



## Development and delivery of a diverse peer support programme for renal service users, their families and carers: an action research collaboration

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### Project background

University Hospitals Coventry and Warwickshire NHS Trust provides kidney care services for more than 3,500 adults with renal disease, from first referral throughout their renal journey. The project leader wanted to develop a multidisciplinary and service user group to unite diverse stakeholders in order to develop a peer support programme. Kidney peer support involves people with kidney disease, who have been trained to help others who are facing similar situations and who can listen to concerns and worries. This support can provide reassurance, increase confidence and help to find solutions.

### Aim

The aim of this project was to increase the range of person-centred support available to service users and carers/family members within the hospital by developing a peer support programme. To achieve this aim, participatory action research (PAR) was chosen as its cyclical nature would allow the knowledge and skills that peer educators needed to emerge, so indicating where gaps between theory and practice exist.

### Implications for practice

- Patients find peer support valuable as it enables lived experiences to be shared
- People's circumstances change over time, impacting on their commitment as peer supporters; it may be beneficial to consider this and make decisions on offering training accordingly
- It may be appropriate to train a service user to deliver peer support training and co-ordinate delivery
- A successful peer support programme requires service-wide understanding and buy-in from the start
- Collaboration with specialists across the country with an interest in peer support, through NHS England, may help to push the agenda forward

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### Key activities and outcomes

#### • Multidisciplinary and service user group

The multidisciplinary and service user group (the PAR group) was developed through invitation. Members of the renal care team already involved in the education of pre-dialysis and dialysis patients were invited to join, as were representatives of the patient population with a diverse range of experiences. Six PAR meetings lasting two hours each were held over an 18-month period, with additional meetings convened as required. The purpose of the group was to integrate the wide-ranging knowledge and experience of the participants into the development of the programme.

#### • Training peer supporters

Over the 18-month period, 10 peer supporters with diverse treatment experiences were trained by the renal advanced nurse practitioner and the researcher, using a one-day training programme developed by NHS Kidney Care, adapted to the hospital context. The hospital's voluntary services supported the day (registering people as volunteers so they could access the hospital volunteer benefits, and handling DBS checks). The training brought positive evaluations, although some patients/family members were unsure of what to expect and so were uncertain whether they had learned what they had hoped to.

#### • Use of peer supporters

Despite widespread publicity for peer support, referrals were low, coming only from advanced nurse practitioners even though feedback from patients who had been referred to a peer supporter was good – especially from those who'd had a sudden onset of renal failure ('It gives you hope that everything might be ok, when you've seen someone who's been through the same sort of thing,' one commented).

To explore the reasons for the low referral rate, a claims, concerns and issues exercise was carried out during a multidisciplinary meeting. It emerged that there was a lack of understanding about the selection and training of individuals and a fear they would provide incorrect information. The researcher and the advanced nurse practitioner were able to explain the training and selection process, the boundaries of the role and the benefits of receiving peer support. Following the CCI exercise, referrals started to come from some consultants.

#### • Evaluation of peer support programme

The use of peer supporters has been mixed. While some were regularly engaged, others were unavailable or unreliable. Those regularly engaged supported the acute start patients (for example, those requiring urgent dialysis), the pre-dialysis education day at the main unit and the education day at a satellite unit. Of those unwilling or unable to participate, some had personal issues or a change of heart or circumstances, while two patients received a transplant and returned to work so were not available.

The peer support programme was also dependent on having sufficient staff to coordinate it. Critically low levels of staffing resulted in the advanced nurse practitioner struggling to manage the peer support programme and develop new peer supporters.