and carers”, “the value of learning from patients and carers’ experiences”, “a good model for patient and carer involvement” and “personal benefits”. The following section provides quotations from KREI members that illustrate these themes:

Providing “a voice” to patients and carers

The patients and carers expressed a view that their involvement in the KREI was providing a “voice” to the patient and carer perspective in education and research activities and that this has the potential to improve patient care, as the following quotations demonstrate:

I am excited to be a member of KREI because it gives us all a voice to help improve the care of renal patients both present and future. We can influence the training of nurses and the research they undertake, so that it is informed and relevant from the patient/carer’s perspective. (Eleanor)

I feel that KREI offers a unique and wonderful opportunity for patients and carers to have a voice in developing practice and opening up a dialogue with tomorrow’s clinicians. This can only be for the good of future patients, nurses, doctors and administrators. (Maxwell)

KREI gives the opportunity to group members to contribute their stories to the training of professionals. Involvement in the group offers a great opportunity for us to use our experiences constructively to improve that of future kidney patients. […] It is really encouraging that City University has chosen to develop this approach. (Marie)

The value of learning from patients’ and carers’ experiences

The value of providing “expertise by experience” to improve the training of clinicians and patient care was another key theme, as these two quotations highlight:

… No-one, however qualified, can know what it is like to have a chronic illness. So I am delighted to be a member of a group which can influence the training of tomorrow’s great clinicians. To help clinicians realise that beyond the purely technical aspects of treatment there is a person, who also if dialysing has to deal with the realisation that their life is being supported by a machine. Also the restrictions on normal life – fluid reduction and diet can be daunting to people who have never thought about its impact. (Peter)

However much experience you have, unless you have been on the receiving end of such medical care you are rarely in a position to understand what the patient is experiencing This to me is the real
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benefit of the KREI. With a group of like-minded patients and carers, we are in a position to influence and guide staff who have to deal with people like us every day but who may not have the time or the inclination to appreciate that, as patients, we are not just statistics but that we are very often experiencing great emotional turmoil as we attempt to come to terms with a life that we thought was healthy but which we are now told is compromised in some way or another. The more we are able to speak of our experiences and provide an insight into the views of patients, the better. (Jeremy)

A good model for patient and carer involvement

The patients and carers were supportive of the vision of the KREI to actively involve patients and carers in the University’s education and research activities, as these quotations show:

It is very brave of the University to embrace the views of patients and carers in the construction of its courses and to embrace them as partners in the education of students, tutors and the culture of the department. It is a model which I am sure will be adopted more widely. (Maxwell)

The requirement to involve “patients” in some way with research projects, quality initiatives education and practice is frequently expressed. However the depth to which patients and their partners, carers and families are involved varies greatly and good practice is not consistently shared. The community is not in the habit of involving patients with the training of professionals; this education initiative pulls together the experience of people like me, and feeds that back into education. It has the potential to inform and improve the quality of care offered through patient input into the curriculum, offering a balance between medical and user-related care. It draws from user experience and offers a model to avoid bad practice which may have been experienced by the patients in the group, and to encourage the good practice which patients may also have experienced. (Marie)

Personal benefits

Many of the patients and carers expressed the personal benefits that they have gained from their involvement so far, as illustrated here:

I am really happy being part of the KREI team, it means a lot to me. It has given me a lot of knowledge and awareness which I have gained as well as shared with fellow colleagues. (Arabella)

I am honoured to be liaising with fellow academics, renal patients and carers who share great enthusiasm to ensure formal courses can be proposed for quality education and learning, which I have always felt is paramount so that best care can be provided to patients throughout their kidney disease journey. The KREI has been a great platform to promote information and share learning. (Kingsley)

Discussion

The narratives from the members of the KREI demonstrate that they perceive their involvement in education and research activities at City University London to be meaningful and with the potential to improve the quality of renal education and research in the future. Of course it must be acknowledged that the KREI is still a relatively new initiative and it is perhaps not surprising that members are still enthusiastic and positive; over time more challenges may emerge. However, a central aim of the KREI has been to involve patients and carers in a meaningful way, so it is encouraging that after the first 12 months the patients and carers perceive their involvement to have purpose and value.

The patients and carers expressed the view that their involvement has the potential to provide the patient and carer “voice” to renal education and research. In particular, the KREI members expressed a desire to influence the education and training of students, the clinicians of the future, in order to improve patient care. Previous studies confirm that the involvement of patients and carers in education has the potential to encourage students to adopt a more patient-centred approach and that this will hopefully produce clinicians capable of delivering improved and more relevant outcomes for patients and their carers (Tew et al., 2004). As already discussed, patient and carer involvement in education and research is relatively absent in the renal field, although more present in other health areas such as mental health and cancer (Cotterell et al., 2008; Rose et al., 2011; Stickley et al., 2011). Thus the KREI has an important role to play in promoting patient and carer involvement in renal care.

The perceived value of the KREI members’ contributions as “experts by experience” was also conveyed and this reflects a common theme in the patient and carer involvement literature, that is, that a strong motive for patients and carers to become involved is the ultimate desire to improve change and improvements to services and practice (Telford & Faulkner, 2004). As the quotations demonstrate, members of the KREI are keen to bring their personal, real-life experiences to education and research activities and emphasise to clinicians and researchers that patients are “real” people and “not just statistics”, as stated by Jeremy. Indeed the contribution of patients’ and carers’ “experiential knowledge” is widely acknowledged in the literature (Beresford, 2003; Morrow et al., 2012) with increasing evidence that it improves the quality of research studies (Staley, 2009).

The patients and carers commended the University and staff members on “embracing them as partners” (Maxwell) in their education and research activities. As commented by Marie, this isn’t something widely practised in the renal field. Again these views are perceived to represent a real achievement of the first 12 months of the KREI. However, it is important to acknowledge that there are different models (or levels) of patient and carer involvement that relate to the extent of control between professionals and patients/carers in the involvement process (Morrow et al., 2012). A widely used classification is the continuum from consultation – collaboration – user (patient and carer) control (INVOLVE, 2004).

It is acknowledged that at the beginning of the KREI the extent of involvement was primarily “consultation”, with patients and carers observing teaching sessions and providing feedback and...
giving their views on the new nursing curriculum. However, over a short period of time the level of involvement has moved towards “collaboration”, with patients and carers more actively involved in teaching sessions, co-applicants on research proposals and co-authors of this publication. Although it is important to acknowledge that staff members are still leading these activities and there remains an imbalance of power. However, as noted by Morrow et al. (2012) the different levels of involvement should not be judged as being better than another as this overlooks the fact that involvement has different purposes in different contexts. As the KREI moves forward, the level of involvement and control in the different education and research activities will need to be openly discussed and negotiated by all the members.

The patients and carers talked about how they had benefited personally from their involvement and again this is a widely reported benefit of involvement, with patients and carers gaining new knowledge and skills as well as improving their confidence and self-esteem (Morrow et al., 2012; Staley, 2009). The value of shared learning with peers was discussed and it is hoped that over time the KREI will continue to provide opportunities for the sharing of information, knowledge and personal development.

It is important to be aware of the limitations of this article. Firstly, this article has reported on a very small and qualitative evaluation of patients’ and carers’ experiences of involvement. More rigorous evaluations of patient and carer involvement in education and research activities, such as an evaluation of students’ knowledge and attitudes before and after a teaching session or course, or an evaluation of patient and carer involvement in a research study, will provide stronger evidence regarding the impact of their involvement. As the KREI activities develop, such evaluations are planned. A second limitation is that only the patients and carers were asked about their experiences of being involved in the KREI and not the academics and practitioners. As reported in the literature, “professionals” often have different motives for involving patients and carers in education and research and also report different experiences and challenges (Morrow et al., 2012; Telford & Faulkner, 2004). In any subsequent evaluation of the KREI, all members should be included in the evaluation and an independent researcher should conduct the evaluation, to provide a greater objectivity.

**Conclusion**

In this article we have discussed an exciting new initiative in renal care to develop collaborative working between patients, carers, academics and practitioners to enhance the quality of renal education and research. Patient and carer members of the KREI reflected on their experiences to date; they reported their involvement to be meaningful and to be providing the patient and carer “voice” to education and research activities. The patients and carers have valued the opportunity to influence the views and attitudes of student nurses by sharing their real-life experiences of kidney disease and treatment in teaching sessions. Personal benefits of involvement have been expressed, such as gaining new knowledge and the opportunity for shared learning.

Patient and carer involvement in renal education and research is not known to be widespread and it is hoped that the activities of the KREI will provide a model for other renal initiatives in the UK and beyond. For example, this article has been co-authored by staff and patient members of KREI; it is the first venture in writing an article together and reflects a shared ethos of collaborative working.

As the activities of the KREI develop over time, it is anticipated that the impact of patient and carer involvement will be evaluated using more rigorous methods of evaluation. As already mentioned, patient and carer members of the KREI have been influential in shaping the designs of two recent research proposals and, if successful, these studies will provide substantial projects where KREI members will be actively involved in all stages of the research process. Involvement in these research studies will provide an excellent opportunity to evaluate more comprehensively the impact of patient and carer involvement. For as commented by Staniszewska et al. (2008), demonstrating impact is an important way of measuring the success of patient and carer involvement and provides the strongest evidence that the involvement is actually making a difference.

**Acknowledgements**

We thank all the members of the KREI advisory board for their contributions to this article and enthusiasm to make positive changes for people with kidney disease.

We are grateful to the British Kidney Patient Association for the £7120 grant to establish the patient and carer advisory group within the KREI. We also thank Dr Nicola Thomas, Dr Helen Noble and Professor Alan Simpson, founding members of the KREI and the advisory group, for their support with writing this paper.

**References**


