You’re not alone: Peer support for people with long term conditions

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| Action required | Kidney units and care providers for other long term conditions should use the learning from this report to implement and routinely use peer support services as part of the local patient care process. |
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As both Head of Advocacy for the NKF (National Kidney Federation) and as a kidney patient since 1996 I know how much peer support means – I’ve witnessed this first-hand through other patients and felt the benefits personally with my own care. It’s therefore encouraging and thoroughly welcome to see the great work NHS Kidney Care has done in recent times reflected in this report in terms of action and review.

Peer support offers a forum where a communication exchange can take place; where the experienced patient, like a seasoned traveller can offer tips and guidance on the choices and journey a new patient may take. One benefit of peer support is that it can reflect the local needs of the kidney community and therefore be representative.

The experienced patient is important in the process and the support taps deep into human nature offering compassion and insight. For many individuals with chronic kidney disease who are attempting to tackle tough and complicated decisions around their health needs, compassion is important – the compassion brings with it caring support and the ability to share experiences.

For the individual, peer support offers an opportunity to discuss and reflect. This importantly enables individuals to acknowledge their health needs, adjust and make key decisions. Participation enables individuals to learn, grow in confidence and come away empowered with the ability to ask more questions of their doctors or nurses. In the long-term, the benefits of peer support mean that some individuals can be better placed to manage their own care. This might perhaps stimulate the confidence to become a self-caring haemodialysis patient or to have home haemodialysis.

Overall, peer support is a tool to improve the health outcomes of individual patients which surely leads to improved quality of life – something which I know every patient wants, and needs.

Without doubt, this report highlights there is still a challenge to be met within the kidney community attaining peer support throughout England. In light of the current programme of shared decision making, including patient decision aids and work on discussion maps, there are effective tools to stimulate and encourage greater individual patient involvement and peer support which is great news. It’s important that the learnt practice and support from hospital trusts continues with staff time being set aside to embed peer support into care plans. Time also needs to be set aside to liaise with the army of Kidney Patient Associations, many of which work tirelessly for their local patients. While it’s also important in terms of legacy that the partnership work of the NKF continues, it is equally important that in doing so, the wider patient voice and its needs are heard and met.

Mr Nicholas Palmer
Head of Advocacy
NKF (National Kidney Federation)
Peer support has many benefits. It can help people with chronic long term conditions adjust to their illness, make choices and alleviate fears about possible treatment options. It can also play an important part in encouraging patients to take greater responsibility for their condition.

The NHS Outcomes Framework sets out the need to drive change in this area. It commits the NHS to ensuring people with long term conditions feel supported to manage their condition, have improved functional ability and spend less time in hospital. The Mandate to the NHS Commissioning Board further sets out an expectation that the NHS will empower and support the increasing number of people living with long term conditions. Importantly it also states that far more people will have developed the knowledge, skills and confidence to manage their own health, so they can live their lives to the full. Peer support is one key way of achieving this.

In 2011 NHS Kidney Care commissioned the Kidney Care Peer Support Programme to embed peer support principles in renal units across England and to raise awareness among clinical teams about the benefit of providing peer support services to patients with kidney disease.

Two strands of work were developed; the first involved the establishment of peer support services in two of the renal network areas in England with delivery across ten trusts. This included recruiting and training peer supporters, engaging clinicians and patients and promoting the peer support services. The second strand of work was a national survey of peer support service provision in renal units across England.

This report outlines the findings of both strands of work and assesses the implications this work has, not just for kidney patients but for others with long term conditions.

The projects found that in order to set up and maintain effective peer support, the following principles help ensure success:

- **Identify motivated clinical champions** with dedicated time to co-ordinate the project locally
- **Engage with the hospital volunteer team** at the start of the project to identify the steps needed
- **Involve patients** when designing a peer support service to maximise adoption and effective implementation
- **Work closely with patient groups** and listen to their ideas and suggestions
- **Recruit a representative pool of patients and carers** from across the whole care pathway
- **Prioritise peer supporters** and accept that some may need to be matched and used more frequently than others based on their personal experience
- **Motivate volunteers** by thinking about how to creatively best use their skills and experience
- **Consider different learning styles** and personal commitments when planning training for peer supporters
- **Follow a multidisciplinary team approach** and accept that senior management support and trust acceptance is needed to help to embed the culture change necessary for sustainability
- **Establish ongoing and effective communication with key staff** to ensure appropriate referrals and team involvement
- **Evaluate the success of the project** on an ongoing basis involving both the service users and service providers.
Executive summary

The evaluation of these projects found that many aspects of establishing a peer support service are generic. They could work across multiple long term conditions and in both primary and secondary care. These include some aspects of recruitment including resource development. Training which focuses more generically on providing peer support, rather than on the specific condition could be delivered to volunteers from different long term condition areas. Such joint working would need to be supported by close integration with condition-specific clinicians who have a key role in recruiting peer supporters as well as referring or encouraging patients to use peer support services.

The findings of the national survey highlight the key role of clinicians both in recruiting patients to the service, and encouraging and enabling access. This finding is corroborated by the experience of project teams in both renal networks. They reported that clinicians are pivotal to the sustainability of the service both by ensuring active flow of referrals into the service, and ensuring the culture change necessary for embedding the service in practice. This further highlights the need to consider how peer support is marketed both to people with long term conditions and the clinicians caring for them.

The contribution of patient support groups has been underlined by this work. These groups have a role not only in supporting peer support services but in driving up the quality of support available. They can help in capturing patient stories – a compelling way of demonstrating the benefits of peer support and encouraging people to use the service or volunteer themselves.

The two networks highlighted in this report are now working with other renal networks and with other long term conditions to share their learning. Embedding peer support, both in the kidney community and across other long term conditions, has the potential to help patients live fuller lives, cope better with their condition and have significantly improved outcomes.

The potential clearly exists to build a thriving community of healthcare volunteers to help support others going through similar experiences. These projects show how the availability of a representative pool of volunteer patients and carers to carry out peer support is essential. The skills and service of the kidney peer supporters are transferable to other areas, such as cancer, diabetes, cardiac, stroke, and liver disease. A local strategy to support recruitment and training of peer support volunteers, as well as developing ways to keep all peer support volunteers motivated and engaged once trained, will give a great foundation on which to secure a sustainable future.
1. Introduction

1.1 Background

The contemporary approach to healthcare for patients with long term conditions centres around the key principles of patient involvement in decision making and the importance of self-care management. This evidence based approach will only be successful when individuals have a good understanding of their condition as well as access to any additional information and support they need to make decisions and self-manage effectively. Peer support is one important way of providing this information and support with a view to ‘enhancing quality of life for people with long term conditions’.6

In common with people living with other complex long term conditions, kidney patients have to contend with making difficult treatment decisions at the same time as they accept being chronically ill7.

Kidney peer support involves people with kidney disease and their carers helping fellow kidney patients and carers who are facing similar situations. The service complements the care and education patients and carers receive from their healthcare team by providing contact with a trained and empathetic individual who has first hand experience of chronic kidney disease (CKD). It offers the service user an opportunity to have discussions and share personal experiences and stories either face to face or over the telephone with an experienced kidney patient or carer who has similar life experiences. Peer support is not a substitute for contact with the professional team, rather it complements and enhances it. Peer support is recommended as a ‘fundamental service component’ of high quality pre-dialysis care in the UK.8

In 2011 NHS Kidney Care published a literature review of peer support across long term conditions9 to consider the effectiveness and potential relevance of peer support as a means of addressing the isolation sometimes experienced by people who dialyse at home and those who care for them. This review concluded that peer support is a valuable method of providing emotional and social support to patients, although there was not enough evidence to prove a direct impact on measured clinical outcomes. While the literature on peer support for people with long term conditions is heavily dominated by peer support for people with cancer, there are very few studies on peer support specific to dialysis or renal disease.9 One randomised controlled trial evaluating the impact of peer support on completion of advance directives found that haemodialysis patients who had received peer support intervention were four times more likely to complete an advance directive and were significantly more comfortable during related discussion than those who did not receive the intervention.10 Another qualitative study reported that most patients who received peer support felt that it was an extremely valuable intervention, helping them feel significantly less isolated and providing them with useful information and reassurance from observing another patient successfully living with kidney disease11.
1. Introduction

1.2 The NHS Kidney Care approach

NHS Kidney Care focuses on high quality affordable care for all kidney patients. The organisation develops outcome measures that improve quality for patients and help the patient voice be heard. They also prioritise the development of levers such as choice, information and commissioning to ensure that national policy is translated into reality for patients.

Central to the NHS Kidney Care approach is the concept that providing patients access to better quality care can improve patient outcomes while leaving a positive and sustainable legacy.

To achieve its goals, in 2011 NHS Kidney Care commissioned the Kidney Care Peer Support Programme to embed peer support principles in kidney units across England and to raise awareness among clinical teams about the benefit of providing peer support services to patients with kidney disease. To this end, two strands of work were developed; the first strand of work involved the establishment of peer support services in two of the renal network areas in England with delivery across ten trusts. This included recruiting and training peer supporters, engaging clinicians and patients and promoting the peer support services. The second strand of work was a national survey of peer support service provision in kidney units across England.

The idea of implementing the Kidney Care Peer Support Programme is based on the recognition that accessing peer support can be beneficial in helping patients with CKD adjust to their illness, make choices and alleviate fears about possible treatment options. It therefore plays an important role in empowering and encouraging patients to take greater responsibility for their condition, which are among the goals of the NHS Outcome Framework domains 2 and 46, the National Institute for Health and Clinical Excellence (NICE) quality standards12, the Renal National Service Framework (NSF) Part 1 Standards 1 and 2, and the NSF Part 2 Quality Requirements 43. Peer support also supports implementation of the Mandate for the NHS Commissioning Board which refers to the need to “empower and support the increasing number of people living with long term conditions”. It also states that “Far more people will have developed the knowledge, skills and confidence to manage their own health, so they can live their lives to the full”. Peer support is one key way of achieving both these outcomes. This programme of work provides an opportunity for clinical teams to engage in new and different thinking about peer support as well as adoption of the culture change required to ensure realisation of the intended benefits.

This publication draws together both the key findings from the national survey of peer support in kidney care, and the evidence and learning from the work undertaken by the two renal networks participating in the initial 12 months of the programme. The report is divided into two sections; the first section summarises the findings of the national survey. The second section is a combined report based on the ‘end of project’ reports from the NHS Kidney Care Peer Support Programme. It incorporates findings from the two renal networks; the North East Renal Network and the West Midlands Renal Network.
2. National survey of peer support in kidney care

In summer 2012 NHS Kidney Care carried out a national survey of kidney units in England to assess existing peer support provision in kidney care and identify opportunities to share learning to support the development of peer support services across the country, and for other long term conditions.

An online survey was sent by email to clinical leads and lead nurses from 52 adult kidney units in England in June 2012. The survey aimed to examine current peer support services and attitudes towards peer support in England. It was piloted by renal specialist nurses and the principle aims of the survey included:

- Creating a national database of kidney peer support services
- Enabling the sharing of peer support knowledge and resources
- Facilitating the development of beneficial peer support services available to all renal patients in the UK

2.1 Findings from the national survey

These findings reflect the provision of peer support in adult kidney units in England in July 2012. 37 out of 52 units responded to the survey, which represents a response rate of 71%. 22 of 37 responding units (59%) reported providing some form of peer support to people with kidney disease; however, the format and process of the services provided varied widely within and between the units (Figure 1). 43.5% of available peer support programmes had been established for over five years, with a further 13% established for three to four years.

Figure 1: Does your unit have any kind of peer support for patients?

*Total number of respondents, n = 37 Units
2. National survey of peer support in kidney care

Units were asked about the number of patients using their peer support programmes, and the number of peer supporters available. The most frequent response was that this information was not available, usually because of the informal nature of these programmes. Two units reported that over 100 patients had accessed peer support, and one unit had between 50 and 100 patients who have accessed peer support. Between 11 and 50 patients had accessed peer support in three units, whilst between one and ten patients had accessed support in another two units. In one unit no patients had accessed peer support at the time the survey was completed as the service was not yet fully up and running. Seven had not recorded numbers as peer support is provided informally.

With regards to available peer supporters, one unit had over 20 peer supporters, two had 11 to 20 and two had six to ten. Four units had one to five peer supporters.
2. National survey of peer support in kidney care

2.1.1 Access and recruitment

A high proportion of respondents (85.7%) indicated that patients accessed the peer support service following referral from a clinician (Figure 2). 95% of respondents indicated that clinicians will be relied on to promote the service to potential users going forward (Figure 3). These findings reflect the key role clinicians could play in embedding this service in practice.

**Figure 2: How will, or do patients access the service? (% response)**

* Total number of respondents, \(n = 21\) Units

**Figure 3: How is, or will the service be advertised to potential users? (% response)**

*Total number of respondents, \(n = 20\) Units
2. National survey of peer support in kidney care

2.1.2 Service provision

Across units, peer support is offered to patients in pre-dialysis or low clearance clinics and those patients with end-stage kidney disease. In some units support is also offered to community based dialysis patients, carers and prospective kidney donors. Peer support is offered for a wide variety of purposes (Table 1), in multiple formats (Figure 4), and over varied time-spans (from one-off encounters to on-going unrestricted ‘buddying’).

Table 1: How is peer support used to improve kidney care in your unit?

<table>
<thead>
<tr>
<th>Service aim (ranked by frequency)</th>
<th>%</th>
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<tbody>
<tr>
<td>To provide information to patients</td>
<td>95.2</td>
</tr>
<tr>
<td>To help patients make treatment decisions</td>
<td>81.0</td>
</tr>
<tr>
<td>To help patients self-manage their kidney disease more effectively</td>
<td>66.7</td>
</tr>
<tr>
<td>To provide emotional support to patients</td>
<td>65.2</td>
</tr>
<tr>
<td>To provide social support to patients</td>
<td>61.9</td>
</tr>
<tr>
<td>To provide a role for patients who wish to help other patients</td>
<td>47.6</td>
</tr>
</tbody>
</table>

*Total number of respondents, n = 20 Units

Figure 4: How is, or will the service be provided (% response)

*Total number of respondents, n = 19 Units
2. National survey of peer support in kidney care

2.1.3 Barriers to formal peer support

Perceived barriers to setting up formal peer support services were operational and included lack of staff time and uncertainty about how to go about setting up the service. They tended not to be due to a lack of interest or confidence in the value of the intervention (Figure 5). Respondents expressed significant interest in resources which might assist in overcoming these barriers such as written guidelines and contact with units already offering peer support. Only five units reported having evaluated their service.

Figure 5: Barriers to setting up formal peer support services (% response)

*Total number of respondents, n = 37 units
3. The peer support projects

In 2011, NHS Kidney Care commissioned kidney care networks in the North East and West Midlands to establish kidney peer support services in their local areas. The aim was to establish a pool of trained peer supporters within each of the networks to give short term practical, emotional and social support to people with CKD, their families or carers based upon a shared common experience. The project was informed by work in the King’s College and Guys and St Thomas’ NHS Foundation Trusts to establish a kidney peer support programme in South London. This had been set out in their ‘No White Coat between Us’ publication in 20087. Further work had also been carried out in Birmingham by the Queen Elizabeth Hospital to develop peer support services for patients with kidney disease.

The participating trusts in both the North East and West Midlands networks benefited from the learning from the work in South London and grounded their projects on the insight gained from the experiences of the team at Guys and St Thomas’ NHS Trust. The West Midlands Network was further able to learn from the local experience of the team at Queen Elizabeth Hospital in establishing a similar scheme. The peer support services developed by both the North East and West Midlands networks was open to all kidney patients; however, both networks paid particular attention to pre-dialysis patients as the experiences of others suggested that this is where there was likely to be the greatest demand.

3.1 The support

Alongside commissioning these projects, NHS Kidney Care provided a package of support to the project teams which provided them with opportunities to access specialist advice, and share experiences and knowledge with others. This was intended to ensure the long-lasting impact and success of the initiative, as well as ensuring the various projects remained motivated as they progressed towards project delivery. This support involved the input of the NHS Kidney Care Programme Lead for the Peer Support projects which provided regular coaching contact and project progress monitoring to the projects. NHS Kidney Care also set up a monthly reporting system which helped the project teams to document their progress, note key learnings and address any risks.

3.1.1 E-Seminars and learning forum

NHS Kidney Care created and facilitated a learning forum for the project which provided opportunities for the two project groups to interact with each other to share common concerns and experiences whilst deepening knowledge and expertise in the process. The learning forum took the form of regular online discussions which were held to monitor progress and facilitate sharing of learning and good practice. The forum also allowed the networks to work in collaboration with colleagues at other trusts including those in Birmingham and London.

3.1.2 Conference exhibitions and poster presentations

As an acknowledgement of the importance of the work being carried out by the project teams, NHS Kidney Care encouraged the submission of abstracts and presentation of posters in major academic and professional conferences. These presentations offered opportunities for the aims and objectives of the initiative and the variety of approaches by the individual project teams to be communicated widely.
3. The peer support projects

3.2 Project learning and outcomes

3.2.1 Overview of project coverage

The geographical distribution of the renal centres in the two renal networks participating in the programme is shown in Figure 6. The West Midlands Renal Network covers eight renal centres (seven adult centres and one children’s centre). One of the local renal centres, Queen Elizabeth Hospital Birmingham had already established a local kidney peer support service which had trained around 35 patients and carers as peer support volunteers. A strategic decision was taken in the West Midlands to implement the programme in two phases to keep the project focused and contained. The initial phase secured commitment from two units, Heart of England NHS Foundation Trust and the Royal Wolverhampton Hospitals NHS Trust. The current phase of this work involves the roll out of the service to the remaining units across the network.

The North East Renal Network covers three renal centres in Middlesbrough, Sunderland and Newcastle. The North East Peer Support programme included all three centres.

Figure 6: Geographical distribution of the renal centres participating in the programme
3. The peer support projects

3.2.2 Project engagement

Patients who were interested in becoming peer supporters were recruited by participating kidney units. In the North East, 22 individuals (including two carers) were invited to participate. 19 of the invited individuals (86%) were in the first group to complete the training in October and November 2011. A further three patients withdrew from the project due to health related issues. In addition, interested patients came forward who would like to take part in the training to become a peer supporter – this will be agreed and decided with the project leads.

In the West Midlands, a total of 26 patients and carers had been trained and successfully registered as hospital volunteers by September 2012. With those from the Queen Elizabeth Hospital, a total of 59 volunteers have now successfully trained and registered as volunteer kidney peer supporters in the area.

In both renal networks, the aim of the peer support volunteer recruitment was to include patients with a range of treatment experiences and life circumstances who would then be matched with other patients wishing to use the peer support service. While peer supporters in both project areas included patients undergoing a range of treatment modalities, both networks found that volunteer peer supporters were more likely to be drawn from the transplant population than dialysis population. This was due to the fact that post-transplant patients typically had more free time to devote to volunteer work.

A total of 13 patients had been successfully matched with peer supporters, and had made use of the peer support services as at August 2012; ten in the North East and three in the West Midlands. In addition, the North East service has also provided support to pre-dialysis open days with the peer supporters in attendance.

3.3 Common challenges and solutions

The participating units worked through a number of different challenges in order to achieve their project aims. However some common challenges and solutions have emerged which could serve as key learning points:

3.3.1 Hospital policies and procedures

Peer supporters were required by the different trusts to apply for a Criminal Records Bureau (CRB) check and also, in some cases, to undergo additional ‘volunteer’ training as a measure to ensure patient safety is maintained. These requirements caused additional delays and had a negative impact on the effectiveness of the volunteer recruitment processes. To overcome this hurdle, project leads needed to engage with human resources, local clinical governance, and volunteer managers in order to ensure their buy-in and avoid the need for an overly complicated registration process. Further, to accelerate the process and minimize delays, volunteers were encouraged to complete the CRB forms as early as possible following their recruitment.
3. The peer support projects

3.3.2 Dedicated time of a clinical champion required

To have an effective peer support service set up and embedded in practice requires active and motivated clinical champions to oversee the project. The role of the peer support champion is essential to providing an effective, efficient and safe peer support service. Without these champions, programmes are likely to become less of a priority for the units involved over time. As this will require the champion to carry out peer support services above and beyond their daily role, dedicated time is required to ensure their commitment to establish and coordinate the service and promote the programme.

The funding from NHS Kidney Care helped to secure dedicated staff time to oversee the project. This secured capacity for the service and ensured conflicting work commitments did not make the project objectives more challenging and difficult to achieve.

3.3.3 Recruitment of peer supporters

Strategies for recruiting patients and carers to the peer support programmes in the various units included posters, using the network’s patient and carer forum, using the local Kidney Patient Association and using the network’s website. However, it was often necessary for the lead nurse to personally target potential peer supporters to encourage response. The local clinical champions wrote personally to patients and carers from across the renal pathway whom they thought would make ideal peer supporters.

Another challenge was the difficulty recruiting from a wide spectrum of patients (including those undergoing haemodialysis and peritoneal dialysis) to enable the most appropriate matching of patients to peer supporters. In reality, achieving a rich pool of volunteers representing a wide range of experiences proved to be aspirational, as more transplant patients volunteered than dialysis patients.

3.3.4 Training of peer supporters

Patients need to have a clear understanding of what the peer support process entails and their involvement in the process. As patients have different learning styles it is important that the information provision should be person centred. The project teams often developed patient information about peer support in the form of leaflets and patient information boards. These were then translated into other languages.

The project teams acknowledged that peer support training needs to be delivered flexibly with consideration given to the timing and duration of training sessions to ensure the training was accessible to all the volunteers, particularly haemodialysis patients who had to work around their dialysis schedules. To this end, flexible training days were offered by the project teams.
3. The peer support projects

3.3.5 Matching peer supporters

The effectiveness of peer support depends on finding an appropriate match of experiences such as ethnicity, culture, age, treatment modality or social background. Careful matching not only gives patients access to relevant treatment experience, it also promotes identification with the peer supporter, which can help patients accept and come to terms with living with kidney disease. It proved challenging to recruit volunteers from across all these areas. An inadvertent consequence of not having a large enough pool of volunteers is that some peer supporters are used more frequently than others. This is based on matching the most appropriate peer supporter to each patient rather than on the ability of the peer supporter.

A key learning from the project has therefore been the importance of building sufficient capacity in the pool of volunteers.

3.3.6 Engagement with staff and managers and referrals into the service

Continuous engagement of staff, clinicians and managers is fundamental to the success of the project, as their participation will help to ensure a continuous flow of referrals to the service. This is necessary for sustainability. Therefore, embedding the service in renal services needs leadership, skill, determination and engagement to be successful.

The lead nurses found that to maintain a steady flow of appropriate referrals they had to continue to promote peer support to their colleagues in the kidney units in a variety of ways, including leaflets and posters, speaking at meetings and promoting the service through clinical directors to reinforce the message.
3. The peer support projects

3.4 Emerging success principles

A number of key themes have emerged across all peer support projects which have enabled the development of top tips for successfully establishing peer support services:

- Having highly motivated clinical champions with dedicated time to co-ordinate the project locally was essential to promote the service and drive up acceptance among staff and patients. Any motivated and experienced member of the kidney healthcare team can take on the clinical champion role, however they need to be given dedicated time to co-ordinate the service locally and provide training to patients, carers and colleagues.

- Engagement of the hospital volunteer team at the start of the project helps to identify the steps needed to successfully implement the peer support service locally. Each hospital has its own processes and policies for volunteer recruitment, and it is important to understand these as they can highlight particular challenges or barriers that need to be overcome.

- Involvement of patients when designing a peer support service could maximise adoption and effective implementation. Working closely with patient groups and listening to their ideas and suggestions is essential to the success of the project.

- Recruiting a representative pool of patients and carers from across the whole kidney pathway, using their skills and knowledge to the maximum, and making the service available not solely to pre-dialysis patients but to the whole of the renal community is essential for the sustainability of the project. A local strategy to support targeted recruitment of sufficient individuals with relevant qualities and experiences who are deemed suitable should be considered.

- As each peer supporter’s kidney journey is different, some may be matched and used more frequently than others based on their personal experience. It is therefore important to find ways to keep all peer support volunteers motivated and engaged once trained. It is important to think creatively how to best use the skills and experience that each peer supporter brings. There is a wealth of alternative activities they can support which can include; pre-dialysis education days, reviewing local patient information provision, and ‘meet and greet’ sessions in clinics.

- Different learning styles and personal commitments drive the need to keep the peer support training design and delivery flexible. Some peer supporters want a fast pace to the training, whilst others want to take their time. Similarly, different personal commitments mean that daytime, evening and/or weekend sessions should be considered.

- Multidisciplinary team approach, senior management support and trust acceptance could help to embed the culture change necessary for sustainability of the project.

- Establishing ongoing and effective communication with key staff to ensure appropriate referrals and team involvement in the service is imperative. Engagement of the multidisciplinary teams is essential to ensure active flow of referrals into the service, which in turn, will ensure its sustainability.

- Ongoing project evaluation is essential in ensuring that this cultural change is, and continues to be, embedded across the renal setting. The evaluation of peer support services in practice should involve both the service users and service providers.
4. Programme implications and future development

The participating projects show how renal units, and care providers for other long term conditions, could implement and routinely use peer support services as part of the local patient care process. These projects have the potential to deliver developments in care quality which will stand the test of time and have lasting positive benefits for patients and service providers.

The findings of the national survey of peer support provision in kidney units in England highlights the key role of clinicians both in recruiting patients to the service, and encouraging and enabling access. This finding is corroborated by the experience of project teams in both renal networks. They reported that clinicians are pivotal to the sustainability of the service both by ensuring active flow of referrals into the service, and ensuring the culture change necessary for embedding the service in practice. This further highlights the need to consider how peer support is marketed both to people with long term conditions and the clinicians caring for them.

The North East programme has developed a cross-unit database of trained peer supporters that allows, once adapted with the support of IT specialists and a central host, for all of the three local units involved to have shared access to a central database of trained peer supporters. This facilitates easier and more accurate matching across units as well as within units. The West Midlands programme have also agreed that the renal network will act as an enabler to cross-unit dialogue to develop a similar pool allowing sharing of trained peer supporters. The two networks are now working with other kidney care networks and with other long term conditions to share their learning.

Whilst all the peer supporters involved in the programmes reported here had experience of kidney disease, either as patients or carers, many will have other long term conditions such as vascular disease and diabetes. As trained peer supporters they could support people with other long term conditions across both primary and secondary care.

Many aspects of establishing a peer support service are generic and could be done across multiple long term conditions. These include some aspects of recruitment including resource development. Training which focuses more generically on providing peer support, rather than on the specific condition could be delivered to volunteers from different long term condition areas. Such joint working would need to be supported by close integration with condition specific clinicians who have a key role in recruiting peer supporters as well as referring or encouraging patients to use peer support services.

The contribution of patient support groups has been underlined by this work. These groups have a role not only in supporting peer support services but in driving up the quality of support available.

The participating units are putting formal evaluation measures and processes in place to capture the learning from the service development and to propose future improvements. As well as formal evaluation, there is enthusiasm in some units to capture patient stories. This can be done using video or through the patient telling their story through the use of pictures. It could be a compelling way of demonstrating the benefits of peer support and encourage people to use the service or volunteer themselves. It will also help colleagues to promote and embed peer support as a part of the service they deliver.
Embedding peer support both in the kidney community and across other long term conditions, has the potential to help patients live fuller lives, cope better with their condition and have significantly improved outcomes.

On-going and effective communication with staff to ensure appropriate referrals and team involvement in the service is imperative to ensure this takes place.

The potential clearly exists to build a thriving community of healthcare volunteers to help support others going through similar experiences. The projects have shown that the availability of a representative pool of volunteer patients and carers to carry out peer support is essential. The skills and service of the kidney peer supporters are transferable to other areas, such as cancer, cardiac, stroke and liver. A local strategy to support recruitment and training of peer support volunteers, as well as developing ways to keep all peer support volunteers motivated and engaged once trained will give a great foundation on which to secure a sustainable future.

5. Conclusion
References


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