Chronic Kidney Disease

Overcoming barriers and facilitating access to peer support for CKD patients and carers

Report to the West Midlands Specialist Renal Commissioners Project Implementation Group:
Increasing the Uptake of Home Therapies

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Section 1. Executive Summary

1.1 Introduction

This Executive Summary set out the main findings from a research study focused on exploring from a patient and carer perspective their needs, wants and expectations from peer support, and how barriers to take-up of peer support may be resolved. It was undertaken between April and September 2012 by researchers from the West Midlands Central Health Innovation Education Cluster (WMC-HIEC) with six NHS Hospital Trusts in the West Midlands.

A key finding to emerge from our WMC-HIEC consultation report ‘Increasing the Uptake of Home Therapies’ (2011) was that there may be real benefits in facilitating stronger patient and carer involvement in the design and delivery of services. Discussions with staff at Renal Units in the West Midlands during early 2012 indicated that a number of Renal Units were already developing peer role models and involving patients in pre-dialysis education to help support patient choice of renal replacement therapies including haemodialysis (HD), home haemodialysis (HHD), peritoneal dialysis (PD) and transplantation. A variety of informal and formal approaches to peer support were being used with variable levels of take-up. The West Midlands Renal Network was also in the process of establishing a telephone peer support programme.

Existing research suggests peer support is popular among renal patients who are users. Nonetheless there appears to be initial low take-up of peer support, and fewer patients participate in peer support than express an interest in using such support. Yet there is evidence that accessing peer support can be beneficial in helping patients with CKD adjust to their illness, make treatment choices, and alleviate fears about possible therapies.

There was an absence of evidence on what might be the reasons for the identified low levels of participation in renal peer support. This suggested a need for qualitative inquiry to explore the perceptions, attitudes and motivations in relation to peer support amongst renal patients and carers, and the issues (emotional, psychological, practical, organisational) that may inhibit them from taking-up peer support. Therefore the study was specifically designed to answer the following research questions:

- How do patients and carers view peer support?
- What would patients and carers ideally want to gain from peer support?
• How can any perceived problems and barriers in taking up peer support be overcome?
• How would patients and carers prefer peer support to be made available?

1.2 Method
The research study adopted a qualitative study design. It used the principles of Grounded Theory as the methodological framework. This was appropriate as little was known about the needs and perceptions of renal patients and carers regarding peer support.

Semi-structured interviews were conducted with a total of 26 patients with CKD and carers of patients with CKD (15 patients, 11 carers), at different stages along the kidney disease pathway. All the patients were receiving treatment at one of six Renal Units in the West Midlands. Since the existing evidence showed that some socio-economic groups were under-represented as participants in peer support, the research sample was purposively selected with the intention of interviewing a diverse range of patients and carers. Interviews were conducted in participant’s homes or Renal Units, dependent on participant choice, and lasted 45 to 90 minutes.

1.3 Key Findings
The findings from this research study centred on three key thematic areas. First, peer support was seen by both patients and carers to have specific attributes and benefits over and above existing support provided by family and friends. These perceptions were based on two contextual influences: informal peer support experience and identified unmet needs. The core mechanisms identified by Dennis (2003) as underpinning how peer support operates - emotional, appraisal and informational – were confirmed by this study and provided a helpful framework by which to examine and explain the perceived additional and different attributes and benefits of renal peer support.

The study identified a substantial overlap between patients and carers regarding the perceived benefits and attributes of peer support. In particular peers were thought to better understand the patient’s or carer’s own feelings and can empathise with their experience. In comparison with clinicians, peer supporters were thought to provide a ‘truer’, more rounded and insightful picture of what a particular therapy involves and how it feels. Significantly carers identified a need for peer support as much as did patients. The carers of HHD patients appeared to have particularly pressing needs to
help them adjust to their new role and responsibilities; they reported side-lining their own worries and concerns during the treatment decision making process.

Second, while informal peer support might occur naturally and is welcomed, a range of emotional and practical barriers constrain motivation to take-up more formalised support. Receptivity to peer support can vary across time and the disease trajectory and is associated with emotional readiness; patients and carers needing to overcome complex psychological hurdles such as acknowledging the need for support. For many study participants it was unfamiliar emotional territory to seek support from people outside their personal networks; not concordant with their self-image and perceptions of how to handle illness. Anticipated poor self-efficacy led some respondents to feel unable to engage in peer support. Practical barriers include limited awareness and understanding of peer support. The term ‘peer support’ did not always have meaning for people leading to a sense of exclusion.

Third, an appealing peer support relationship was described as a reciprocal sharing, rather than one-way help. Whilst many patients and carers were of the opinion they would value learning from those more experienced and established on their treatment therapy, they were resistant to being passive recipients of support. A more equal exchange is sought, involving a balance of giving and support. Establishing rapport is also considered important if the peer support encounter is to be successful; rapport being closely aligned with creating the safe and empathetic ‘place’ where sharing and exchange might take place. To better establish rapport, patients and carers wanted to be involved in choosing their own peer supporter. This was particularly important for patients (and their carers) choosing HHD as their treatment modality and may perhaps indicate a desire for a sense of greater control over their illness and treatment.

1.4 Conclusions
The study has achieved a better understanding of what patients and carers need, want and expect from peer support. It has also identified how some of the actual or perceived practical, emotional and psychological barriers to the take-up of peer support by renal patients and carers may be resolved.

Most study participants were very wary of appearing ‘needy’ or being labeled as ‘not coping’. Therefore it is important renal clinicians offer patients and carers greater ‘permission to engage’. This could be done through making peer support a constituent of the ‘menu’ of options routinely offered by staff as part of a clinical care plan. In
addition, peer support should be positively promoted on an on-going basis by renal clinicians, as suitable for any patients with CKD and their carers. Since the term 'peer support' was not universally understood, there may be a need for clearer definitions and information. Also in terms of communications, emphasis might be given to explaining how peer support encounters enable experiences to be shared and exchanged.

The study identified that receptivity and needs for peer support may vary over time, so flexibility of provision is needed. Consideration should be given to making peer support available across the CKD pathway with some choice offered in terms of timing and delivery, within the necessary constraints of clearly defined structures and boundaries. If certain peer support formats are not available locally, signposting might be used to alternative options. Creating opportunities for rapport to be built with potential peer supporters should also be considered, including initial face-to-face meetings.
Section 2. Introduction

This report presents the findings from a research study examining renal patients and carer needs and expectations from peer support. The study was undertaken by researchers from the West Midlands Central Health Innovation Education Cluster (WMC-HIEC). The WMC-HIEC is hosted by the University of Birmingham and includes arrange of stakeholders from across Birmingham and the Black Country. The WMC-HIEC aims to facilitate high quality patient services by quickly bringing the benefits of research and innovation directly to patients and by strengthening the co-ordination of education and training so that it supports a fit for purpose workforce equipped to deliver excellence.

The study was undertaken within the Chronic Kidney Disease (CKD) workstream of the WMC-HIEC. The overall aim of the WMC-HIEC CKD topic was to work in partnership with academia, industry and NHS staff in the West Midlands Renal Units for adult patients, to explore ways of increasing the uptake of home dialysis. The agreed focus was towards patients using or preparing to enter Renal Replacement Therapy (RRT). These patients would be experiencing End Stage Renal Disease (ESRD) at stage 5 of the CKD pathway.

A key finding to emerge from our WMC-HIEC consultation report ‘Increasing the Uptake of Home Therapies’ (2011) [University of Birmingham ethics approval number ERN_10-0199] was that there may be real benefits in facilitating stronger patient and carer involvement in the design and delivery of services. A number of Renal Units were already developing peer role models and involving patients in pre-dialysis education to help support patient choice of renal replacement therapies including haemodialysis (HD), home haemodialysis (HHD), peritoneal dialysis (PD) and transplantation. The West Midlands Renal Network was also in the process of establishing a telephone peer support programme.
Section 3. Context and literature review

3.1 Introduction and context
A diagnosis of renal disease can be devastating for people, creating difficult physical and emotional life changes with accompanying social, emotional and psychological problems. Provision of peer support is based on the premise that those who have been in a similar position can help support their peers in relation to both the experience and treatment of this disease. The NHS Institute for Innovation and Improvement (2008) recognises peer support as a ‘fundamental service component of high quality pre-dialysis care’. The Renal Association also recommends ‘access to expert patients’ in its clinical practice guideline for educating patients and carers for renal replacement therapy (Farrington and Warwick, 2009).


3.2 Content of the review
This summary literature review uses social science based literature published in the UK and internationally around peer support. Since only eight papers were identified covering six peer support programmes in the context of dialysis or renal disease (Brunier et al, 2002; Perry, 2005; Hughes et al 2008 and 2009; Greenhalgh, 2009; Chen et al, 2007 and 2011; Harden et al, 2012), the review covers literature on peer support for long term conditions in general. This literature is predominantly focused on support groups for people with cancer, in particular breast cancer. Few studies include the needs or perspectives of carers.

3.3 Peer support – definitions and mechanisms
Peer support is a complex, multifaceted concept with diverse meanings and characteristics dependent on the context of use. It can be delivered in a range of different ways in terms of mode, format, duration, personnel and intended outcomes. Nonetheless, peer support interventions within the context of care for long term
conditions generally have the objective of providing support based on sharing of experience and information, and mutual exchange, among peers with the same chronic condition.

Mead et al (2001) developed a definition of peer support in respect of mental health as being “a system of giving and receiving help founded on the key principles of respect, shared responsibility, and a mutual agreement of what is helpful”. Perry et al (2005) described peer mentoring for long-term dialysis patients as, “an important people-to-people method (that involves) training of selected patients to support and empower other patients.” Woolacottt et al (2006) emphasised some of the same components when outlining the key characteristics of self care support networks as having “limited health professional involvement and the aim of the group is not purely to educate or train, but rather to support giving and receiving advice and practical help to other network members.” A similar but more comprehensive definition by Dennis (2003) has been widely used in the literature on peer support: “the provision of emotional, appraisal and informational assistance by a created social network member who possesses experiential knowledge of a specific behaviour or stressor and similar characteristics as the target population.”

Formal peer support differs from the informal in that it involves creating specific roles taken up by people who have completed training, and performing a clearly defined role. The primary initial qualification of those being trained is experience of the same condition. With few exceptions, peer support is rarely described or considered for use in relation to patients with co-morbidities (Wu et al, 2012).

In essence, the core mechanisms underlying how peer support operates are as described in the definition of peer support by Dennis (2003) – emotional, appraisal and informational. In more detail, emotional support involves expressions of empathy, caring, encouragement, reflection, attentive listening and reassurance between patients. There is usually an absence of criticism. As a consequence there is generally enhanced self-confidence and self-esteem, and a reduction in negative feelings. Rudy et al (2002) described this as facilitative and ‘nurturant’ support.

Appraisal support is based on affirming the appropriateness of a peer’s feelings, emotions and behaviours; encouraging optimism and positive expectations; and providing reassurance that problems and frustrations can be effectively dealt with.
Informational support involves the provision of knowledge relevant to problem-solving, including information about resources and options for action, thereby increasing coping skills. Helgeson et al (2000) suggested that sense of control over the illness experience may also be enhanced.

Professional-led rather than peer-led support groups may include additional components such as skills training or education related to the support function. For example, sessions on managing medications or stress (Doull et al, 2005).

### 3.4 Peer influences on treatment decision making

Several studies identify the strong influence that other patients’ experiences can have on renal patients in relation to treatment choices. A systematic review by Morton et al (2010) reported how patients could be inspired to carry out dialysis themselves through a process of imagining themselves in a similar position to another patient with whom they have spoken. The review of 18 qualitative studies, 14 of which focused on preferences for dialysis modality, also found that some patients dismissed a particular therapy because of complications experienced by someone else. As a consequence it was felt peers may have been more influential than clinicians in the decision making process. A conclusion of the review was that peer influence is a powerful and persuasive method for patients to gain knowledge of their treatment options, since meeting other patients and listening to their experiences helped patients and their carers to conceptualise the reality of those options. Therefore it was felt patient care could be improved through the formal incorporation of peers with chronic kidney disease (CKD) as mentors or educators into the ‘orientation’ of new patients to the renal unit.

Similarly, a small-scale qualitative study undertaken among 9 pre-dialysis patients by Tweed and Caeser (2005) identified the strong influence of other patients who came to speak to them about treatment options. Peer comparison was used by the patients to help them make decisions, often through instilling optimism that they would be able to cope with their future treatment.

An interesting retrospective study recently reported in the American Journal of Kidney Disease by Liebman et al (2012) showed that many patients start dialysis with HD, despite choosing PD as their modality of choice and only a minority of patients transition to PD. The study involved 227 incident dialysis patients who had all received dialysis modality education at a single centre in the USA. Of the 124 patients who
chose PD at the time of education, only 59 started dialysis therapy with PD, and 65 started with HD. The researchers found few predictors of this mismatch between dialysis choice and treatment take-up and suggested peer influence may explain some of the discrepancy. Hearing about a particularly good or bad experience with a particular dialysis modality, after dialysis modality education, was thought to have possibly caused patients to change their initial decision. Although the study did not collect data on whether patients knew and/or sought input from current dialysis patients.

A systematic review of the evidence about persuasiveness of narrative information by Winterbottom et al (2008) found information presented in the first person (for example, the patient’s account) was more than twice as likely to influence other people’s choices than information presented in the third person (for example, the doctor talking about the patient’s experience). A total of 17 studies were included in the evaluation, the majority (59 per cent) of these studies employed third person narration, and 41 per cent first person narration. The authors argued that these findings applied to the CKD context would mean patients new to dialysis modality decisions, making their choice by judging another patient and/or their experience rather than engaging systematically with the extensive dialysis modality information provided by renal services.

A more recent paper by Winterbottom et al (2012) reported on two studies comparing the impact of patient and doctor stories on hypothetical dialysis modality choices among an experimental population. 1,694 participants in total viewed online information about haemodialysis and continuous cycling peritoneal dialysis and completed a questionnaire. In one study using actors, treatment information was varied by presenter, order of presenter and mode of delivery. In the second study also using actors, information was varied by presenter, order of presenter, inclusion of a decision table, and sex of the ‘patient’ and ‘doctor’. Results from the study showed that participants were more likely to choose the dialysis modality presented by the patient. The researchers did not view these findings positively and recommended renal services be cautious in terms of using patient stories about dialysis, to support patient decision making. They argued there is risk that CKD patients making dialysis decisions on the basis of another patient/s’ opinions and experiences will use heuristic processing – a quick intuitive approach focusing only on a subsection of the choice details – and not systematically evaluate all the pros and cons.

Interestingly Winterbottom et al (2011) make a distinction between the role that patients play through peer support and their role in treatment decision making. Whilst
acknowledging the benefits of ‘expert’ patients in terms of helping other patients to cope and adjust to their illness, they argue that patients should make a dialysis choice based on their own values and judgements, not those of other patients.

Other studies argue the importance of peer support in enabling patients to make such choices. A non-peer reviewed study by Elias (2008) suggested strategies such as peer mentors are needed to help pre-dialysis patients make decisions and come to terms with the consequences of those decisions. The small-scale qualitative study explored the experiences of 14 patients from a pre-dialysis clinic in London when making decisions about renal replacement therapy. Elias found information alone was not sufficient to enable patients to make decisions since most of those interviewed were still struggling to come to terms with the consequences of having kidney disease, resulting in a reluctance to engage with decisions about treatment. Significantly this was not because of a perceived lack of information. It was suggested supplementary use of peer mentors could make information-giving more relevant and useful.

Most of the renal patients interviewed in a qualitative study conducted by Hughes et al (2009) were actively seeking specific information to help them reach decisions about treatment and approached the peer support encounter with this in mind. The study involved semi-structured telephone interviews with 20 people from two Renal Units in London, UK who had received peer support in a previous 9 month period. The peer support service was designed to help patients at the stage of adapting to chronic illness and making treatment choices. It was set up as an additional service available to patients and carers who wanted it, complementary to care and education provided by professionals, and managed by link nurses in each unit who matched each patient with a suitable peer supporter. These were volunteer patients who had been trained and prepared for the role. The service was accessed by a patient contacting the link nurse directly or being referred by a clinician. Patients were offered one or two individual meetings or telephone conversations providing information and short-term emotional support.

Findings from the study showed that in most cases participants had already formed a clear preference for a particular treatment therapy and sought a peer supporter’s experience to confirm it would be right for them. A few participants had been undecided between PD and HD and for them meeting a peer supporter with experience of both types of treatment had helped them come to a decision. Respondents valued the
explanations for being given in lay terms and the opportunity to hear about the ‘lived experience’ which they appreciated for its authenticity.

3.5. Peer support theory

Some researchers note the absence of theoretical models underpinning trials of peer support programmes (Dennis, 2003; Campbell, 2004). However, there is a good body of literature on the theoretical processes that help explain why peer support may be beneficial, as discussed below. Understanding these concepts is important in the design, development and evaluation of peer support interventions.

Social support is an important component of peer support. Social support has been defined as information leading a person to believe they are cared for, loved, esteemed and valued, and that they belong to a network of communication and mutual obligation (Cobb, 1976). In the face of a stressor, social support from others can provide practical solutions that directly address or remove the source of stress, or they may be able to provide emotional relief from the stress through empathetic concern and distraction (Proudfoot et al, 2012). It is not only through actual support that people benefit though, but the belief that support is available. Kimmel (2001 and 2002) reported that patient perceptions of increased social support correlated with less depression and greater satisfaction with life.

The beneficial impacts of social support appear to be effected in one of three ways: a direct effect, a buffering effect, or a mediating effect. The direct effect model is based on influencing and promoting positive health behaviours through peer supporters providing advice, role models and encouragement (Berkman, 1985; Bloom, 1990). This model posits that peer support directly influences health outcomes through various mechanisms (Dennis, 2003). These include decreasing isolation and feelings of loneliness; influencing health practices and deterring inappropriate behaviours or responses; promoting positive psychological states and individual motivation; providing information regarding access to medical services or the benefits of behaviours that positively influence health and wellbeing; and preventing the risk or progression of, and recovery from physical illness (Rook, 1990; Cohen 2000 and 2003; Dennis, 2003).

The buffering model, based on Lazarus and Folkman’s stress, appraisal and coping theory (1984), proposes that peer support protects individuals from potentially harmful influences of stressful events. The coping process incorporates the combined goals of problem-resolution and emotion-regulation while utilising affective, cognitive and
behavioural response systems. One way this operates is through support group participants learning and modelling coping skills from other participants and as they do so, building confidence in their ability to cope and enhancing their sense of self-efficacy. In choosing, performing and maintaining a particular behaviour, individuals weigh four sources of self-efficacy information: previous attempts at performing the behaviour, observation of peers, encouragement from influential others, and physiological responses such as fatigue, stress and anxiety (Bandura, 1977 and 2004).

The mediating effect model predicts that peer support acts as an intervening variable indirectly influencing health through emotions, cognitions and behaviours (Stewart and Tilden, 1995). Within this model peer relationships can indirectly influence health through assisting in the interpretation and positive reinforcement of a person's accomplishments; providing role modelling; and, teaching coping strategies and conveying information about ability (Dennis, 2003).

Social comparison theory has also been used to explain how peer support operates. This model based on the work of Festinger (1954) claims that under conditions of threat, people are motivated to seek the company of others in order to compare the appropriateness of their thoughts, feelings and behaviours. In particular, they are motivated to compare themselves with peers who face the same or similar circumstances. As they discover these peers share comparable feelings and thoughts, they experience a normalising effect (Gottlieb and Wachala, 2006). This self evaluation and comparison process may then lead to a decrease in uncertainty and anxiety (Dunn et al, 1999).

Research has identified that people can engage in upward, downward or lateral comparisons with similar peers. For example, they may look upward to someone who appears to be coping better than they are so they can learn from that person. These social comparisons tend to be private and can be quite powerful in their effects on mood and self-evaluation (Buunk et al, 1990).

Another underlying theory as to how peer support brings benefits is the helper therapy principle. Based on research by Riessman (1965) this principle maintains that people gain good feelings about themselves when they can be useful to others by providing, not just receiving support. According to Skovholt (1974) the benefits derived from helping others include an enhanced sense of interpersonal competence from impacting on another’s life, the ability to receive personalised feedback from working with others,
and an improved sense of self and personal value that results from the social approval received by those helped. Participating in peer support groups provides the opportunity to be such a ‘helper’.

**Experiential knowledge** provides a further theoretical mechanism underpinning peer support. Peer supporters are able to provide advice grounded in experiential knowledge that is typically more practical than advice based solely on clinical knowledge (Walsh and Connelly, 1996). They can share their experience and clearly convey information using ‘patient talk’ – using lay terms, actual feelings and personal experiences – rather than the medical terminology of clinicians. Through providing understandable, practical strategies peer supporters may be able to help patients navigate the lifestyle changes required to manage their illness (Proudfoot, 2012).

**Optimal matching theory** is less favoured in the literature but suggests illness creates the need for social support in many different areas including physical needs, relationships and finances. Delivering 'need specific support' therefore offers maximum adjustment (Cutrona, 1990). This theory would suggest people seeking informational support will not benefit from emotional support and *vice versa*. Campbell et al (2004) argues that matching theory may explain why different types of peer support are sought, for example by ethnic minorities, men and women.

### 3.6 Impacts and outcomes

There is inconclusive evidence to demonstrate the effectiveness of peer support in terms of beneficial physical and mental health outcomes. Evidence from studies among renal patients is generally positive but insubstantial. It is also difficult to isolate the effects of peer support from the combination of other interventions being measured in several of the available studies.

The more substantive body of evidence on evaluations of peer support for other long term conditions, particularly cancer, shows conflicting results. Some studies report positive outcomes and others fail to find measurable benefits or show negative results. Yet there is some evidence peer support is perceived by patients themselves to have distinctive benefits. Whilst this evidence is predominantly from small-scale, qualitative and non-controlled studies that have focused on the patients’ perspective, these studies indicate there might be general health and wellbeing benefits perceptually associated with peer support. It is also notable that some individual studies reporting on both descriptive and quantitative outcomes reveal positive comments from participants, but
contradictory quantitative findings of only small, non-existent or negative results. This raises the question as to whether the methodologies used to determine peer support effectiveness would be enhanced by giving more focus to the patient (and carer) dimension.

3.6.1. Outcomes among renal patients

Whilst the evidence base is insufficiently robust and substantive, there is some evidence of positive outcomes from studies of peer support among renal patients. A controlled randomised intervention study conducted among dialysis patients in the USA by Perry et al (2005) found that communicating information on advance directives (ADs) through peer mentoring significantly influenced the completion of ADs. End-of-life education, by offering ADs, being mandatory for all patients admitted to Medicare-participating hospitals in the USA. 280 dialysis patients aged over 18 years, from 21 dialysis units across a single state, were recruited to the study. 38 per cent of patients were African American and 62 per cent white. Patients were randomly assigned to receive AD information in one of three ways: through a peer mentoring intervention, through printed material, or only through routine means provided by the dialysis unit. A survey was undertaken at baseline and follow-up, 2 to 4 months later, measuring several psychosocial variables – depression, subjective well-being, death acceptance, anxiety and suicidal thinking. During the 2-4 months study period, patients assigned to receive the peer intervention were contacted by peers on 8 occasions, including 5 telephone contacts and 3 face-to-face meetings. Discussion between peer and patient was structured to cover specific subjects including the value of AD completion, reasons patients might be concerned or worried about filling out an AD, what makes life worthwhile, what gave patient and peer strength during hard times, and the value of contributing to others.

Results from the study showed that communicating information on ADs through peer mentoring significantly influenced completion, compared with distributing standard printed material or no specific designed intervention. Interestingly the influence was most prominent among African Americans, not only increasing actual completion of ADs and comfort discussing ADs, but also improving subjective well-being and anxiety during the study period. These effects of peer mentoring did not appear among white patients, although printed material on ADs decreased reported suicidal intention. On the basis of these findings the researchers conclude that peer mentoring, ‘a relationship-centred person-to-person approach’, may be more effective in some cultural groups because of its oral, rather than written, traditions. However there are some
methodological weaknesses associated with this study, notably the short duration of the intervention and conduct of the follow-up survey after only 2-4 months.

Peer support is an integral part of a new integrated paediatric-adult clinical service in Oxford, UK for young adult patients with kidney failure, the impacts of which were surveyed in a before and after study by Harden et al (2012). The study demonstrated the significant positive impact the clinic had on patient adherence to regular medication and engagement with healthcare providers, as judged by reduced transplant failure rates. It is not possible though to isolate the specific effects of peer support from the effects of the overall intervention. The study compared the clinical outcomes of patients transferring in 2006-2011 through a new integrated service, with those of a historical set of patients transferred directly to the adult renal service in 2000-2005. The former patient group contained 12 paediatric transplant recipients with a median age of 17.5 years. The latter patient group contained 9 patients with functioning kidney transplants, median age 18 years.

Part of the intervention involved the establishment of a dedicated young adult clinic in the adult Renal Unit, bringing together patients with advanced CKD or receiving renal replacement therapy. The clinic was initially held in the adult hospital out-patient department, but was judged only to have partial success because of limited peer interaction which was hampered by the hospital environment. Therefore in 2008 the clinic was moved out of the hospital into a student college and sports centre where it is held every six weeks. The objective was to develop a natural young adult environment mirroring a youth club, to catalyse peer interaction between all patients. The addition of a youth worker acts as a bridge between clinicians and patients. Results from the study revealed that in the historical control group, 6 of 9 patients developed transplant failure at a median of 40 months after transfer to adult care. In the intervention group, there were no transplant failures at a median follow-up of 26 months after transfer. Late acute rejection occurred in 33 per cent of the control group and none in the intervention group. The researchers suggested that support from a youth worker, and interaction with peers in a similar medical situation, can help young adult patients overcome issues faced by managing a chronic illness while going through the challenges of adolescence.

Peer support also appears to be popular among renal patients. The qualitative study conducted by Hughes et al (2009) showed that the majority of renal patients were positive about their experience of peer support. The study identified several key benefits of peer support. First, being able to talk to someone ‘who’s gone through what
you’re going through’, who could sympathetically listen and empathise. Second, being reassured or encouraged and gaining in confidence, leading to greater sense of control. For some this came from the provision of practical information, for others it came from knowing ‘I wasn’t on my own.’ Third, access to practical information based on the lived experience of treatment for kidney disease, information not available from clinicians. Participants also appreciated this information being conveyed in lay terms. Fourth, help in adjusting to chronic illness and coming to terms with starting treatment. Fifth, help making or confirming treatment decisions.

It is interesting to note that for the majority of patients involved in the study, these benefits were experienced after just one short meeting with a peer supporter. Respondents’ accounts of the process indicated they were adept at directing this encounter so the peer supporter addressed their specific needs for information and emotional support. This led the researchers to suggest the popularity and perceived value of peer support among users may have some association with the control users have over when, how and for what purpose they call on peer support. Also to the flexibility of peer supporters in providing an immediate and appropriate response to individual user-defined needs.

A small-scale prospective RCT conducted in Taiwan by Chen et al (2011) examined the impact of a self-management support programme, including peer support, among late-stage CKD patients. Although the study findings indicated the self-management programme may slow renal progression and reduce hospitalisation, it is not possible to separately assess the effects of peer support from those of the overall programme. The study involved 54 incidental pre-dialysis CKD patients aged 18 years and over from a single renal outpatient clinic. 27 patients were randomised into an intervention group and the same number into a control group. The self-management support intervention included: provision of health information from clinicians; clinician-led patient education on CKD self-management; telephone-based clinician support; and a clinician-led peer support group held twice a month. The control group received standard care from the same clinicians but no self-management support.

Patients were followed-up over 12 months. Renal function measurements took place prospectively at monthly intervals over this period. To evaluate CKD progression, laboratory data at inclusion, 6 months, and 12 months were compared. Data on CKD-related hospitalisation was also analysed. Results showed that rates of renal progression were significantly lower, and hospitalisation events significantly fewer
among patients in the intervention group as compared with the control group. The intervention had no significant effect however on all-cause mortality, or the number of patients entering dialysis therapy.

An earlier study by Chen et al (2007) reported significantly improved outcomes among HD patients who participated in a mutual support group. The study sample involved only 15 patients, recruited to a newly established support group that met a total of 8 times over 3 months. Group participants completed a questionnaire prior to starting the course and two weeks after the sessions ended. The questionnaire measured three outcomes: physical symptoms, social support and quality of life. Significant improvements were shown across all these areas. Nonetheless, the findings should be treated with caution since the study has several notable methodological flaws: low sample size, no control group for comparison, no further follow-up beyond 2 weeks, and the study questionnaire used non-validated measurement scales.

### 3.6.2. Outcomes among patients with other long term conditions

Turning to the more substantive evidence on peer support for other long term conditions, impacts and outcomes show conflicting results. Some studies report positive outcomes and others fail to find measurable benefits or show negative results. Although descriptive studies generally report positive feelings about peer support from among participants.

A Cochrane systematic review carried out by Dale et al (2008), assessed the evidence of peer support telephone-delivered interventions on improving physical, psychological, behavioural and other health outcomes of patients and carers. Results showed some positive impacts and no evidence of negative impacts from the interventions. Yet several studies found no beneficial impacts. Seven RCTs were included in the review. All the RCTs involved peer support telephone interventions based on verbal communication, where the peer was someone selected to provide support because they had similar or relevant health experience. In all studies the intervention was delivered by telephone to participants in their own home. Five of the studies compared a peer telephone intervention against a control arm receiving usual care or no intervention. Two of the studies had an additional third arm based on professional telephone support. All but one of the studies reported that peer supporters received some training. A wide range of conditions were covered by the studies, and there was considerable variation in the outcomes measured.
Dale et al reported that none of the studies found any differences over time between intervention and control groups, in physical health outcomes, self-efficacy or quality of life. There was some evidence of effectiveness in terms of reducing potential depressive symptoms among mothers with postnatal depression and of improved behavioural health outcomes in terms of: encouraging dietary change in patients after myocardial infarction, greater continuation of breastfeeding in mothers with newborn babies, and prolonging regular mammography screening in women over 40 years of age. The researchers used Dennis’s categories of emotional, appraisal and information support (Dennis, 2003) to analyse the type of peer support provided by the different studies. On this basis, studies that included informational support (with or without appraisal support and emotional support) were found to be more effective than those without any informational support.

A systematic review of studies evaluating cancer support programmes from 1980-2002, undertaken by Campbell et al (2004), identified consistent informational, emotional and educational benefits from ‘real life’ peer support. It should however be noted that the researchers assessed the evidence as being of only moderate quality, given a general lack of methodological rigour and use of non-validated outcome measures. A total of 21 papers were included in the review, reporting on 17 different peer support programmes provided by peers. Studies that evaluated “real-life” peer support as opposed to that provided in RCTs showed positive benefits. The non-RCTs revealed high participant satisfaction, although low response rates and lack of feedback from non-respondents and drop-outs suggests this may be a highly biased assessment. All the evaluated programmes included educational or informational support, and both men and women were found to have a better understanding of the cancer experience and to be better informed as a result of receiving peer support. Hope, encouragement and reassurance were common emotional benefits described in virtually all of the peer support programs. Telephone and Internet support programs were reported to be particularly beneficial to patients with less common forms of cancer, to homebound patients, to geographically distant patients and to those desiring privacy.

The three RCTs included in the review did not show such benefits and there was no evidence of improved quality of life. The larger and more robust RCT undertaken by Helgeson (2000, 2001) nonetheless highlighted some noteworthy short and long-term differences. The study involved 230 women in the USA recently diagnosed with breast cancer who were randomly allocated to groups that provided either education alone, education with peer discussion, only peer discussion, or a control group with no
intervention. The education group provided expert information, with interchanges among women limited, to avoid contamination with the peer discussion intervention. Peer discussion groups were facilitated to focus on positive and negative feelings, and self-disclosure. The combined group started with education and ended with discussion. Six months post-intervention results showed diminished mental health and physical functioning, and fairly strong negative effect, in the peer group compared to no peer discussion group. Only a sub-group of women benefited from the peer discussion group – those who lacked emotional support from their partners, or who reported more negative interactions with their partners. Conversely women who started out satisfied with the level of emotional support received from their partner, deteriorated over time in physical functioning. Whereas at 3 years follow-up these negative affects had disappeared and all groups, including those in peer support, were recorded as having moderate but not significant improvements in vitality, social functioning and mental health.

In consideration of these findings, Campbell et al (2004) suggested that while formative evaluations may focus on participant satisfaction, programme delivery and short-term benefits, improved psychological and physical health may appear much later, supporting the need for long-term follow-up. Although the researchers noted that all the interventions studied in the RCTs were set up for the purpose of evaluation, and may not be representative of real support groups.

A wide ranging systematic review by Woolacott et al (2006) of the clinical effectiveness of patient and carer self care support networks, found some evidence for a beneficial effect, but the data was of insufficient quality to draw firm conclusions. The researchers reviewed 46 studies of health and social care support networks. The majority of these studies, even the RCTs, were found to be of poor quality. Findings from the more robust studies suggested some self care networks in certain settings can be beneficial. However since these studies comprised a trial of weight watchers, three trials of carers in Hong Kong, and one of a TB club in Ethiopia, the researchers felt the findings had limited applicability to the UK healthcare environment.

A systematic review undertaken by Hoey et al (2008), reported high levels of satisfaction with cancer peer-support programmes, whilst evidence for psychosocial benefit was mixed. In total 43 research papers were reviewed that included data from at least one peer support programme for people with cancer. Most of the research was reported in descriptive studies, with only 10 papers reporting on 8 RCTs. The majority
Overall results from the descriptive studies indicated strong appreciation of the peer support experience and some perceived psychosocial benefits associated with peer support. Regardless of the way peer support was delivered, having contact with other people with cancer was found to assist cancer patients in practical, social and emotional ways. Four papers reporting on RCTs (Gustafson et al, 2001; Rudy et al, 2001; Weber et al, 2004; Vos et al, 2004) found increases in perceived social support among the intervention group, and three papers (Huts et al, 1986; Rudy et al, 2001; Lieberman et al, 2003) found improvements on some psychosocial outcomes either during or post-intervention. Improved psychosocial functioning was reported for a one on one face-to-face peer support model and group Internet model. Three RCTs (Jacobs et al, 1983; Helgeson et al, 1999; Helgeson et al, 2000) found no significant effect of peer support on health-related quality of life or psychosocial distress. On the basis of these findings the researchers tentatively recommended that in respect of peer support models, priority be given to one on one face-to-face and group Internet peer support.

In comparison, an evaluation conducted by Eysenbach et al (2004) found no robust evidence of positive effects on health and social outcomes of computer based peer to peer communities and electronic self support groups. A total of 38 studies were evaluated in Eysenbach’s (2004) study: 20 of which were RCTs, and 11 before and after studies. The researchers proposed that lack of identified effect was partly a result of most communities of this nature having been evaluated only in conjunction with more complex interventions, or involvement with health professionals. Nonetheless they found some interventions did show an effect and in only two of the evaluated studies was the control favourable over the virtual community in terms of health outcome. In some studies an association between greater use of peer to peer groups and better outcomes was observed, but the direction of causation (whether increased use led to better outcomes or an improvement in outcomes such as depression due to other factors led to increased use) was not clear.

Gottlieb and Wachala (2006) also identified peer support as being highly popular among cancer patients. They reviewed 44 empirical studies of professionally-led cancer support groups that included both RCTs and descriptive, cross-sectional, non-
experimental studies. The reviewed studies were confined to face-to-face support groups led by one or more professionals (nurses, physicians, mental health specialists and social workers), rather than by peers. Participants tended to view the emotional support, and experiential and expert knowledge, as the most helpful elements of the group experience. They reported feeling less alone, better understood and more hopeful following their group experience and that they wanted their group to continue beyond the final session. Outcome evaluations revealed improvements in mental health and psychological functioning, but methodologically these findings were not convincing.

Solomon (2004) in assessing the literature on peer support for people with a mental health condition could find only non-robust evidence of positive benefits. Evidence based largely on uncontrolled studies suggested peer support improved symptoms, increased participants’ social functioning and social networks, and enhanced their quality of life.

A more recent review of the literature on peer support workers employed in mental health services by Repper and Carter (2011), identified some weak evidence of improvements on a range of issues that can impact on the lives of people with mental health problems. Papers were included in the review if linked to studies on peers offering support for people with mental health problems, and working in statutory or professionally-led services. Many of the studies were qualitative, and often had small sample sizes and descriptive cross-sectional or longitudinal designs. Only 7 of the included studies were RCTs. The RCTs presented inconsistent findings and used varied outcome measures. There was no robust evidence that peer support workers made any difference to mental health outcomes of people using the services. When a broader range of studies were included (follow-up studies, naturalistic comparison studies, and qualitative studies) the benefits of peer support workers were more apparent. Findings indicated that what peer support workers were able to do more successfully than professional staff is first, promote hope and belief in the possibility of recovery. Second, promote and increased self-esteem, self-efficacy and self-management of difficulties; and social inclusion, engagement and increased social networks. The researchers noted that these were outcomes people with lived experience of mental health difficulties have associated with their own recovery. In conclusion they argued that peer support offers distinctive beneficial features not currently provided by professional staff – support based on experience rather than professional expertise, more reciprocal relationships, and more egalitarian conversations.
Miyamoto and Sono (2012) found many qualitative studies reported the importance of peers as positive role models of recovery among people with mental health difficulties. Notably service users mentioned feeling respect, humanity and trust in terms of their engagement with peer supporters.

A recent meta-analysis by Pfeiffer et al (2011) revealed that peer support interventions for depression resulted in greater improvement in depression symptoms than usual care. However, the researchers themselves questioned the reliability of these findings given the poor evidence base, in particular heterogeneity in the peer support participants and interventions. The meta-analysis included ten RCTs. Three trials compared peer support to usual care, two trials compared peer support to cognitive behaviour therapy (CBT) and five trials compared peer support to both usual care and CBT. In the majority (seven) studies, peer support was associated with a statistically significant reduction in depressive symptoms when compared with usual care. There was no evidence of significant difference in depression outcomes between peer support and CBT. The researchers concluded that peer support may have similar efficacy to group CBT in improving depression symptoms.

Finally, whilst not specifically peer support, it is useful to consider evidence relating to lay-led education and expert patient programmes (EPP). A Cochrane review by Foster et al (2009) of RCTs on lay-led self-management education programmes, including the EPP, identified small, statistically significant, short-term improvements in participants self-efficacy, self-rated health and cognitive symptom management. 17 RCTs were reviewed in total, the interventions being defined for the purposes of the review as structured programmes for people with chronic conditions that were primarily educational, primarily addressing self-management of disease and where the majority of the course was delivered by lay people. There was no evidence though, that such programmes improve psychological health, symptoms, or health-related quality of life, or significantly alter healthcare use, at six-month follow-up.

The two-arm pragmatic RCT used to evaluate the EPP in community settings in England by Kennedy et al (2007), reported significant improvements in self-efficacy and self-reported energy. A total of 629 patients with a wide range of self-defined chronic long term conditions were involved in the study. 313 were randomly assigned to the intervention group, and 316 to the waiting-list control group. The intervention cohort participated in 6 weekly, lay-led group sessions to teach self care skills. The sessions
covered learning relaxation; better breathing; healthy eating and nutrition; exercise; how to build levels of fitness, flexibility and strength; how to communicate more effectively, make informed decisions, use problems solving skills, work with health care professionals, and deal with anger, fear, frustration, isolation, fatigue and depression. Patients in the control group were on a waiting-list to access the intervention after 6 months. Primary outcomes measured were self-efficacy, reported energy and routine health utilisation at six months. Secondary outcomes included psychological wellbeing and measures of self-care behaviour. All measures were collected at baseline and 6 months from randomisation. Health related quality of life was measured using the EuroQol. Results for the primary outcomes showed higher scores among the intervention group than among the control group for overall self-efficacy and energy, but no reported differences in healthcare utilisation. As a secondary outcome, the intervention group reported marginally significant better psychological wellbeing scores than the control group.

3.6.3 Benefits of being a peer supporter

In addition to studies on the effectiveness of peer support on the recipient there is some evidence of positive effects for the provider. An exploratory study using a longitudinal design, conducted in Canada by Brunier et al (2002), found no quantitative evidence of change in psychological wellbeing among peer support volunteers, although qualitative responses suggested beneficial outcomes. The study involved a small sample of 31 peer support volunteers, patients with end stage renal disease (ESRD) or their family members, who had graduated over a two-year period from three Kidney Foundation of Canada Peer Support Volunteer Training Programmes. Over the one-year study period the volunteers were matched to ESRD patients by peer support coordinators, with each volunteer seeing on average five patients.

Information on the psychological wellbeing of the volunteers was collected using both quantitative and qualitative measures. Their level of psychological wellbeing was measured by the Mental Health Inventory. At the first qualitative interview the volunteers were asked open-ended questions as to why they were interested in being a peer support volunteer. At each of three subsequent interviews they were asked a second set of open-ended questions about what it was like for them at that time as volunteers. Quantitative results from the study showed that the volunteers’ levels of psychological distress and wellbeing remained stable over the year whilst the qualitative findings revealed some positive changes. The volunteers said they had formed very strong supportive relationships with one another. Some volunteers also
reported they had been able to come to terms with their illness through being a volunteer. Furthermore many participants identified with how they themselves benefited from counselling others, and felt fulfilled and satisfied with their role.

Studies by Schwartz et al (1999) and Arnstein et al (2002) reported beneficial effects in relation to peer supporters with other chronic disease conditions. However being a peer supporter has also been found to present significant challenges including becoming too emotionally involved, having significant extra responsibilities, and feeling the inconvenience of extra effort when dealing with their own illness (Arnstein et al, 2002).

3.7 Risks
Little attention has been given to the negative effects of peer support. Patients who drop out of peer support programmes are rarely followed-up to understand the reasons why this happened; despite attrition rates often being high (see section 1.8). There has also been limited examination of any unintended consequences. Yet receiving support can be associated with increased distress and has the potential to be a threat to self-esteem when it elicits feelings such as inferiority, dependence, failure and powerlessness (Barrera, 1986).

There is some available evidence of risks associated with peer support. Campbell et al (2004) reported several difficulties experienced in support groups that may impact negatively on participants, including upsetting discussions, member conflicts and difficulty dealing with member death. Gottlieb and Wachala (2007) drew attention to the risk that support group participants may drop-out if they sense their existing family/friends network do not approve of this helping arrangement, disagree with the information and viewpoints of group participants, or feel threatened by accounts of the group’s discussion. They also highlighted a potential risk of support group discussions drawing attention to problems not previously considered or not considered problems, resulting in participants feeling more distressed. Doull et al (2005) raised the issue that participation in peer support programmes may carry with it the potential effect of stigma.

In addition, several studies have found adverse outcomes from peer support. These include failed social attempts, reinforcement of poor behaviours, and diminished feelings of self-efficacy (Dennis, 2003; Gises Davis, 2006).

Furthermore, it is important to recognise that peer support may not suit everyone. Among the renal patients interviewed by Hughes et al (2009), a minority reported
negative experiences of receiving individual peer support. They described being made anxious and frightened by meeting a peer supporter. The researchers thought it possible this might have resulted from misjudgement by the peer supporters of the patient’s information requirements and emotional state, or the patients acquiescing to be referred for peer support rather than making a positive choice.

Helgeson et al (2000, 2001) suggested that the breast cancer survivors who benefited least from their experience of peer group participation may have had perceptions of their network relationships altered by attending the group. Women who came to the group, who perceived their relevant relationships to be helpful, may have heard stories from other group members that led them to re-evaluate their existing social relationships. Alternatively the researchers speculated that the peer discussion intervention could have increased negative interactions - with network members and/or discussing problems more frequently at home.

3.8 Participation levels
There appears to be low take-up of peer support among renal patients, reflecting similar low levels of participation in peer support programmes for other long term conditions, notably cancer. Furthermore, fewer patients participate in peer support than express an interest in using such support.

Referrals were initially low to both the kidney and stroke peer support schemes set up as part of a modernisation project in inner London (Hughes et al, 2008; Greenhalgh et al, 2009; Hughes et al, 2009). It also took longer than anticipated to reach what was regarded as a reasonable level of referrals despite considerable efforts to stimulate interest in the new service.

Low take-up levels were reported by the majority of studies included in a systematic review of evaluations of cancer peer support programmes conducted by Campbell et al (2004). A total of 21 papers published during the previous 20 years, reporting on 17 peer-led support programmes were reviewed, although only 3 of these studies were RCTs.

A pragmatic cluster RCT undertaken by Smith et al (2011) to examine the effectiveness of peer support for people with type 2 diabetes found many patients not interested in participation. The peer support intervention was introduced to 20 general practices in the Republic of Ireland and ran over a two-year period. A total of 395 patients with type
of those patients who agreed to participate never attended any meetings.

A retrospective study by Michaelec (2006) was undertaken among 958 breast cancer survivors diagnosed in one region of the USA from late 1980s to 1999. Asked whether or not they had participated in any breast cancer support group since their diagnosis, most said they had never participated in a support group.

A RCT conducted by Simpson et al (2002) reported that whereas 39 per cent of breast cancer patients agreed to participate in a brief 6-week support group, only 28 per cent actually attended. In total 89 women patients were randomly assigned to either treatment or control groups. The intervention group received a psycho-educational support intervention involving 6 weekly 90-minute group sessions led by professionals, whereas the control group received no support. A small-scale, non-RCT study by Bui et al (2002) found a significant proportion of patients with colorectal cancer interested in support group programmes but only a minority of patients participating in such programmes. The Canadian based study involved a survey among 44 patients to measure interest and barriers to participation in a support programme designed to meet the social, emotional and other non-medical aspects of cancer care through a range of structured peer support and coping skills programmes. Whilst 14 patients expressed interest in participation, only 4 patients attended any support programmes.

Additionally, several studies report high attrition from peer support programmes. Gottlieb and Wachala (2006) reviewed 44 empirical studies of professionally-led cancer support groups that included both RCTs and descriptive, cross-sectional, non-experimental studies. The reviewed studies were confined to face-to-face support groups led by one or more professionals (nurses, physicians, mental health specialists and social workers) rather than by peers. On the basis of these studies they estimated that at least 20 per cent of those invited to join a cancer support group decline to do so, and a further 20 per cent of those who do attend any support group meeting, drop out before the final session or post-test. Woolacott et al (2006) also identified small numbers of participants and high drop-out rates as a characteristic of many peer-led support networks for patients and carers in health and social care. This led the researchers to suggest that participation in such networks is not universally welcomed.
The emergence of online support groups does not appear to have substantially increased levels of participation in peer support. Studies have shown that use of online patient support groups is also limited. A secondary data analysis of the National Cancer Institute’s Health Information National Trends survey in the USA by Anderson et al (2009) found only 3.8 per cent of 3,244 Internet users had used an online support group. Uden-Kraan et al (2011) reported a similar level of contact with peers via the Internet (4.4 per cent) among 679 patients being treated at two Dutch hospitals for arthritis, breast cancer or fibromyalgia.

3.9 Participant characteristics

Patients from some socio-economic groups (older, male, lower educational attainment, lower social class) appear less motivated to take-up peer support. Deans et al (1988) undertook a survey among patients attending cancer support groups in Scotland and identified that women significantly outnumbered men (81 per cent as compared with 19 per cent). In common with Deans et al (1988), a group comparison study using a structured telephone interview among male and female cancer patients, conducted by Krizek et al (1999), found men far less likely than women to join a support group. The 217 study participants, 130 women with breast cancer and 87 men with prostrate cancer, were selected from surviving patients treated at a single cancer centre in the USA. Results showed that whereas 33 per cent of women had attended at least one support group, only 13 per cent of men had done so. Interestingly, a comparison of attendance rates among those patients who recalled being told about the support groups showed a much smaller gender difference; 35 per cent of women and 24 per cent of men who were aware of the support groups attended. Furthermore, the males who attended support groups were as likely as their female counterparts to continue attending. Bui et al (2002) found gender did not relate to level of interest in participation, but that actual attendance may be gender related, with lower recorded levels of attendance among males than females.

Bauman et al (1992) studied the participation of 154 cancer patients in two open-ended, professionally facilitated support groups in the USA, one for patients with leukemia and one for patients with lymphoma, and found well-educated patients were more likely to participate than less educated patients. The systematic review of evaluation studies of volunteer delivered peer support programmes undertaken by Campbell et al (2004) found most participants were highly educated. Other studies have also indicated that higher levels of education are positively associated with support-group participation.
(Deans et al, 1988; Krizek, 1999; Bui et al, 2002).

Bui et al (2002) identified support group attendees as being younger than non-attendees (59 years as compared with 65 years). Attendees of volunteer-run cancer peer support programmes in studies reviewed by Campbell et al (2004) were also identified as younger than the at-risk group, with the exception of prostate cancer. Although a survey conducted by Voerman et al (2007) specifically among prostate cancer patients in The Netherlands, showed that lower age was a key factor influencing intention to participate in social support groups. Several studies draw attention to the disproportionate under-representation in peer support of certain other groups, notably people of lower socio-economic status (Krizek et al, 1999; Campbell et al, 2004; Voerman et al, 2007;) and minority ethnic groups (Krizek et al, 1999; Campbell et al, 2004).

A UK-based study among cancer patients conducted by Grande et al (2006) similarly found that support group members were more likely to be female, younger, and better educated. Yet it appeared psychosocial variables could be more important determinants of support group membership than demographic or clinical characteristics. The study results were based on a cross-sectional quantitative postal survey that compared responses from 63 participants in a community cancer support group with a random sample of 44 cancer patients from the Cancer Registry. To help explain why people may use support groups as part of dealing with cancer, the study utilised two health psychology theories: Leventhal’s self-regulatory model of illness representations (1997) and the theory of planned behaviour (Ajzen, 1988, 2002). Data collected through the survey included variables based on these two theories.

Coping associated with patients’ cognitive appraisal of illness has been extensively researched within Leventhal’s (1997) model. Perceptions of cure and controllability of the illness have been found to be positively associated with problem-focused coping, cognitive reappraisal and support seeking. In contrast, cognitive representations of the illness as long-term and with serious consequences are correlated with coping that involves avoidance, denial and emotional expression. Since support group participation implies an active, open approach to cancer that goes beyond a person’s immediate network, the researchers hypothesised the coping strategies most likely to correlate with participation would be ‘adaptive’, involving problem-focused coping and support seeking. Conversely, ‘maladaptive’ strategies such as denial, disengagement and emotional venting were thought less likely to lead to group participation.
The researchers also postulated that whether ‘adaptive’ coping strategies lead to support group participation will depend on people’s beliefs about such groups. The theory of planned behaviour posits that the intention to perform the behaviour depends on the attitude towards the behaviour, the influence of others and perceived behavioural control. It was therefore proposed by the researchers that support group participation is more likely if people believe participation will be beneficial, that others think they should participate and that it is easy to join a group.

Survey findings highlighted that in accordance with the theory of planned behaviour, group members held more positive beliefs about the benefits of support group participation, felt others were more supportive of participation, and perceived less difficulty in joining a group. They felt more control over their cancer and used adaptive coping, but also felt more distress over their cancer and general anxiety, in line with the Leventhal’s model.

In line with these findings, Bauman et al (1992) noted that cancer patients in their study who were members of support groups tended to seek help from other health professionals, and continued to adopt more help-seeking behaviour in and out of the support groups. Voerman et al (2007) also identified that higher interest in participation in prostate cancer support groups was linked to lack of social support and a more positive attitude towards group participation.

### 3.10 Barriers to engagement

Grande et al (2006) recognised low participation levels might indicate that many more patients could benefit from peer support than those currently participating, but need for change would depend on identifying reasons for lack of participation. If for example, lack of participation is due to patients having adequate support elsewhere or preferring to cope through disengagement then change is not necessarily needed. Whereas if low participation levels are the result of misconceptions, lack of encouragement, and surmountable barriers, participation in peer support programmes ‘could and should’ be increased by addressing these issues to ensure ‘patients can make informed, supported choices.’ Whilst the study did not explore the hurdles that may prevent people from translating an intention into action, the researchers acknowledged patients were likely to face several barriers in joining support groups, both practical (health, mobility, transport, family, work), and psychological (lack of confidence).
Bui et al (2002) identified the main reasons for non-participation in support group programme as: having enough support already (mentioned by 43 per cent of non-attendees), lack of understanding or inability to speak English (36 per cent), live too far away (35 per cent), have no need (33 per cent), and not feeling well (25 per cent). Notably, patients' lack of awareness of support was the most changeable barrier to participation, in that ‘encouragement from medical staff’ was found to be the key independent predictor of interest in participation. This appeared in part to be a result of failure by clinicians to promote the programme since only in the support group of patients who later recalled being encouraged, was there found to be a positive association between encouragement and intent. More than a third of patients (36 per cent) did not recall receiving any encouragement to participate although all patients were routinely informed using a standardised approach. This finding led the researchers to argue the importance of clinicians delivering effective and comprehensible encouragement. Additionally they suggested patients may not have recalled being encouraged to participate because of information overload at the time of the clinic visit therefore underlining the need to repeatedly make patients aware of the service available to them.

Most studies reviewed by Campbell et al (2004) highlighted low referral rates as a barrier to success, particularly when relying on the health care system to identify newly diagnosed patients. Yet only one study (Coreil, 1999) asked participants how they heard about peer support. The reviewers perceived this as a critical issue since many patients were found to be unaware of any available support, and it was thought others may hesitate to make a self-referral.

Clinicians may exert considerable positive or negative influence over patients’ access to peer support. It was suggested by Brunier et al (2002) in the context of their study on the psychological well-being of renal peer support volunteers, that health care professionals may be uncertain whether chronically ill patients with a limited number of hours of special training are able to counsel other patients. Therefore they may not refer patients to peer support programmes. In a non-peer reviewed paper, Hughes et al (2008) explained a key reason for low referral rates to a new renal peer support service was because clinicians perceived the service as only for patients having difficulties accepting or deciding about treatment, therefore it was not being offered routinely to all patients. Clinicians who had told patients about peer support also reported feeling discouraged if patients said they did not want it the first time it was offered. To boost low referral rates, changes were made to how the peer support programme was
promoted: it was emphasised to clinicians that they should routinely offer peer support since all patients could benefit; and the service was publicised directly to patients who were encouraged to self-refer. Another non-peer reviewed paper, presented by Day (2012), reported slow referrals from medical and nursing to a renal peer support programme at a hospital in the West Midlands. Therefore efforts were being made to encourage more patient self-referral through patient targeted information and publicity.

Some studies suggest clinicians fear losing some of their own influence and authority if peer supporters are given too significant a role. The narratives of several professionals interviewed in a UK-based qualitative study by Curtis et al (2007) in relation to a breast feeding peer-support project, indicated concern about losing authority.

A related obstacle to participation was addressed by Krizek et al (1999). In their study among cancer patients, despite lower participation levels, men reported no less interest than women in sharing their concerns and comparing their emotional and physical progress with other patients. This finding was felt by the researchers to indicate that if support groups were targeted to men and women in a way that ‘got them in the door’ the support aspect will be valued by all participants. As a potential strategy to increase men’s participation, they proposed the description ‘information session’ be used as an alternative to ‘support group’.

Timing of the support offer may be another factor influencing levels of participation. A two-phase evaluation of a breast cancer peer support programme in the USA carried out by Dunn et al (1999) reported that peer support visits were most welcomed and helpful if they occurred in the early post-operative period when treatment demands and support needs were considered greatest by patients. Qualitative research undertaken by Smith et al (2011) as part of their evaluation of peer support for people with type 2 diabetes, indicated that participants thought they would have benefited from peer support around the time of diagnosis. Whereas those participating in the peer support intervention were recruited on the basis of having had type 2 diabetes for at least a year.

3.11 Conclusions
This section has explored published research literature in relation to peer support. It has covered key aspects in relation to: peer support theory, impacts and outcomes of peer support programmes, participation levels, participant characteristics, and barriers to engagement.
Existing research suggests peer support is popular among renal patients who are users. Nonetheless there appears to be initial low take-up of peer support, and fewer patients participate in peer support than express an interest in using such support (Hughes et al, 2008; Greenhalgh et al, 2009; Hughes et al, 2009). Yet there is evidence that accessing peer support can be beneficial in helping patients with CKD adjust to their illness, make treatment choices, and alleviate fears about possible therapies (Perry, 2005; Hughes et al, 2009; Greenhalgh et al, 2009; Chen et al, 2011; Harden et al, 2012).

Similar issues have been reported in relation to peer support programmes for other chronic conditions, notably cancer. There is often limited use of peer support, and lower numbers of patients participate in peer support than express interest in using such programmes (Bui et al, 2002; Campbell et al, 2004; Woolacott et al, 2006). Patients from certain socio-economic groups (older, male, less educated, lower social class) appear less motivated to take-up peer support (Bui et al, 2002; Campbell et al, 2004; Grande et al, 2006; Voerman et al, 2007).
Section 4. Methods

4.1. Introduction

The literature review found a paucity of literature in relation to renal peer support. There was also an absence of evidence on what might be the reasons for the identified low levels of participation in peer support amongst renal patients. Very few studies included any examination of the needs or perspectives of carers. This suggested a need for qualitative inquiry to explore what are the perceptions, attitudes and motivations in relation to peer support of both renal patients and carers of renal patients, and issues (emotional, psychological, practical, organisational) that may inhibit them from taking-up peer support.

Peer support can be delivered in a range of different ways in terms of mode, format, duration, personnel and intended outcomes. Discussions with staff at Renal Units in the West Midlands during early 2012 indicated that a number of Renal Units were already developing peer role models and involving patients in pre-dialysis education to help support patient choice of renal replacement therapies including HD, HHD, PD and transplantation. A variety of informal and formal approaches to peer support were being used with variable levels of take-up. In parallel, the West Midlands Renal Network was undertaking a pilot of a telephone peer support model.

Therefore on the basis of the literature review findings and learning from discussions with staff at Renal Units, this study was designed to explore from a patient and carer perspective their needs, wants and expectations of peer support. Also to examine how any barriers to take-up of peer support may be overcome and recommend service improvements, where appropriate. The research questions explored were:

- How do patients and carers view peer support?
- What would patients and carers ideally want to gain from peer support?
- How can any perceived problems and barriers in taking up peer support be overcome?
- How would patients and carers prefer peer support to be made available?

4.2. Design

The research study adopted a qualitative study design. It used the principles of Grounded Theory (Strauss and Corbin 1998, Corbin and Strauss 2008), as the
methodological framework. This was appropriate as little was known about the needs and perceptions of renal patients and carers regarding peer support and the study intended to utilise an iterative process to test emerging ideas.

Semi-structured questions were used to enable the key areas of research interest to be explored during the interview, without being overly prescriptive in terms of content and direction. This was to allow participants as far as possible to express in their own language what they considered to be relevant and important issues.

A minimum sample size of 8 patients and 8 carers across the participating research sites was decided upon, in order to meet the aims and objectives of the study. It was also decided that a maximum of 10 patients and 10 carers would be recruited per research site to limit the intrusion and disruption for patients, carers and staff. The flexibility of the sample size was in accordance with the principles of qualitative research which expect saturation to determine the end of data collection.

4.3. Recruitment of respondents

Within the renal unit of each NHS Hospital Trust a member of staff acted as a gatekeeper by making the initial enquiry of interest of patients and carers. Since existing evidence showed that some socioeconomic population groups were underrepresented as participants in peer support, the intention was to interview a diverse group of patients and carers.

Interested patients and their carers were sent an email (or letter with prepaid reply envelope) directly by the researchers, with an Information Sheet explaining the full purpose of the interview, the reasons as to why they were being invited to take part, and what participation would involve. Patients and carers willing to take part in an interview were asked to respond within ten days by email, letter or telephone, identifying a convenient interview date, time and location. The researcher confirmed the date, time and location (own home or Renal Unit) for interview by email (or letter) assuring the participant this could be revised depending on their needs.

4.4 Ethics

Ethical permission was obtained from NRES Committee East Midlands – Derby 1 Research Ethics Committee (ERN 12-0334). The study was also approved by the
A key aspect of the ethics application was the design of consent procedures, and avoidance of risk and burden as far as possible for research participants. Informed consent from patients, and carers of patients, was viewed as an ongoing process. Ethical processes were informed by the three key principles identified by Christians (2000:146): “respect for persons, beneficence, and justice”.

All patients and carers expressing interest in participation, after a clinician acting as gatekeeper had made the initial enquiry of interest, were provided with information about the study by email (or letter with prepaid reply envelope). This gave them an opportunity to consider in more detail whether they wished to participate and to raise questions. Appendix 1 contains the information sheet for patients, and Appendix 2 contains the information sheet for carers. The voluntary nature of participation was stressed at all times, including ability to stop the interview, withdraw or to omit a question as the interviewee wished. At the end of the interview consent was revisited as interviewees were invited to comment on and amend the interview transcripts. Appendix 5 contains the consent form for patients, and Appendix 6 contains the consent form for carers.

CKD is an extremely serious condition and patients were likely to have other chronic illnesses. Therefore there was potential for participants to feel tired or in pain, or to become upset when talking about their condition. Mindful of these issues, it was ensured that interviews would not be conducted with any participants whilst they were dialysing. Participants were to be informed they did not have to answer a question if they did not wish to. They were also to be informed they could have a break from the interview whenever they wished. Participants who exhibited distress or identified a need to explore issues beyond the research remit had the opportunity to be referred for additional support to the psychological support services provided by their own Renal Unit. The Chief Investigator was a trained counsellor and mediator and therefore could act as a conduit for debriefing and taking responsibility for ensuring appropriate ongoing support for participants if necessary.

4.5 Conduct
A total of 26 individual semi-structured interviews were undertaken among adult patients with CKD, and adult carers of patients with CKD (15 patients and 11 carers),
across six NHS Hospital Trusts within the West Midlands. The interviews were undertaken between July and September 2012. The criteria for the patient sample selection were adult patients with CKD, attending or receiving treatment at one of the six chosen Renal Units in the West Midlands, and willing to take part in an interview. The criteria for the carer sample selection were adult carers in a paid or unpaid role of supporting an adult patient with CKD, attending or receiving treatment at one of the six chosen Renal Units in the West Midlands, and willing to take part in an interview. At the same time exclusions put in place ensured there was no participation from among those patients or carers who were clinically unstable or too unwell to be interviewed, or lacked the capacity to give informed consent. Additionally patients were excluded if they insisted on being interviewed during dialysis.

A single face-to-face interview of 45 to 90 minutes took place in each research participant’s own home or renal unit, dependent on participant choice. Two semi-structured interview schedules were be used in this research, for a) patients and b) carers.

Each interview schedule had 14 open-ended questions. Appendix 3 contains the interview schedule for patients and Appendix 4 contains the interview schedule for carers. All participants were asked to briefly describe themselves and their treatment (or that of the person they cared for), and about their knowledge and use of peer support. Participants who had used peer support were to be asked about their experience, what worked well and what could be improved. Those participants that had not used peer support were to be asked about their interests, expectations, needs and wants in relation to peer support. Socioeconomic information was also collected from all participants. During the course of each interview, participants had read out to them a description of peer support: ‘Peer support is where you have the opportunity to talk with another patient or patients (carer or carers) who are in the same situation as yourself’.

Before an interview commenced, the nature and purpose of the interview was explained and any concerns discussed. It was stressed that the interviews were entirely voluntary, questions could be unanswered without explanation and all responses were confidential to the University of Birmingham researchers. If the participant wishes to proceed, they were asked to sign a consent form and asked if they were happy for the interview to be recorded. At the end of the interview, participants were invited to have their interview transcript sent to them, to comment on or amend. Appendix 5 contains the consent form for patients, and Appendix 6 contains the consent form for carers.
4.6 Analysis

Principles of grounded theory were achieved through openness, thoroughness in collecting the data, and consideration of all the data in the theory development phase. In addition, the data was collected until theoretic saturation was obtained. To help reduce any possible bias during collection of data, ongoing discussions were held between the study researchers concerning interview procedure, approach to asking questions, and data analysis. The primary author undertook the majority of the data analysis although the second author regularly reviewed and confirmed the analysis. Observational notes were made during and at conclusion of all interviews providing an interpretation of each participant’s approach and personal expressions, associations between the participant’s voiced views and the researcher’s feelings and experience of the interview exchange. Any emerging hypotheses were also recorded. Data collected from the interviews was analysed simultaneously with the ongoing conduct of fieldwork.

Transcripts of the semi-structured interviews were analysed separately using inductive thematic analysis since this allowed the organisation and classification of statements without subscribing to any particular theory. The analyses were conducted separately for patients and carers to allow any different themes to emerge. Each of the transcripts was read several times by one researcher to identify super-ordinate and sub-themes linked to aspects of participants' needs, wants and expectations. Emerging themes from each participant were determined and the themes then collated across patients or carers. Several patient and carer transcripts were read by a second researcher so that the identified themes could be discussed and validated. The emergent themes were then analysed by the researchers within the context of several identified relevant underpinning theoretical models: social comparison theory (Festinger, 1954); helper therapy theory (Riessman, 1965); stress, appraisal and coping theory (Lazarus and Folkman, 1984); self-efficacy theory (Bandura 1977, 2004); the theory of planned behavior (Ajzen 1988, 2002); and the theory of reciprocity (Gouldner, 1960).
Section 5. Results

5.1 Introduction
This section presents a synthesis of the findings from the research study designed to explore from a renal patient and carer perspective - their needs, wants and expectations of peer support; and barriers and enablers to facilitating participation in peer support. The research questions explored in the study were:

- How do patients and carers view peer support?
- What would patients and carers ideally want to gain from peer support?
- How can any perceived problems and barriers in taking up peer support be overcome?
- How would patients and carers prefer peer support to be made available?

5.2 Participants
A total of 26 respondents participated in the study, 15 patients and 11 carers. Patients ranged in age from 36 years to 77 years, whilst carers varied in age from 56 years to 67 years. Patients were at different stages along the kidney disease pathway, including pre-dialysis; training for HHD; on dialysis treatments (HD, HHD, PD, CAPD); awaiting kidney transplant; and transplanted patients. All but 3 respondents were married. Most patients and carers were not working, but 4 carers and 2 patients said they were working full or part-time. The study sample contained 10 participants who claimed to have no educational qualifications, and 16 participants who reported having GCSE/O’ qualifications or above. There was a disappointing lack of ethnic diversity in the sample. All the patients and carers recruited to the study were White British apart from one male patient who described himself as British Asian. Details of the study participants are shown in Table 1.
None of the respondents said they had engaged in formal peer support, although all participants had some experience of informal peer support. Only two patients reported having been offered formal peer support, but both had declined to take-up the offer.

Table 1: Details of study participants (self-reported)

<table>
<thead>
<tr>
<th>Designation</th>
<th>Gender</th>
<th>Age (yrs)</th>
<th>Location</th>
<th>Marital Status</th>
<th>Working Status</th>
<th>Educational qualifications (GSCE/O level +)</th>
<th>Current Therapy</th>
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<td>Rural</td>
<td>Married</td>
<td>Working p/t</td>
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<td>Waiting</td>
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<td>Working f/t</td>
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</tr>
<tr>
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</tr>
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<td>Working f/t</td>
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<tr>
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</tr>
<tr>
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<td>65</td>
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<td>Married</td>
<td>Working p/t</td>
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<td>HHD (9 months)</td>
</tr>
<tr>
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<tr>
<td>Patient</td>
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<td>Not working</td>
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<td>PD (18 months)</td>
</tr>
<tr>
<td>Carer</td>
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<td>Urban</td>
<td>Married</td>
<td>Not working</td>
<td>Yes</td>
<td>Pre-dialysis</td>
</tr>
<tr>
<td>Patient</td>
<td>Female</td>
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<td>Urban</td>
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<td>Not working</td>
<td>Yes</td>
<td>Pre-dialysis</td>
</tr>
<tr>
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<td>Not working</td>
<td>No</td>
<td>CAPD (14 months)</td>
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<tr>
<td>Carer</td>
<td>Female</td>
<td>64</td>
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<tr>
<td>Patient</td>
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<td>59</td>
<td>Rural</td>
<td>Married</td>
<td>Not working</td>
<td>No</td>
<td>Training HHD</td>
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</tbody>
</table>

5.3 Thematic qualitative analysis

Seven main themes and several subthemes were identified from analysis of the qualitative data. The main themes were: perceived benefits of peer support over other sources of support; limited awareness and understanding; the peer support occasion; emotional readiness; permission to engage; balance of support and giving; importance of building rapport; choice and control. The themes are illustrated with quotations below.

5.4 Perceived benefits of peer support over other sources of support

Peer support was seen to have specific attributes and benefits. Despite the absence of any formal peer support experience, almost all respondents readily provided positive accounts of how they felt peer support could deliver against their needs. Perceptions
were based on two contextual influences. First, across the study sample there was wide use of informal peer support involving patients and carers talking to others in the same situation as themselves. These conversations generally resulted from incidental encounters at Renal Units: whilst patients and carers were in the waiting area, on the HD ward, or during training for HHD. Although a few participants mentioned having actively sought engagement with other patients, for example by joining online kidney patient forums or making a request to renal staff for the opportunity to talk with other patients 'like them'. Most informal peer support was patient to patient, or carer to carer, but two female carers mentioned talking in depth with patients they had met whilst training for HHD. Some of these informal encounters had led to more regular contact, attachments and friendships among patients and carers.

_We were on the Unit together. We trained together and we used to talk about it a lot together and I think it helped both of us._ (Carer 2)

Second, it was apparent that kidney failure engenders a different conception of self in relation to others. Almost all respondents talked about significant changes to their personal identity. Patients mentioned having to adjust their lives and lifestyle to meet the ongoing demands of treatment, and how this changed relationships with different family members, friends and work colleagues. Many patients on home therapies, whose partner was their carer, expressed concern about how their partner was coping with the additional responsibilities involved and how this could impact on their relationship. In turn carers often mentioned how the worries and responsibilities interlinked with being a carer could put stresses on the relationship with their partner. Some carers of patients training on HHD, or on HHD for only a few months, described feeling as if their own identity had been overwhelmed. They had put the needs of their partner first when making the choice of treatment therapy and not considered the implications for their own lives and lifestyle. As a consequence, participants tended to look afresh at and evaluate their existing relationships and support networks resulting in an awareness of some significant unfulfilled needs and wants.

_We can’t arrange to go out with people because we won’t let them down. And it’s a kind of burden because you haven’t got your social life now._ (Carer 9)

_Probably if I come to terms with it then it’s all him and none of me. You know, it’s as if he’s taken over. And there won’t be any of me left._ (Carer 1)
Across the research sample peer support was perceived to have specific attributes and benefits, based on this combination of informal peer support experience and identified unmet needs. The perceived attributes and benefits are set out in Figure 1. The core mechanisms identified by Dennis (2003) underpinning how peer support operates – emotional, appraisal, and informational – were confirmed by this study. They provide a helpful framework by which to examine and explain the perceived benefits of peer support over other forms of support as described by the study respondents.

Figure 1: Perceived attributes and benefits of peer support

- **Informational Sharing**
  - Lifestyle impacts, changes and adaptations
  - Experiential knowledge
  - Practical adaptive coping skills
  - Experimentation
  - More control
  - Reduced uncertainty
  - Empowerment

- **Emotional Sharing**
  - Empathy
  - Friendly and non-judgmental
  - Safe place
  - Encouragement
  - Understood, accepted
  - Belonging, community
  - Less isolated

- **Appraisal Sharing**
  - Mutual identification
  - Comparison
  - Affirmation
  - Authenticity
  - More positivity
  - Normality
  - New possibilities

Adapted from Dennis, 2003

### 5.4.1 Informational support

Particular attributes associated with informational support were: lifestyle impacts, changes and adaptations; experiential knowledge; practical adaptive coping skills; and experimentation. Some respondents put particular emphasis on the value of wanting to know more about what to expect in relation to the future course of their condition and treatment, and the impact on their lifestyle.

*To learn, share experiences, you know, get an idea of what’s coming up next. What should I expect, you know, if I encounter a problem? Should I be worried? It’s just having that someone who’s been through that before to be able to talk to.* (Patient 7)
Other participants talked enthusiastically about gaining knowledge on particular personal issues in relation to their illness or treatment. Emphasis was often put on how a particular treatment ‘feels’ as opposed to the mechanics involved. Interest was also expressed in learning about how to address the impacts of a treatment on personal lives and relationships:

*General everyday things, sex and things like that. You know just because you become ill or a carer doesn’t mean you don’t want to have a sex life... But if you’ve got someone you could talk to ...another carer to find out if they’ve been in that situation.* (Carer 6)

Several patients, predominantly male, mentioned the value of being able to share practical adaptive coping skills with other patients on the same treatment therapy as themselves. They sometimes recounted in considerable detail a particular practical change they had made to their dialysis regime or equipment used as a result of learning from another patient. Different problems or aspects of needling were frequently mentioned as useful topics for discussion with peers.

*You find little quirks you know that maybe they’re doing and you’re not which makes life sometimes a little bit easier.* (Patient 8)

Respondents associated certain specific benefits with informational sharing, in particular feeling more in control over their illness and treatment. Other benefits mentioned were reduced uncertainty about how their condition and treatment might progress over time, and a sense of empowerment.

*I think you can gain strength as you think oh yeah they’ve been through all that. They’re alright. I’ll be alright...And it’s useful because you get a sense of direction of where you might be going, what to expect next.* (Patient 5)

### 5.4.2 Emotional sharing

Core attributes linked to ‘emotional sharing’ were: empathy; friendly and non-judgemental; safe place; encouragement; and reassurance. Whilst these were important attributes for both patients and carers, they were especially salient among carers. There were frequent references from carers of patients newly on HHD,
feelings of being alone and isolated in their new role. Their general impression was that not only had they put the needs of their partners above their own, but so did clinicians and their family and friends. Whereas choosing HHD as a treatment therapy can increase a patient’s sense of freedom, their carers often felt a corresponding curtailment of freedom.

On your own and isolated and you know you sort of think, I’m the one that’s supposed to be doing everything, I’m supporting you, where’s my support? (Carer 5)

Sense of responsibility for their carer role and fear of something going wrong in their absence, made many such carers worried about leaving the house whilst their partner was dialysing. Some carers mentioned feeling ‘tied’ to their home. They wanted empathy and reassurance in relation to their feelings, and the comfort of knowing they were not alone because someone else appreciated and understood what they were emotionally experiencing.

Somebody with the same sort of, who’s got empathy with the way I feel now, but they did feel like this...It’s almost like a grieving situation. I’ve lost and I’m actually grieving for myself. (Carer 1)

The most significant benefits of emotional support described by patients and carers were feeling accepted and understood and therefore less isolated. Some participants also said informal peer support had given them the sense of being part of a shared community, based on a common bond of shared experience and language.

It’s about the feeling of isolation, feeling you’re not alone. Somebody else has been through it. It’s that comfort...emotional support that somebody’s there. (Patient 7)

5.4.3 Appraisal sharing
The main attributes associated with ‘appraisal sharing’ were: mutual identification, comparison, affirmation and authenticity. Validation of their own feelings and behaviour was a strong motivator for interest in peer support among both patient and carer interviewees. Most respondents wanted affirmation of the normality of their own experiences. They were also keen to make active comparisons between themselves and others in a similar position.
Talk to other people and see whether they’re moving roughly down the same route that you are, or whether you are just, well whether you’re better or worse, you know. It’s just a matter of trying to think well is everything normal you know. (Patient 6)

Significantly almost all patients and carers wanted to compare positively upwards not downwards, with others. This stemmed from a desire to be guided to new possibilities and opportunities in handling kidney disease and its treatment. In this context many respondents stressed it was important peer supporters be realistically positive and optimistic. Offering a beacon of hope and reassurance, but grounded in reality, that on the basis of similar experience things can definitely improve. In essence they wanted role models, not sources of pity.

How do they get through it? Sometimes you just want to hear the other side of it. I’m going through all this rubbish every day, I’ve had enough. Somebody to turn round and say, there is an ending to it. It will come to an end. You can lead a normal life. (Patient 15)

It was clear from the accounts of some respondents, how uplifting it was to hear about certain lifestyle possibilities from a peer with whom they identified as being in a similar situation. One patient on HHD spoke enthusiastically about having discussed with another patient the feasibility of herself and her husband going abroad on holidays. Another respondent described the gratitude she felt after a fellow carer had encouraged her to recognise she could garden without guilt or fear, whilst her husband was on the dialysis machine in the house.

That’s been really good because we didn’t realise, you know, that you could, that there would be places abroad that you could go to. (Patient 14)

5.4.5 Different to friends and family support

Peer support was perceived as being additional and different to support from family and friends by almost all respondents. Irrespective of the strength and closeness of their personal relationships, most participants claimed it was not possible for their family or friends to fully understand the feelings associated with their predicament. Several patients explained that the physical and emotional effects of their illness and treatment
were so different to anything they had previously experienced only fellow patients could ever know what it felt like.

A strong desire to protect those people close to them from the reality of their feelings was reported by some patients and carers. For example, a female carer said she tried hard to keep hidden from others her worries about not being able to cope with the responsibilities involved in caring for her partner on HHD. She did not want to give any indication of struggling in her new role as this might lead her partner to doubt the wisdom of choosing HHD; despite her anxieties, she had no desire to change the decision. She believed only another carer could relate to and understand such sentiments. Several patients talked about not wanting to ‘burden’ any of their family members with the depth of their concerns about their kidney disease. There was a strong desire among these patients to protect those people closest to them from their real feelings; for fear they would be unable to cope with the ‘truth’. Whereas a patient peer supporter was viewed as being able to take on board and relate to these emotions, because based on their own experiences, such emotions would be considered understandable and acceptable.

*Helpless, scared, frightened. It’s hard. Reassurance that’s what you need... You don’t want to pile it on my kids. My husband as much as you know as he can be there, he doesn’t want to listen. He can’t cope with the fact I’m poorly. (Patient 15)*

*I could probably tell them things I don’t want to burden (−) with...Just to have somebody to talk to about how I’m feeling that I don’t want to upset (−) with. (Patient 3)*

For one respondent, peer support was perceived as a time when she might relax the positive persona she wanted to project to her family and be true to her feelings:

*It also gives you permission I suppose so, you know, if somebody says it’s ghastly having PD then actually that gives you permission to say yeah actually this is really horrible. I don’t have to pretend this is nice. It’s not...So you don’t have to be that strong person. (Patient 5)*

The language and technology associated with kidney disease therapies were also thought to act as a barrier to communications with family and friends. Several study
participants recounted examples of when they had tried to tell people close to them about particular aspects of their treatment therapy, but had recognised there was limited understanding.

You can talk about it with your family and whatever, friends, but they’re not in that situation so they don’t really know what you’re talking about you know.... if you say you’ve got air in the tube they don’t really know what you’re talking about. So it isn’t helping because you’re just telling them really. (Carer 2)

5.4.6 Different to support from clinicians

Appreciation of the information and support provided by nurses and consultants was consistently expressed by respondents across this study sample. Yet it was recognised that clinicians cannot provide the real insights that come from a patient’s or carer’s lived experience of CKD and its treatment. Nor were clinicians seen as able to offer experiential empathy. Whereas peer supporters were perceived as having the potential to provide a ‘truer’, more rounded and insightful picture of what a particular therapy involves and how it feels.

Not because the medics are bad or anything, it’s just because they’ve just not walked that journey in the same way. They’ve sort of walked alongside you and are more observing, whereas this is more living it. (Patient 7)

They will just know the symptoms rather than the actual overall feelings of how you’re going to be. (Patient 2)

Talking to a patient or carer peer was considered very different to a discussion between patient/carer and clinician. The latter was characterised as being more hierarchical and clinician-led; conversations tending to be predominantly medical focused. By contrast, peer support discussions were viewed as less constrained and more between equals. There was less of a clinical perspective with more emphasis given to emotional, practical and lifestyle issues. The language used between peers was also viewed as different; discussions being more in layperson’s terms.

The nurses don’t see it from the patient’s and carer’s point of view because they’re trained nurses and so their mind set is such that it’s slightly different from the totally lay perspective. (Carer 11)
5.4.7 Not for everyone

Peer support was not appropriate for every patient and carer. Three respondents in this study sample, all male, rejected peer support as having any likely personal benefit, although they recognised many others could potentially profit from such encounters. Two of these male respondents claimed their active dislike of sharing emotional thoughts and feelings would be too strong a barrier to allow them to ever engage in peer support. Another male participant said he felt sufficiently well-supported and therefore could not see how peer support might provide any additional benefits to assist him in coping with his illness and treatment.

5.5 Limited awareness and understanding

‘Peer support’ can be an excluding and ambiguous term. Several patients and carers were unfamiliar with the description and it did not always have any meaning for them. This unfamiliarity led some people to instinctively feel ‘peer support’ must reference something not for them or were de-motivated by the unknown. There were other respondents who misinterpreted the term, variously ascribing ‘peer support’ to mentoring services offered at work, support provided by renal clinicians and technicians to patients dialysing at home, or support put in place at schools for children having problems with discipline.

*I wouldn’t know really….It’d go over me.* (Carer 3)

*It’s fear of the unknown.* (Patient 14)

Until the term ‘peer support’ was explained to them, many respondents were unaware this was a descriptor that could be applied to the encounters and conversations they informally engaged in with other patients or carers, in a similar situation to themselves.

*That’s what I do, but I didn’t know I was doing it, the name for it.* (Patient 12)

Furthermore ‘peer support’ was judged a somewhat cold and unfriendly term by those for whom it was unfamiliar. Spontaneous reactions were that it sounded formal, professional and inflexible; not especially welcoming and accessible. As one respondent said on initially hearing the words:

*It sounds very sort of boxed, very sort of settled – not settled in a nasty sense but very, we’re going to do this and that….It sounds a bit hard.* (Patient 15)
Without some additional explanation and de-mystification, the term ‘peer support’ was therefore thought to act as a barrier to take-up among some patients and carers. Only a few interviewees felt fully comfortable with the term, understanding its meaning and what the process would involve.

5.6 The peer support occasion

Peer support was not viewed as being time-specific in its value and relevance. There appeared to be different peer support ‘occasions’ across time and the kidney disease pathway when peer support might be appropriate for any individual. Whilst practical issues such as travel requirements, time availability and state of health have important influence, these ‘occasions’ are primarily associated with a complex mix of emotional readiness and differential strengths of need.

Respondents provided insight into how their emotional ‘mood or ‘frame of mind’ at particular time-points across the kidney disease pathway, might inhibit or encourage them to respond to a motivational need to talk to another patient or carer. Some participants described occasions when they had particularly strong support needs, but recognised it would have been emotionally too difficult for them to discuss such needs with a peer at that moment. There were other occasions when their support needs might be different, but they felt emotionally more willing and able to engage with peers.

I think there’s different stages you need it...Sometimes you just feel like I don’t want to talk about it, I don’t want to know....Sometimes it’s you’re overloaded with what’s happening to you. (Patient 15)

I think it would be better now because I’m more aware of things whereas (before) I was probably a bit too frightened to say anything. (Patient 14)

The individuality of the peer support ‘occasion’ was evident in the highly varied responses from patients and carers to the question of when it would be most useful for them to use peer support. For example, some participants thought it would have been beneficial to have taken-up peer support when they first received the diagnosis of kidney disease. They believed that talking with other patients or carers might have helped reduce the uncertainty they felt at the time about their condition, its future course and its effect on their life. In turn better preparing them to make treatment decisions. Others claimed they were too overwhelmed by the shock and fear of the
diagnosis to have had the emotional capacity to talk at that point with other patients or carers.

*I think it would have been useful for when I was first diagnosed. In hindsight I would have had a lot of questions that I could have asked people of what my future would hold, because you want to know what’s going to happen to you.* (Patient 2)

*Not at the initial diagnosis because you need to get to grips with that...but sort of within a few weeks.* (Carer 4)

The value of using peer support to help with decision-making about choice of HHD was raised by several respondents. It was thought that listening and talking to people already using HHD might have given them more confidence and assurance about choosing the therapy. Also to help reduce worries about training and better prepare them for what they would experience when first dialysing at home. Interestingly there were other participants who felt they did not know enough at the decision-making stage to be able to ask questions of other patients or carers. They said they would have preferred to use peer support after being on HHD for a few weeks. Only by this stage did they feel sufficiently experienced to know what to discuss and ask about in terms of additional advice and support from peers.

*It might have made you feel more confident in going for it you know, instead of being so frightened and nervous. Because it’s a big step and really when you haven’t spoken to somebody or you don’t know anybody in the same situation it’s hard.* (Carer 2)

*I think until you experience it, you don’t always have the questions...I think you need these (peer support) when you’re actually in the midst of doing it.* (Patient 6)

### 5.7 Permission to engage

Acknowledging a need for support was difficult for many of the patients and carers in this study. It was unfamiliar emotional territory to seek support from people outside their personal networks; not concordant with their self-image and perceptions of how to handle illness. There was an inherent challenge to their self-esteem. A frequently
expressed concern was that by taking-up formal peer support they would appear lacking in social resources or overly ‘needy’. One carer had the impression peer support was only for people with serious problems, ‘like the Samaritans or Alcoholics Anonymous’. Several participants intimated there was greater attraction for them in peer support if they were more the provider than recipient of support; being more familiar with and preferring the helper role.

*Projected to me is you are a needy person and I don’t like that picture of myself.*
(Carer 7)

Self-referral, or self-reporting an interest in peer support to clinicians, worried a few interviewees since this might be inappropriately and negatively interpreted as a criticism of available clinician-based support. They felt clinicians might not understand their need for additional, different support. Fear of negative professional judgement was another barrier to engagement in peer support. A number of participants expressed concern that if they took-up peer support, it might give clinicians the impression they did not have the ability to handle their chosen therapy. This was a particular worry for some patients and carers considering HHD. They did not want to threaten their desired projected image to clinicians of being sufficiently independent and capable of handling the treatment themselves.

*I don’t want them to think I don’t know how to do it and all this.* (Patient 9)

*Even if they weren't judging you, I think you'd feel they were, well I would. They’ve trained me, they think I’m ready.* (Carer 2)

Anticipated poor self-efficacy led some interviewees to feel unable to engage in peer support. Viewing peer support as intrinsically a social event prompted preconceptions they would not be able to fulfil the social requirements. Since peer support was an unfamiliar interpersonal situation they were sensitive and wary about their capacity to participate as well as being uncertain about their role and responsibilities. A variety of social behavioural characteristics were mentioned as reasons why they would perform negatively in a peer support encounter including: being too shy, reserved, not very sociable, unable to express their needs, hesitant in coming forward, unconfident, and preferring to listen rather than talk.
I’m not very sociable. I find it hard to talk to people I don’t know so I’d find it difficult to be honest. (Patient 3)

In this context, a number of participants spoke about wanting their clinicians to confirm they were suitable for peer support, or to affirm it was acceptable for them to engage in peer support. Their responses demonstrated an implicit need for direct encouragement to participate from among the clinicians with whom they were familiar and who personally knew them.

I think the nurses would be a great help because they obviously know what sort of people the patients are and they can perhaps encourage them. (Patient 14)

5.8 Balance of support and giving
An attractive peer relationship was felt to be centred on sharing and reciprocity rather than one-way help. Whilst many patients and carers were of the opinion they would value learning from those who were more experienced and established on their treatment therapy, they were generally resistant to being passive recipients of support. A more equal exchange was sought that would involve a balance of both giving and support. For some respondents there was some resistance to over-benefiting from peer support and entailing a ‘support debt’. Viewing peer support in the context of more familiar social exchanges, it was thought such an imbalance in the relationship would make them feel ill at ease rather than relaxed and comfortable.

I wouldn’t feel right if they were just, somebody was just giving me hundred percent and I wasn’t giving them something back. I’d feel beholden to them and I wouldn’t want that.....It would make me feel uncomfortable.....If I thought it was one-sided I wouldn’t even do it. I’d want to help them as much as they were helping me. (Carer 2)

Achieving a sense of shared ownership was a key motivator for wanting the encounter with a peer supporter/s to be framed around a mutual sharing of feelings and experiences. It was recognised that such exchanges would have some natural imbalances and be different to most social interactions in that peer supporters would need to be trained: as good listeners; to be sensitive; to provide positive but honest advice. Yet the responses of many interviewees showed that to encourage their participation in peer support, how important it was in terms of their self-esteem and self-efficacy, they perceived peer support as a sharing process. Potentially this could also
help mitigate negative self-perceptions of support receipt; in particular, worries about being seen as ‘needy’.

I can accept it on an equal basis. I can offer somebody support and I can accept their support emotionally, I can deal with that. But for me to need support, emotional support, and not give anything back would be very hard. (Patient 5)

5.9 Importance of building rapport

The importance of establishing rapport with peer supporters if encounters were going to be successful was raised as a significant issue by most patients and carers. Without rapport it was widely assumed the relationship would not work. For the majority of participants, rapport was closely aligned with creating the safe, trusting and empathetic ‘place’ where sharing and exchange could take place; the right emotional context for honesty and disclosure, especially of personal issues.

I think you always want to make that contact with someone before you trust. (Carer 6)

If you build up like a rapport with people I could probably tell them things, how I’m feeling, that I don’t want to burden (carer) with. (Patient 3)

Reflecting on peer supporter characteristics they felt would help build rapport, most respondents judged commonality of kidney disease and therapy experience to be insufficient. Similarly, only a few interviewees put emphasis on specific socio-economic features. Two younger women with children said they would prefer peer supporters who had similar family circumstances as it would be easier for them to relate to each other. A single young woman expressed slight reservations that given the age profile of other HHD patients at her unit, it might be difficult to find a peer supporter similar in age. Another two male respondents emphasised the importance of having male peers to engage with, although one of these respondents suggested that gender alone was not sufficient.

If there was somebody who was similar to me who I could relate to as a person, not just because of being in a carer role.... That would mean more to me than somebody who was specifically because of the kidney problem. (Carer 7)

Well you can get more personal with a man, into depth with it, but something has to happen to ignite that thing. (Patient 12)
In general, participants struggled to describe the qualities in a peer supporter needed to make a positive connection. These were considered fairly intangible personal aspects, linked more to persona, outlook, sensitivity and tone, rather than anything clearly definable. Some respondents used their informal peer support experience as a benchmark, often describing a natural filtering process among patients or carers they encountered that led them to engage only with those to whom they could better relate. In this respect, almost all interviewees gave some account of other patients or carers they had met with whom they found no bond or association, or at worse claimed to have actively disliked. Interestingly several respondents thought the ‘right person’ with whom they could establish rapport might vary over time, dependent on their emotional and physical state, and particular needs, at that point.

“You don’t get on with everybody do you? You don’t immediately feel a connection there.” (Patient 6)

Achieving rapport with peer supporters was widely perceived as difficult without at least some face-to-face contact. For example, the accounts of two enthusiastic users of internet renal patient forums showed they often wanted supplementary face-to-face contact with peer supporters. This had enabled them to establish a stronger connection, allowing more meaningful discussion. Whilst recognising the practical advantages of telephone-based peer support, some respondents were nonetheless unenthusiastic, anticipating somewhat cold and impersonal encounters as a result of not being able to build rapport with an unseen person. It was suggested there should be at least some initial face-to-face contact to enable a personal connection to be made before any telephone encounter. In this respect, some participants proposed that such initial meetings with potential peer supporters should take place in a social rather than clinical environment, to better create a relaxed atmosphere conducive to encouraging positive contacts to be made. Even if the meeting took place in a renal unit, it was recommended this be in a room separate from the clinic, possibly over tea and coffee.

“Online it’s more information, more factual, whereas face-to-face it’s going to be more, I wouldn’t say once the guards come down, but you know what I mean, once people open up more, you find that you probably have more of an interact, more enriching conversation. That helps both people....it’s that bond.” (Patient 7)
I don’t think I could just, you know, have a one to one (on the phone)...if it’s personal things. (Patient 2)

5.10 Choice and control

Having choice and control in relation to certain aspects of the timing and delivery of peer support were important considerations for some interviewees. Need for empowerment in relation to their peer support was expressed most strongly among patients and carers who were either training to use, or already on, home dialysis therapies. It appeared to reflect and accord with their motivations for choosing home therapies: more control and ownership over their dialysis regime, and the opportunity for greater choice and flexibility over when and how they dialyse. Choice and control were also integral reasons as to why informal peer support was attractive to them.

Being able to take a key role in choosing their own peer supporter or supporters was viewed as especially important, mainly because of the desire to ensure rapport exists as a precursor to shared exchange and reciprocity, as discussed in section 3.8. It was also recognised that preferred choice of peer supporter/s might vary over time, dependent on changing needs. Having the opportunity to choose the timing of when peer support takes place is another critical issue for some interviewees, particularly since they recognised peer support might personally be needed on different occasions during the course of their illness and treatment (section 3.5). For example, one patient indicated she would prefer to ‘dip in and out’ of using peer support dependent on the strength of her needs relative to other competing demands at any particular time. Furthermore, whilst a few respondents felt a single encounter might be sufficient to meet their needs at any one time, most people anticipated wanting longer engagement with their peer supporter/s.

Preferences varied considerably in relation to peer support format, and there was a strong desire among many interviewees for choice in this area. Internet was the primary choice of format for some participants because it provided quick and easy access to the views and opinions of a wide range of different peers in a similar position to them. Since Internet exchanges did not involve direct person-to-person contact this was also attractive for several more introverted respondents. There were other respondents who described wanting only to participate in peer support if it involved a group of patients or carers. They instinctively felt this type of peer support would be more comfortable and relaxed since less would be demanded of them. They could choose when and with
what issues to actively engage, whilst at other times they might prefer to just take a ‘back seat’ and listen.

I’m not very sociable. I find it hard to talk to people I don’t know so I’d find it difficult to be honest… I think I’d probably open up a lot more on an Internet because you’re not face to face. (Patient 3)

I think a group situation… It’s a more relaxed situation. I don’t think you would feel you’ve got to talk to people about it. Whereas in a one-to-one situation, that’s what you’re there for, to talk. You could basically sit and listen and join in if you wanted to… that’s much simpler than trying to hold a conversation. (Patient 4)

One-to-one peer support encounters were the preferred choice of some patients and carers for a variety of different reasons. Several people said they would feel too shy to engage in group peer support as they would have to socialise with a number unfamiliar people. Others said it would be easier to build rapport with a single peer supporter enabling them to more easily discuss personal and intimate issues. For a number of respondents the appeal of a one-to-one encounter was the perceived ability to have more control over the subject matter discussed. They felt they would be better able to focus the discussion onto their own needs, whereas in a group scenario there was always a danger that others, with issues of less interest to them personally, might dominate proceedings. Some people said they could only perceive themselves engaging in one-to-one peer support that was face-to-face, for reasons of being able to build rapport and mutual understanding. Non-verbal aspects of the encounter were also thought potentially helpful; being able to see that a peer supporter was feeling well and coping with their treatment. Others thought there were advantages to one-to-one encounters by telephone, mainly because of the convenience: no need to travel and therefore less time consuming.

I think you can both concentrate on your circumstances together and not anyone else’s… With a group you tend to be a bit too many people and you talk about a subject for a certain amount of time and then the subject turns to somewhere else, where on a one-to-one basis you’re talking to somebody to concentrate on you and that one person. (Carer 6)
Because you can’t see a face…You can’t relate to people. It’s not personal really is it? You can’t see their face. You might never have met the person so you can’t put an image to their face. I’d find that rather strange you know. I like to know who I’m talking to. (Patient 14)

Using a combination of peer support formats appealed to a few respondents. For example, use of the Internet plus supplementary face-to-face contact with peer supporters. There were other respondents who recognised having a choice of alternative formats would better suit their needs since these were likely to change over time.

To start off with I think a group is less threatening in the sense that you don’t feel that you’ve got to say something if you don’t really want to. But with an opportunity for it to be either a one-to-one, or a group, because different people need different things at different times. (Patient 15)
Section 6: Conclusions and discussion

6.1. Conclusions

This study was designed to explore from a patient and carer perspective their needs, wants and expectations of peer support. It also examined how any perceived problems and barriers in taking up peer support might be overcome. Semi-structured interviews were conducted with a total of 26 patients with CKD and carers of patients with CKD (15 patients, 11 carers), at different stages along the kidney disease pathway. All the patients were receiving treatment at one of six Renal Units in the West Midlands. Since existing evidence showed that some socio-economic groups are under-represented as participants in peer support, the research sample was purposively selected with the intention of interviewing a diverse range of patients and carers. Interviews were conducted in participants’ homes or Renal Units, dependent on participant choice, and lasted 45 to 90 minutes.

Findings from the research study centred on three key thematic areas. First, peer support was seen by both patients and carers to have specific attributes and benefits over and above existing support provided by family and friends. These perceptions were based on two contextual influences: informal peer support experience and identified unmet needs. The core mechanisms identified by Dennis (2003) as underpinning how peer support operates - emotional, appraisal and informational – were confirmed by this study and provide a helpful framework by which to examine and explain the perceived additional and different attributes and benefits of renal peer support. In particular peers were thought to better understand the patient’s or carer’s own feelings and can empathise with their experience. In comparison with clinicians, peer supporters were thought to provide a ‘truer’, more rounded and insightful picture of what a particular therapy involves and how it feels.

Second, while informal peer support might occur naturally and is welcomed, a range of emotional and practical barriers constrain motivation to take-up more formalised support. Receptivity to peer support can vary across time and the disease trajectory and is associated with emotional readiness; patients and carers needing to overcome complex psychological hurdles such as acknowledging the need for support. For many study participants it was unfamiliar emotional territory to seek support from people outside their personal networks; not concordant with their self-image and perceptions of how to handle illness. Anticipated poor self-efficacy led some respondents to feel unable to engage in peer support. Practical barriers include limited awareness and
understanding of peer support. The term ‘peer support’ did not always have meaning for people leading to a sense of exclusion.

Third, an attractive peer relationship was felt to be centred on sharing and reciprocity rather than one-way help. Whilst many patients and carers were of the opinion they would value learning from those more experienced and established on their treatment therapy, they were resistant to being passive recipients of support. A more equal exchange is sought, involving a balance of giving and support. Establishing rapport is also considered important if the peer support encounter is to be successful; rapport being closely aligned with creating the safe and empathetic ‘place’ where sharing and exchange might take place. To better establish rapport, many study participants wanted to have a role in choosing their own peer supporter/s.

It was concluded that healthcare professionals could offer greater ‘permission to engage’, and promote peer support as an intervention suitable for anyone with CKD and their carers, not just those who are ‘needy’. The term ‘peer support’ was not universally well understood, so in communications there may be a need for clearer definitions and explanatory information; emphasising how peer support encounters enable experiences to be shared and exchanged. Peer support should be made available across the CKD pathway with some choice offered in terms of timing and delivery, within the necessary constraints of clearly defined structures and boundaries. Creating opportunities for rapport to be built with potential peer supporters should be considered, including initial face-to-face meetings. If certain peer support formats are not available locally, signposting might be used to alternative options.

Some of these recommendations have been used by the West Midlands Renal Network to refine and develop how their pilot peer support programme is introduced and promoted to patients and carers. In particular there is now emphasis on peer support being routinely offered and suitable for anyone with CKD and their carers, and the peer relationship enabling experiences to be shared and exchanged. Also opportunities are being made available for informal face-to-face meetings between patients and carers, and peer supporters, in advance of telephone peer-to-peer support.

6.2. Discussion and recommendations for future work

This study has achieved a better understanding of what patients and carers need, want and expect from peer support and identifies how actual or perceived barriers to the take-up of peer support by patients and carers may be resolved. Based on their use of
informal peer support and experience of unmet needs, almost all study participants clearly identified a range of benefits and attributes associated with peer support. The core mechanisms found to underpin these attributes and benefits reflect those identified by Dennis (2003) i.e. informational, emotional and appraisal. The main perceived benefits of peer support accord with the beneficial effects of participation in peer support identified in existing literature: feeling more in control (Helgeson et al, 2000; Hughes et al, 2009); reduced uncertainty (Dunn et al, 2009); sense of empowerment (Ussher et al, 2006; Repper and Carter, 2011); being understood and accepted (Hughes et al, 2009; Proudfoot et al, 2012); belonging and community centred (Cohen et al, 2000); less isolated (Rook, 1990; Cohen, 2000); sense of normality (Gottlieb and Wachala, 2006); and the potential for more positivity and new possibilities (Campbell et al, 2004; Repper and Carter, 2011).

The study identified a substantial overlap between patients and carers regarding perceived benefits and attributes of peer support. Carers expressed need for peer support as much as did patients. The carers of HHD patients appear to have particularly pressing needs to help them adjust to their new role and responsibilities; they reported side-lining their own worries and concerns during the treatment decision making process. Several carers in our study described feeling a sense of lost personal opportunities in relation to their work, travel and hobbies; anxiety about the future; ‘isolated’ and ‘neglected’. We recommend further work is undertaken to explore how renal staff may better support the needs of carers, and encourage carers to incorporate their needs into the shared decision making process around treatment choice.

The present study revealed the importance of perceived reciprocity in the peer support relationship if take-up of peer support is to be encouraged. Both patients and carers expressed rejection of a one way gift of help. The importance of reciprocity has been much emphasised in the literature on peer support in mental health services. For example, Mead et al (2001) identified that peer support relationships are valued for their reciprocity, giving an opportunity for sharing experiences, both giving and receiving support and for building up a mutual and synergistic understanding that benefits both parties. Similarly Repper and Carter (2011) argued that reciprocity is integral to a positive peer to peer support relationship.

Dunn et al (1999) suggested reciprocity is more likely to develop where there is minimal social distance, shared interest or commonalities in life experiences. Good ‘matching’ of peer and peer supporter has been a core feature of several peer support programmes.
Hughes et al, 2008, 2009) with clinicians providing a brokerage role, ‘matching’ on the basis of characteristics such as relevant treatment experience, gender, age group, ethnicity, family circumstances and employment status. Participants in this study interlinked establishing rapport with the development of reciprocity. To better establish rapport, they wanted to be involved in choosing their own peer supporter. This was particularly important for patients (and their carers) choosing HHD as their modality and may perhaps indicate a desire for a sense of greater control over their illness and treatment, in line with Leventhal’s model (1997). Interestingly the study by Hughes et al (2009) also raised questions about the value of ‘matching’ patients with peer supporters and the effects of this as well as other ‘brokerage’ aspects on the peer support relationship. Further research may be of value to explore the differential impacts between ‘chosen’ and ‘matched’ peer supporters.

The present study revealed that receptivity and needs for peer support may vary over time. Interestingly the two patients in this study who had been offered and declined to take-up formal peer support, both associated their rejection with inappropriate timing. One patient explained that at the time peer support was proposed, they had felt burdened with adjusting to their diagnosis and the implications of their illness, as well as handling the demands of being a wife and mother. Another patient described the offer of peer support coming when he was just starting treatment and feeling insufficiently experienced to be able to discuss practicalities with a peer. These responses are congruent with findings from the literature indicating that timing of the peer support offer can be a factor influencing levels of participation (Dunn et al, 1999; Smith et al, 2011). Flexibility of peer support provision is therefore needed across the kidney disease trajectory.

Finally, there was a disappointing lack of ethnic diversity in the sample for this study. All the patients and carers recruited to the study were White British apart from one male patient who described himself as British Asian. Several studies in the literature reported differences originating in patient cultural experiences, in how participants respond to peer support programmes (Kimmel, 2001; Perry et al, 2005). Other studies draw attention to the disproportionate under representation of minority ethnic groups in peer support (Krizek et al, 1999; Campbell et al, 2004). Therefore it is important further research is undertaken to explore the barriers and enablers to facilitate the participation in peer support of renal patients and carers from other ethnic groups.
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Appendices
Appendix 1: Information sheet for patients

Information Sheet for Patients

An invitation to participate in a study on peer support for renal patients
We are inviting you to take part in a study on peer support for renal patients and carers. The study will gather the views of patients with chronic kidney disease and their carers on what is needed and wanted from peer support. You have been selected to participate because you are a patient with chronic kidney disease. You do not have to have used peer support to be able to participate.

Before you decide whether to participate, it is important for you to understand why the study is being conducted and what it will involve. Please take time to read this sheet and discuss it with your friends, relatives and/or GP if you wish. Ask us if there is anything that is not clear or if you would like more information before deciding whether or not to take part. Our contact details are at the end of this information sheet.

Whether you decide to participate or not will have no effect on the treatment you receive now or in the future.

Purpose of the study
The purpose of the study is to find out renal patients' and carers' views on peer support. To understand what patients and carers would ideally want to gain from peer support, whether there seen to be any problems or difficulties in using peer support, and how peer support could best be made available.

Who has reviewed the study?
The study has been reviewed by the East Midlands – Derby 1 Research Ethics Proportionate Review Sub-Committee.

Benefits of the study
The information provided will contribute to a better understanding of what renal patients and carers, need, want and expect in relation to peer support. This information will help inform future peer support service design.
What the study involves
You are invited to participate in an individual and confidential face-to-face interview with a researcher from the University of Birmingham who will ask questions about your thoughts and opinions of peer support. The researcher will also ask some questions about yourself and your treatment. The interview will take place in a venue to suit you: in your own home or in the hospital Renal Unit. It will last 45 to 60 minutes.

All comments will be recorded and written down after the interview. Names and place names will be removed from interview transcripts. Your identity will be protected. No participants will be named in any report or publication arising from this work. Comments will not be attributed to any individual.

After the interview you are able to have a copy of what was said during the interview to comment on and change if you wish to. The interview data will be stored in a secure environment at the University.

At the end of the interview you will be asked if you are interested in participating further in the research study. If you wish further involvement you will be invited to a workshop with other renal patients and their carers. At the workshop the draft research findings will be presented and you will be able to discuss these with the other patients and carers. The views expressed during the discussion will be included in the final research findings.

You will also be invited to a second workshop with other renal patients and their carers, to share the research findings with Renal Unit staff.

You can attend either or both workshops, or neither. If you are interested in attending either workshop, we will provide information about the workshop and assist with any travel arrangements in association with the staff at your Renal Unit.

Participation in the study is entirely voluntary. You are free to withdraw at any time before, during or up to 4 weeks after the interview, and do not have to say why you want to withdraw. Withdrawal will not affect the treatment you receive now or in the future. To withdraw please email, phone or write to Francesca Taylor whose contact details are given below.
If you would like to receive a copy of the report we produce based on the findings from the study, please let us know.

Further information
We thank you for your interest in helping us. If you are interested in participating in an interview, we would be pleased to answer any questions you might have. Please contact us if you would like to discuss any aspect of this project.

What to do next
If you would like to participate in an interview, please contact Francesca Taylor, the researcher by Friday 3 August. Please let her know what date and time it would suit you to have the interview where you would like the interview to take place, at your own home or in your hospital Renal Unit. She will then get in touch with you to confirm the date, time and place for the interview that best suits you.

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E-mail: f.taylor@bham.ac.uk
Appendix 2: Information sheet for carers

Information Sheet for Carers

An invitation to participate in a study on peer support for renal patients and carers

We are inviting you to take part in a study on peer support for renal patients and carers. The study will gather the views of patients with chronic kidney disease and their carers on what is needed and wanted from peer support. You have been selected to participate because you care for a patient with chronic kidney disease. You do not have to have used peer support to be able to participate.

Before you decide whether to participate, it is important for you to understand why the study is being conducted and what it will involve. Please take time to read this sheet and discuss it with the patient you care for, and your friends, relatives and/or GP if you wish. Ask us if there is anything that is not clear or if you would like more information before deciding whether or not to take part. Our contact details are at the end of this information sheet.

Whether you decide to participate or not will have no effect on the treatment the patient you care for receives now or in the future.

Purpose of the study

The purpose of the study is to find out renal patients’ and carers’ views on peer support. To understand what patients and carers would ideally want to gain from peer support, whether there are seen to be any problems or difficulties in using peer support, and how peer support could best be made available.

Who has reviewed the study?

This study has been reviewed by the East Midlands – Derby 1 Research Ethics Proportionate Review Sub-Committee.
Benefits of the study
The information provided will contribute to a better understanding of what renal patients and carers, need, want and expect in relation to peer support. This information will help inform future peer support service design.

What the study involves
You are invited to participate in an individual and confidential face-to-face interview with a researcher from the University of Birmingham who will ask questions about your thoughts and opinions of peer support. The researcher will also ask some questions about yourself and the treatment of the patient you care for. The interview will take place in a venue to suit you: in your own home or in the hospital Renal Unit. It will last 45 to 60 minutes.

All comments will be recorded and written down after the interview. Names and place names will be removed from interview transcripts. Your identity will be protected. No participants will be named in any report or publication arising from this work. Comments will not be attributed to any individual.

After the interview you are able to have a copy of what was said during the interview to comment on and change if you wish to. The interview data will be stored in a secure environment at the University.

At the end of the interview you will be asked if you are interested in participating further in the research study. If you wish further involvement you will be invited to a workshop with renal patients and their carers. At the workshop the draft research findings will be presented and you will be able to discuss these with the other carers and patients. The views expressed during the discussion will be included in the final research findings.

You will also be invited to a second workshop with renal patients and their carers, to share the research findings with Renal Unit staff.

You can attend either or both workshops, or neither. If you are interested in attending either workshop, we will provide information about the workshop and assist with any travel arrangements in association with the staff at your Renal Unit.

Participation in the study is entirely voluntary. You are free to withdraw at any time before, during or up to 4 weeks after the interview, and do not have to say why you
want to withdraw. Withdrawal will not affect the treatment the patient you care for receives now or in the future. To withdraw please email, phone or write to Francesca Taylor whose contact details are given below.

If you would like to receive a copy of the report we produce based on the findings from the study, please let us know.

**Further information**
We thank you for your interest in helping us. If you are interested in participating in an interview, we would be pleased to answer any questions you might have. Please contact us if you would like to discuss any aspect of this project.

**What to do next**
If you would like to participate in an interview, please contact Francesca Taylor, the researcher by Friday 3 August. Please let her know what date and time it would suit you to have the interview where you would like the interview to take place, at your own home or in your hospital Renal Unit. She will then get in touch with you to confirm the date, time and place for the interview that best suits you.

Francesca Taylor  
University of Birmingham  
School of Health and Population Studies  
Room G42 90 Vincent Drive, University of Birmingham  
Edgbaston, Birmingham B15 2TT  
Tel: 0121 414 7661  
Mobile: 07775531674  
E-mail: f.taylor@bham.ac.uk
Appendix 3: Interview schedule for patients

A Study on Peer Support for Renal Patients and Carers:
Interview Schedule for Patients

I am a researcher from the University of Birmingham. The purpose of this interview is to find out about your thoughts and views of peer support; there are no right or wrong answers. The interview should take about 45 to 60 minutes. I would just like to remind you that I will be recording the interview. This is just so I don’t miss anything that you say. What you say will be confidential to the University research team. No individual will be identifiable. All interview records will be stored securely.

I have a series of questions to ask, but hope the discussion will be informal and that you will say anything you like. If you do not wish to answer a question we will move onto the next one. You can also withdraw from the interview at any time before, during or up to 4 weeks after the interview, and do not have to say why. This will have no effect on the treatment received by you, now or in the future.

Please could you read through and answer the questions in the Consent Form and say if you’re happy for the interview to be recorded. Please could you also sign the Consent Form?

Please let me know if you would like a break at any time during the interview.

Interview questions
1. Can you tell me a little about yourself?

2. Are you currently on dialysis?

3. How long have you been on dialysis?

4. What do you know about peer support?
   How and when did you find this out?
5. Peer support is where patients and carers with experience of chronic kidney disease help other kidney patients and carers facing similar situations. It is additional support to that provided by your doctors and nurses. Have you used peer support? What is the main reason why?

**If not used peer support:**
6. How interested are you in peer support? Please explain why.

7. What do you expect using peer support would be like? How do you think it might work? How do you feel about that?

8. Do you feel there are any ways in which you might benefit from using peer support?

9. Are there any worries or concerns you have about peer support?

10. What, if anything, do you feel would need to change to make you less worried or concerned?

11. Do you think peer support is suitable for someone like you?

12. Thinking now about how peer support could be designed to best suit you:
   How would you like to find out about peer support? What would you want to know?
   How would you most like to access peer support? What qualities would you prefer in a peer supporter? When would it be most useful for you to use peer support?
   Over what length of time?

13. Are there any other questions or comments you think are important that we have not covered?

**If used peer support:**
6. Thinking about your experience of peer support, was it what you expected?

7. What worked well for you?

8. What, if anything, did you find most helpful about using peer support?

9. Did you experience any problems of difficulties about using peer support?
10. What are your views on how these problems or difficulties could best be overcome?

11. What, if any, changes would need to happen to make peer support a better experience?

12. Thinking now about how peer support could be designed to best suit you:
   How would you like to find out about peer support? What would you want to know?
   How would you most like to access peer support? What qualities would you prefer in a peer supporter? When would it be most useful for you to use peer support? For what length of time?

13. Are there any other questions or comments you think are important?

Ask all participants:
Finally, I would like to ask you some questions about yourself.

14. i. What is your age?
   ii. What is your gender?
   iii. What is your marital status?
   iv. What is your working status?
   v. What is your highest educational qualification?
   vi. Do you live in a rural or urban area?
   vii. How would you describe your ethnicity?

Thank you for your time and help. The information you have provided will help the way renal services are delivered in the future. Can I check again that you are willing to allow what you have said to be included in any report or publication arising from the study, on the basis that your identity will be protected and your name will not be included?
Can I remind you that if you have any further thoughts or concerns about anything you have said, my contact details are on the Information Sheet.
Would you like to see the notes of this interview to comment on or amend? If so, how would you like me to send them to you, by post to your home or email? You can return these to me any time over the next 4 weeks.

Thank you and goodbye.
Appendix 4: Interview schedule for carers

A Study on Peer Support for Renal Patients and Carers:
Interview Schedule for Carers

I am a researcher from the University of Birmingham. The purpose of this interview is to find out about your thoughts and views of peer support; there are no right or wrong answers. The interview should take about 45 to 60 minutes. I would just like to remind you that I will be recording the interview. This is just so I don’t miss anything that you say. What you say will be confidential to the University research team. No individual will be identifiable. All interview records will be stored securely.

I have a series of questions to ask, but hope the discussion will be informal and that you will say anything you like. If you do not wish to answer a question we will move onto the next one. You can also withdraw from the interview at any time before, during or up to 4 weeks after the interview, and do not have to say why. This will have no effect on the treatment received by the patient you care for, now or in the future.

Please could you read through and answer the questions in the Consent Form and say if you’re happy for the interview to be recorded. Please could you also sign the Consent Form?

Please let me know if you would like a break at any time during the interview.

Interview questions
1. Can you tell me a little about yourself and the patient you care for?

2. Is the patient you care for currently on dialysis?

3. How long has the patient you care for been on dialysis?

4. What do you know about peer support?
   How and when did you find this out?

5. Peer support is where patients and carers with experience of chronic kidney disease help other kidney patients and carers facing similar situations. It is
additional support to that provided by your doctors and nurses. Have you and/or the patient you care for used peer support? What is the main reason why?

If not used peer support:
6. How interested are you in peer support? Please explain why.

7. What do you expect using peer support would be like? How do you think it might work? How do you feel about that?

8. Do you feel there are any ways in which the patient you care for might benefit from using peer support? Are there any ways you might benefit?

9. Are there any worries or concerns you have about peer support?

10. What, if anything, do you feel would need to change to make you less worried or concerned?

11. Do you think peer support is suitable for someone like you and the patient you care for?

12. Thinking now about how peer support could be designed to best suit you and the patient you care for:

13. How would you like to find out about peer support? What would you want to know? How would you most like to access peer support? What qualities would you prefer in a peer supporter? When would it be most useful for you to use peer support? Over what length of time?

14. Are there any other questions or comments you think are important that we have not covered?

If used peer support:
6. Thinking about your experience of peer support, was it what you expected?

7. What worked well for the patient you care for? What worked well for you?

8. What, if anything, did you find most helpful about using peer support?
9. Did you experience any problems of difficulties about using peer support?

10. What are your views on how these problems or difficulties could best be overcome?

11. What, if any, changes would need to happen to make peer support a better experience?

12. Thinking now about how peer support could be designed to best suit you and the patient you care for: How would you like to find out about peer support? What would you want to know? How would you most like to access peer support? What qualities would you prefer in a peer supporter? When would it be most useful for you to use peer support? For what length of time?

13. Are there any other questions or comments you think are important?

**Ask all participants:**

Finally, I would like to ask you some questions about yourself.

14. i. What is your age?
    ii. What is your gender?
    iii. What is your marital status?
    iv. What is your working status?
    v. What is your highest educational qualification?
    vi. Do you live in a rural or urban area?
    vii. How would you describe your ethnicity?

Thank you for your time and help. The information you have provided will help the way renal services are delivered in the future. Can I check again that you are willing to allow what you have said to be included in any report or publication arising from the study, on the basis that your identity will be protected and your name will not be included?

Can I remind you that if you have any further thoughts or concerns about anything you have said, my contact details are on the Information Sheet.
Would you like to see the notes of this interview to comment on or amend? If so, how would you like me to send them to you, by post to your home or email? You can return these to me any time over the next 4 weeks.

Thank you and goodbye.
Appendix 5: Consent Form for patients

UNIVERSITY OF BIRMINGHAM

A Study on Peer Support for Renal Patients and Carers:
Consent Form for Patients

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I have read the Information Sheet for Patients
(version2, dated 08.05.12) or had it explained to me

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I have had time to ask questions and I am happy with the answers

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I understand what taking part in the interview will involve

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I agree that the interview can be recorded then written down

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I agree that you can include what I say in any report or publications arising from the project, but my identity will be protected and my name will not be included

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I agree that my age, gender, education level, ethnic group, employment status, marital status, treatment type and treatment location, can be included alongside what I say

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I understand that I can stop taking part at any time and do not have to say why I want to stop

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I agree to take part in the interview

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Name of participant  Date  Signature
_________________________  ____________  __________________

Name of researcher  Date  Signature
_________________________  ____________  _______________
Appendix 6: Consent form for carers

A Study on Peer Support for Renal Patients and Carers:
Consent Form for Carers

Yes  No
(please tick appropriate box)

I have read the Information Sheet for Carers
(version2, dated 08.05.12) or had it explained to me

I have had time to ask questions and I am happy with the
answers

I understand what taking part in the interview will involve

I agree that the interview can be recorded then written down

I agree that you can include what I say in any report or
publications arising from the project, but my identity will
be protected and my name will not be included

I agree that my age, gender, education level, ethnic group,
employment status, and marital status; and the treatment
type and treatment location of the patient I care for, can
be included alongside what I say

I understand that I can stop taking part at any time and
do not have to say why I want to stop

I agree to take part in the interview

Name of participant  _______________  Date  ____________  Signature  _______________

Name of researcher  __________________  Date  ____________  Signature  _______________