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**Supporting the emotional and psychological needs of end-  
stage renal disease patients  
Study Report**

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CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

# Contents

	<b>Page</b>
<b>1. Executive Summary</b>	<b>4</b>
<b>2. Introduction and Background</b>	<b>11</b>
<b>3. Methodology</b>	<b>14</b>
3.1. Design	14
3.2. Ethics	16
3.3. Recruitment of respondents	17
3.4. Conduct	20
3.5. Analysis	22
<b>4. Results</b>	<b>23</b>
4.1. Introduction	23
4.2. Participants	23
4.3. Findings	24
<b>5. Discussion</b>	<b>67</b>
<b>6. Recommendations</b>	<b>72</b>
<b>7. References</b>	<b>74</b>
<b>8. Appendices</b>	<b>91</b>
Appendix 1 Details of study 1 patient participants	91
Appendix 2 Details of study 2 patient participants	91
Appendix 3 Patient Issues sheet	92
Appendix 4 Training provided for renal consultants	93
Appendix 5 Intervention film scripts for study 2	100
Appendix 6 Literature review (see separate document)	
<b>9. Tables</b>	
Table 1 Characteristics of the study patients	24

# 1. Executive Summary

## 1.1. Introduction

This Executive Summary set out the main findings from an evaluation of interventions to support the emotional and psychological needs of patients with end-stage renal disease. It was undertaken between June 2013 and January 2014 by researchers from the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Research and Care West Midlands (CLAHRC WM) with two NHS Hospital Trusts in the West Midlands.

A key finding to emerge from our West Midlands Central Health Innovation Education Cluster (WMC HIEC) research study 'Evaluation of case study sites for home therapies for people with chronic kidney disease' (2013) was that there are considerable needs amongst dialysis patients related to their emotional and psychological adjustment during the transition to dialysis and in the early months on dialysis. These needs were often unrecognised and therefore not responded to by their clinicians.

To understand better the context to these findings, a literature review was undertaken to identify and examine existing evidence on the emotional and psychological needs and support for end-stage renal disease patients. The review identified that the impact of emotional and psychological problems on end-stage renal disease patients' health and wellbeing can be significant. In relation to first, poor clinical outcomes including increased hospitalisation rates, mortality, and influence on timely listing for kidney transplantation. Second, behavioural compliance and medication adherence. Third, influence on patients choosing to withdraw from dialysis treatment. Fourth, acceptance and understanding of diagnosis and information provided, as well as treatment decision-making.

Yet renal clinicians appear to have difficulty recognising and responding to their patients' emotional and psychological needs, particularly those with lower level, mild to moderate needs. The indications are that only a minority of patients receive adequate support and treatment for these needs.

Whilst research on what end-stage renal disease patients themselves want and need in terms of emotional and psychological support is limited, studies clearly show they want

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improved support, particularly in the areas of adjustment, coping, and maintaining control. There is also little research specifically relating to interventions that support end-stage renal disease patients' lower level emotional and psychological needs. Although there is some evidence indicating positive impacts from specific therapeutic interventions including exercise and other types of intervention that address difficulties of coping and adjustment. There is a sizeable body of literature however relating to long term conditions in general that shows the benefits of physical activity programmes, peer support, mindfulness-based therapy, and cognitive behavioural therapy (CBT), including computerised CBT.

Evidence from the literature on long-term conditions also suggests clinicians can achieve significant positive health-related outcomes for their patients simply by adjusting their communication to give more explicit attention to emotional issues. Yet patients often fail to express their emotional concerns in consultations with clinicians. This may be because patients do not feel it is the role of their clinician to address such issues, they are discouraged by clinicians concentrating on the physical aspects of their disease, they do not want to burden their doctors, or a lack of empathy shown by their clinician.

Interventions that involve patients providing clinicians with written information about their emotional needs and concerns in advance of consultation, or that encourage patients to ask more questions during consultations, have been found to encourage discussion of emotional issues, improving patient's psychological wellbeing and reducing anxiety.

Discussions with clinicians from Renal Units in the West Midlands indicated that despite the existing evidence, there is some hesitancy to address emotional issues in clinical consultations with end-stage renal disease patients. Clinicians are reluctant to change established communication practice without evidence to the contrary it will result in emotional difficulties being raised that cannot be effectively responded to, and/or lengthen the consultation time.

Therefore on the basis of the literature review findings and learning from discussions with staff at Renal Units, the evaluation was designed to answer two key questions:

- Can two simple pilot interventions designed to adjust renal consultant-patient communication in routine consultations encourage consultants to talk explicitly with patients about their emotional feelings and concerns?
- From the patient perspective, what are their views in terms of needs, wants and expectations of interventions designed to support their lower level emotional and psychological needs?

## **1.2. Method**

The evaluation adopted a qualitative research design involving two linked studies. The first study used a qualitative design to evaluate how renal consultants and patients reacted to two simple pilot interventions designed to adjust consultant-patient communication and encourage consultants to talk explicitly with patients about their emotional feelings and concerns. One intervention involved participating renal consultants using a question based on National Institute for Health and Clinical Excellence (NICE) evidence-based guidance during routine out-patient consultations with patients. The second intervention involved patients using a Patient Issues sheet to identify 2 to 3 issues they would like to talk about and taking the sheet with them into their consultation. The participating renal consultants were trained by a renal psychologist to help them handle the issues raised by patients.

The second study also used a qualitative design to evaluate the views of patients about five evidence-based interventions, presented to patients as short audio-visual films, individually focused on the benefits of: training in mindfulness; peer support; computerised CBT; clinic time to discuss emotional needs (NICE evidence-based question and Patient Issues Sheet); and physical activity programmes managed and supported by the kidney unit (cycling while on dialysis and walking).

For the first study, semi-structured interviews were conducted with a total of 36 end-stage renal disease patients currently on dialysis (peritoneal dialysis or in-centre haemodialysis), for no more than 12 months, and 5 consultants who regularly hold consultations with end-stage renal disease patients on dialysis, from two Renal Units in the West Midlands. A telephone interview was undertaken with each patient and a face-to-face interview with each consultant.

For the second study, 9 semi-structured interviews, and 2 mini-focus groups each with 3 participants, were conducted among end-stage renal disease patients from the same two Renal Units in the West Midlands. A total of 7 patients were at the pre-dialysis stage of treatment and 8 patients were currently on dialysis (peritoneal dialysis or in-centre haemodialysis) and for no more than 12 months. The interviews and mini-focus groups were conducted in participant's homes or Renal Units, dependent on participant choice.

### **1.3. Key Findings**

Patients liked both pilot interventions. The NICE evidence-based intervention prompted favourable reactions from patients asked the question in their consultation, as well as from patients not given the intervention but who were read the question and asked their views as part of their research interview. The key reasons patients mentioned for liking the intervention were first, its capacity to make them feel more emotionally cared for by their consultant. This was irrespective of whether or not a patient was currently experiencing any emotional difficulties. Second the intervention's ability to encourage patients to express their emotional worries. Some patients thought even if they were experiencing worry and anxiety they would be unlikely to disclose these feelings without an enabling prompt. Encouragement also came from being given the opportunity to speak out about emotional feelings. Another reason for patients liking the intervention was because it was thought beneficial for consultants to know how their patients feel emotionally in order to provide appropriate and better care. A minority of patients disliked the intervention, believing an admittance of feeling down or miserable would imply someone was depressed and they feared the associated stigma. There were also some patients who thought it personally unnecessary to be asked the question. Nonetheless across the study sample there was only one patient who said there should not be general use of the intervention by renal consultants.

For the second pilot intervention, the evaluation identified three main reasons why patients liked the Patient Issues sheet. First, the sheet was valued for being a helpful aide memoire enabling patients to recall during their consultation the issues they wanted to discuss. Second for being informative about the type and scope of issues that other renal patients might experience. The sheet provided useful guidance as to the kind of issues they could ask their consultant about. Third for giving the 'permission to engage'; the sheet was seen as allowing patients themselves to raise questions

about issues of personal interest for discussion with their consultant. The only dislike expressed about using the sheet, voiced by a single participant, was feeling under pressure to select three specific issues to talk about whereas they had only one issue of concern.

In general, patients who raised any issues for discussion with their consultant in response to one of the pilot interventions were satisfied with how the issues were handled. They felt pleased and comforted by the consultant taking time to answer their questions. For some patients it was the first occasion their consultant had provided information on an issue of particular emotional concern to them that might have been troubling them for a while. Several patients clearly experienced a sense of empathy from how their consultant handled the issue. Other patients whose consultants adopted more of a practical-focused response, with no consideration of any possible emotional or psychological factors, sometimes felt less helped and supported. There were also a few patients who expressed dissatisfaction because they thought their consultant had prevented or closed down discussion of issues they raised, and seemingly preferred to carry on with their normal consultation agenda.

Participating consultants used the two pilot interventions in very different ways. Five different approaches were identified from the study data: empathetic sharing; solution-seeking; patient-led; explanatory; and patient-typology targeted.

Overall the reactions of consultants to the pilot interventions were mixed but generally favourable. Those who expressed the most positive views about the NICE evidence-based question particularly liked the intervention because they found it 'opened the door' to an improved understanding of a patient's emotional wellbeing – adding to what was already known about their medical health – and enabling better whole-patient care. The intervention was also liked by some consultants because it helped identify patients with emotional support needs whom they might not have expected to have emotional difficulties. The main dislike of the question was that its direct and downbeat content might negatively impact on the mood and tempo of a consultation.

Whilst clinician views of the Patient Issues sheet itself were very favourable, opinions were more mixed about how the intervention as a whole worked. For some consultants the sheet failed to live up to expectations in terms of prompting patients to raise questions on aspects of their emotional care which were unaddressed. Few patients

spontaneously used the sheet without consultant encouragement and support. Yet one consultant using the sheet in a two-way manner with their patients, together looking at and discussing issues marked on the sheet, really liked the intervention and found it promoted discussion of issues patients wanted to discuss.

A considerable level of unmet emotional need was revealed among patients participating in the evaluation. While more than a third of patients across the two studies mentioned existing emotional concerns, or recently experiencing emotional difficulties, only a small minority had used a support intervention prior to participating in the evaluation. Very few patients were aware of any available interventions to meet lower level emotional and psychological needs. Only one patient mentioned talking to their renal consultant as their usual coping strategy.

The evaluation also revealed that some consultant approaches to consultations in general make patients feel better cared for emotionally, including: treating and respecting patients as individuals in a personal relationship with their consultant; having an on-going conversation from consultation to consultation which constitutes part of a continuous relationship; aspects of a patient's behaviour or condition being positively commented upon; providing clear and understandable explanations in layman's language; and, encouraging questions and responding by listening attentively and communicating with empathy.

Participating in a physical activity programme, either walking or cycling while on dialysis was the most popular of the five interventions shown to patients as audio-visual films. The main reason given for liking the intervention was because there were perceived to be both emotional and physical benefits derived from exercising. They liked the premise that through using the exercise programme they could lose weight, improve their blood pressure and achieve a better emotional mood. Another perceptual advantage seemed to be there was no explicit association between the intervention and experiencing depression and therefore it could feel less stigmatising than some interventions. Each of the other interventions received a more mixed response with some patients very keen and others not at all. Computerised CBT had the least favourable response mainly because of the impression that being an 8-week course, lengthy and skilled computer usage was required. Also female patients in particular said they would prefer to speak to someone face-to-face if they were feeling low.

## 1.4. Conclusions

The evaluation identified that both pilot interventions, the NICE evidence-based question and the Patient Issues sheet, could impact positively on what was talked about in consultations. The form, manner and context in which consultants and patients used each intervention tended to determine how effective it was in encouraging explicit discussion about emotional feelings and concerns.

There were two aspects of the NICE evidence-based intervention that seemed to provide the means to encourage emotional disclosure. First, its capacity to make patients feel more emotionally cared for by their consultant; simply by asking the question consultants were showing emotional support was available. This provided reassurance about the acceptability of disclosure. Second its role as an enabling prompt. By asking a direct question, patients who lacked confidence or ability to spontaneously express emotional feelings could be given the opportunity and a helping hand by their consultant to speak out. Whilst some consultants were uncomfortable about using such a direct, specific question, most patients liked and supported its use.

The evaluation revealed that the Patient Issues sheet successfully overcame some significant barriers inhibiting patient question-asking in consultations; in particular patients perceiving it unacceptable to ask questions, and forgetting the questions they want to ask. However there were also some important enabling factors requiring consultant support, notably the opportunity and confidence to ask questions, before many patients would make active use of the sheet. Patients willing and able to spontaneously introduce the sheet into the consultation without consultant assistance appeared to have higher levels of self-efficacy, although we did not specifically measure this dimension. There were many other patients in the study who seemed to have lower levels of self-efficacy. For them, use of the intervention required consultant support. The intervention therefore seemed to work best in having an impact on what was talked about when used in a two-way communication process between patient and consultant, and as an integral part of the consultation.

The evaluation has achieved a better understanding of what patients need, want and expect from interventions to support their lower level emotional and psychological needs and identified how these can be met better. Most patients wanted improved emotional and psychological support. Yet receptivity to the evidence-based

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interventions shown as audio-visual films varied across the study sample, dependent on a complex mix of emotional status, anticipated self-efficacy, existing support networks, type of dialysis treatment, emotional readiness to share feelings with others, and relevance of perceived benefits. It was also apparent that motivation to take-up an intervention can vary over time. Nonetheless patients in general felt reassured and better supported simply by knowing that consultant-endorsed support was available, if and when required.

For many patients, fear of the stigma of being perceived as suffering from depression is a significant psychological barrier to taking-up a support intervention. Any perceived association with depression tended to make an intervention less attractive, whilst those perceived as inclusive and suitable for any renal patients were more motivating. This would suggest any intervention for mild to moderate emotional difficulties should be promoted by clinicians as being 'normal' support for renal patients.

Patients can feel more cared for emotionally as result of certain behaviours and communications by their renal consultants. Whilst such approaches are unlikely to address emotional and psychological difficulties, they can play a significant moderating role in relation to some of the trauma and distress effects, and provide a valuable sense of emotional support. Whether or not a patient felt emotionally cared for was also shown to play a role in facilitation of emotional disclosure in relation to use of the two pilot interventions.

## **2. Introduction and Background**

This report presents the findings from an evaluation of interventions to support the emotional and psychological needs of patients with end-stage renal disease. The study was undertaken by researchers from the National Institute for Health Research (NIHR) Collaborations for Leadership in Applied Research and Care West Midlands (CLAHRC-WM). The CLAHRC-WM is hosted by the University of Birmingham and includes a range of stakeholders from across Birmingham and the Black Country. It aims to develop and promote a more efficient, accelerated and sustainable uptake of clinically innovative and cost-effective research interventions into better patient care.

A key finding to emerge from our West Midlands Central Health Innovation Education Cluster (WMC-HIEC) research study 'Evaluation of case study sites for home therapies CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

for people with chronic kidney disease' (Combes, Sein and Allen, 2013) was that there are considerable needs amongst dialysis patients related to their emotional and psychological adjustment during the transition to dialysis and in the early months on dialysis. These needs were often unrecognised and therefore not responded to by their clinicians. There was also some evidence that emotional and psychological distress can impact negatively on patients' ability to engage with treatment decision-making. The study results suggested many patients might benefit from some form of emotional and psychological support during the transition to end-stage renal failure, the most feasible interventions probably being low level interventions that could be incorporated into everyday clinical practice and are relatively easy and cheap to implement. It was recommended that further research be undertaken to review the effectiveness of low level interventions and assess the appropriateness of different interventions for renal patients.

To understand better the context to these findings, a literature review was undertaken to identify and examine existing evidence on the emotional and psychological needs and support for end-stage renal disease patients. The review identified that the impact of emotional and psychological problems on end-stage renal disease patients' health and wellbeing can be significant. In relation to, first, poor clinical outcomes including increased hospitalisation rates (Hedayati et al 2005, 2008, and 2010), mortality (Kimmel et al 2000; Lopes et al 2002; Lopez, 2004; Boulware, 2006), and influence on timely listing for kidney transplantation (Szeifert et al, 2012). Second, behavioural compliance and medication adherence (Taskapan et al, 2005; Cukor et al, 2009; Theofilu, 2012). Third, influencing patients' choice to withdraw from dialysis treatment (Cohen et al, 2002; McDade-Montez et al, 2006). Fourth, impact on acceptance and understanding of diagnosis and information provided, as well as treatment decision-making (Tong et al, 2009; Morton et al, 2010; Major and Glass, 2010; Schell et al, 2012).

Yet renal clinicians appear to have difficulty recognising and responding to their patients' emotional and psychological needs, particularly those with mild to moderate needs at lower levels of the 'pyramid of psychological problems' (Bass et al, 1999; Weisbord et al, 2007; Schell et al, 2012). Indications are that only a minority of patients receive adequate support and treatment for these needs (British Renal Society, 2002; Watnick et al, 2003; Hedayati et al, 2008).

Whilst research on what end-stage renal disease patients themselves want and need in

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terms of emotional and psychological support is limited, studies clearly show they want improved support, particularly in the areas of adjustment, coping, and maintaining control (Ormandy et al, 2007; Tong et al, 2009; Schipper and Abma, 2011). There is also little research specifically relating to interventions that support end-stage renal disease patients' lower level emotional and psychological needs. Although there is some evidence indicating positive impacts from specific therapeutic interventions including exercise (Van Vilsteren et al, 2005; Ouzoni et al, 2009; Greenwood et al, 2012; Anand et al, 2012), and other types of intervention that address difficulties of coping and adjustment (Leake et al, 1999; Tsay et al, 2004). There is a sizeable body of literature however relating to long term conditions in general that shows the benefits of physical activity programmes (National Collaborating Centre for Mental Health, 2010); peer support (Zabalegui et al, 2005; National Collaborating Centre for Mental Health, 2010; Dennis, 2003; Hughes et al 2009; Taylor and Gutteridge, 2013); mindfulness-based therapy (Baer, 2003; Hofmann et al, 2010; Fjorback et al, 2011; Khoury et al, 2013); and cognitive behavioural therapy (CBT), including computerised CBT (Proudfoot et al, 2004; Kaltenthaker et al, 2008; National Collaborating Centre for Mental Health, 2010; Foroushani et al, 2011).

Evidence from the literature on long-term conditions also suggests clinicians can achieve significant positive health-related outcomes for their patients simply by adjusting their communication to give more explicit attention to emotional issues (Kaplan, Greenfield and Ware 1989; Griffin et al 2004; and White, White and Russel, 2007). Yet patients often fail to express their emotional concerns in consultations with clinicians (Anderson et al, 2008; Butow et al, 2002). This may be because patients do not feel it is the role of their clinician to address such issues (Ryan et al, 2005), they are discouraged by clinicians concentrating on the physical aspects of their disease (Maguire, 1985), they do not want to burden their doctors (Maguire, 1985), or a lack of empathy is shown by their clinician (Maguire et al 1996; Butow et al, 2002; Pollack et al, 2007; Anderson et al, 2008).

Interventions that involve patients providing clinicians with written information about their emotional needs and concerns in advance of consultation, or that encourage patients to ask more questions during consultations, have been found to encourage discussion of emotional issues, improving patients' psychological wellbeing and reducing anxiety (Greenfield et al, 1988; Butow et al, 1994; Brown et al, 2001).

Discussions with clinicians from Renal Units in the West Midlands during early 2013  
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indicated there is some hesitancy to address emotional issues in routine clinical consultations with end-stage renal disease patients. Clinicians expressed reluctance to change established communication practice without evidence to the contrary that it will result in emotional difficulties being raised that cannot be effectively responded to, and/or lengthen the consultation time.

Therefore on the basis of the literature review findings and learning from discussions with staff at Renal Units, the evaluation was designed to answer two key questions:

- Can two simple pilot interventions designed to adjust renal consultant-patient communication in routine consultations encourage consultants to talk explicitly with patients about their emotional feelings and concerns?
- From the patient perspective, what are their views in terms of needs, wants and expectations of interventions designed to support their lower level emotional and psychological needs?

### **3. Methodology**

#### **3.1. Design**

The evaluation adopted a qualitative research design involving two linked studies. Study 1 used a qualitative design to evaluate how renal consultants and patients reacted to two different pilot interventions designed to offer end-stage renal disease patients 'lower level' emotional and psychological support. One intervention involved participating renal consultants during routine consultations, for half the patient sample, using a question based on National Institute for Health and Clinical Excellence (NICE, 2009) evidence-based guidance, for asking patients about their emotional and psychological difficulties. The final wording for this question was agreed by the consultants participating in the study, at the conclusion of their training. The wording decided upon was:

'During the last few weeks have you been feeling down or miserable at all?'

The second intervention involved half the patient sample (not receiving the other intervention), being asked to complete a Patient Issues (PI) sheet while waiting in the

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Renal Unit prior to their consultation. The intervention design was based on findings from the literature review that highlighted the value of patients providing clinicians with written information about their emotional needs or using question prompt sheets, in terms of encouraging discussion of emotional issues during consultations (Butow et al, 1994; Brown et al, 2001).

Wording on the sheet asked patients to mark from the issues shown relating to their illness, which 2 or 3 issues they would most like to talk about with their clinician during their consultation that day. A range of individually circled emotional as well as physical issues were included together on the sheet. The issues selected for inclusion were based on evidence from the literature review of key emotional and physical symptoms that end-stage renal disease patients claimed to experience (Weisbord et al, 2007; Bass et al, 1999). The issues ranged from feelings about treatment and the impact on patients' lives, to practical and clinical issues. There were also blank circles for patients to add their own issues they would like to talk about. Patients were asked to have the sheet with them during their consultation. The sheet was yellow in colour to make it easier for patients to read, and more obvious to consultants. Appendix 3 contains the Patient Issues sheet.

Both pilot interventions were only used after participating consultants had received training from a renal psychologist on how to handle patient responses. Before the evaluation commenced, the interventions were trialled by the participating consultants among a minimum of 2-3 patients each, with follow-up training provided by the renal psychologist, in relation to how patient responses were handled. Appendix 5 contains details of the training programme.

Study 2 also used a qualitative design to evaluate the views of renal patients about 5 evidence-based interventions presented to patients as short audio-visual films. The interventions were selected on the basis of existing evidence of their effectiveness in addressing the emotional and psychological needs of renal patients, as well as the capacity of the two research sites to provide the interventions for end-stage renal disease patients. Each film included visual clips of the intervention in use with an explanatory voice-over, followed by two actor patients talking about the intervention benefits. The five interventions were: training in mindfulness; peer support; computerised CBT; clinic time to discuss emotional needs (NICE evidence-based question and Patient Issues Sheet); and physical activity programmes managed and

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supported by the kidney unit (cycling while on dialysis and walking). The intervention scripts were tested among patient representatives before being finalised for filming.

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

For Study 1, a minimum sample size of 56 patients, 28 patients from each of the two study sites, was decided upon, in order to meet the aims and objectives of the study. It was also decided to recruit within each study site, up to 3 renal consultants. For Study 2, there was an agreed minimum sample size of 16 patients, 8 patients from each of the two study sites, including 4 pre-dialysis patients and 4 patients who have been on dialysis (HD, HHD or PD) for no more than 12 months. For each study, a purposively selected sample was planned based on the study inclusion criteria and to give maximum variation of age, gender, ethnicity and dialysis treatment type.

### **3.2. Ethics**

Ethical permission was obtained from NRES Committee London-Fulham Research Ethics Committee (13/LO/0443). The study was also approved by the Research Governance office of each of the two NHS Hospital Trusts involved in the study.

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 clinicians was viewed as an ongoing process. Ethical processes were informed by the three key principles identified by Christians (2000) - *“respect for persons, beneficence, and justice”*.

All patients eligible to participate in either study 1 or study 2, and consultants who had expressed an interest in participating in study 1, were provided with information about the study by letter or email, prior to consent being taken. This gave them an opportunity to consider in more detail whether they wished to participate and to raise questions. 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.

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End-stage renal disease is an extremely serious condition and patients were likely to have other chronic illnesses. Therefore there was potential for patient participants to feel tired or in pain, or to become upset when talking about their condition. Mindful of these issues, it was ensured that patient 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 or mini-focus group 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 a named nurse within their own Renal Unit.

### **3.3. Recruitment of respondents**

#### **Study 1**

Consultants identified as being interested in participation through initial visits by the study researchers to each Renal Unit, were sent an Information Sheet and Consent Form by the study researchers, explaining the full purpose of the study and what participation would involve. They were asked to sign the Consent Form. Participating consultants were to include the interventions in their routine consultations with all patients that had the identified characteristics of the study patient sample, until the study sample has been achieved.

One Hospital Trust provided the research team with an anonymised list of all patients who had started on dialysis in the last 12 months, fitted the study inclusion and exclusion criteria, and attended routine consultations with one of the participating consultants. Original plans to select a minimum sample of 28 patients from the site based on achieving maximum variation in age, sex and ethnicity across the different types of dialysis were amended in light of there being only 34 patients on the list. It was decided to include all 34 patients in the potential study sample. Every two weeks during the fieldwork period, a medical secretary in the Renal Unit provided one of the study researchers with an anonymised list of patients scheduled to attend consultations with participating consultants. The study researcher then identified patients within the study sample.

At the other Trust, a Renal Unit staff member identified a list of all patients who had started on dialysis in the last 12 months, fitted the study inclusion and exclusion criteria, CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

and attended routine consultations with one of the participating consultants. Again the original plans to select a minimum sample of 28 patients from the site based on achieving maximum variation in age, sex and ethnicity across the different types of dialysis were amended in light of there being only 41 patients on the list, all of whom were included in the potential study sample. Each week two medical secretaries provide the research team with anonymised lists of patients within the study sample who would be attending a routine consultation the following week at the Renal Unit with one of the participating consultants.

The lead consultant of each Renal Unit sent a letter to the selected patients a week before they were due to attend a routine consultation at their Renal Unit, with an Information Sheet explaining the full reasons why they were being invited to take part, and what participation would involve. When each patient came to the Renal Unit, before their consultation, the nature and the purpose of the study was again explained to them by a study researcher and any concerns discussed. This discussion took place privately, in the majority of cases in a private room away from the general waiting area. In order not to influence the consultation process and discussion content, the Information Sheet explained that patients were being invited to participate in a study to gather the views of patients on their most recent clinical consultation with their consultant; participation was not linked to consultation discussion of emotional issues.

If the patient wished to participate they were asked to sign a Consent Form. Also a convenient date and time for telephone interview was identified, 7-14 days after the consultation. All those patients consenting to be interviewed were telephoned on the agreed date and time and the patients were again asked to give their consent before the interview commenced. One patient was interviewed more than 14 days after the consultation because the patient requested a later interview date.

Patients that consented to participate in the study were randomly allocated to receive one of the two pilot interventions. Just over half the patient sample - 21 patients - were asked to complete a PI sheet before their consultation. The remaining 16 patients did not receive the PI sheet but were identified to receive the NICE evidence-based question intervention.

Within one Hospital Trust, 5 eligible patients (15% of the total) refused consent to participate in the study, and 15 patients (37% of the total) in the second Hospital Trust.

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There are several hypotheses to explain the higher level of refusals in the second Hospital Trust: all eligible patients were on HD (with an older age profile than PD patients); it was not always possible to take consent in a separate private room away from the waiting area; unlike in the first Hospital Trust, there was no renal nurse to first identify eligible patients for the study researcher; a different study researcher had main responsibility for taking consent.

Two patients were interviewed in Punjabi with translation undertaken by a study researcher. Another three patients were interviewed along with a relative who had also attended the patient's consultation, with the relative undertaking interpretation, which may have had some influence on the patients' reported responses.

## **Study 2**

Within each Hospital Trust a member of staff identified all those patients currently on dialysis who were eligible for participation, based on the inclusion and exclusion criteria. A study researcher then removed from this sample, all patients who had participated in study 1. In addition, in one Trust a study researcher, and in the other Trust a member of staff, selected from anonymised spreadsheets a purposively selected patient sample of pre-dialysis patients, based on the study inclusion criteria and to give maximum variation of age, gender and ethnicity.

The lead consultant of each Renal Unit then sent a letter to the selected patients, with an Information Sheet explaining the full reasons why they were being asked to take part in the study and what participation would involve. It was also explained they would be contacted during the following week by a member of staff from their Renal Unit asking them whether they were interested in taking part in the study and were willing for their name and phone number to be passed onto the study researchers. A total of 29 patients from one Hospital Trust were sent a letter, 14 patients who were currently on dialysis, and 15 pre-dialysis patients. In the other Hospital Trust, a total of 24 patients were sent a letter, 12 patients who were currently on dialysis and 12 pre-dialysis patients. Patients who were willing for their contact details to be passed on to the study researchers, were then contacted by a researcher to arrange a convenient date, time and location for the interview or mini-focus group, dependent on the patient's choice, assuring the participant this could be revised dependent on their needs.

### **3.4. Conduct**

#### **Study 1**

36 individual semi-structured telephone interviews were conducted among adult patients with end-stage renal disease. In addition 5 face-to-face individual semi-structured interviews were undertaken with participating renal consultants. None of the consultants was newly qualified. The interviews were conducted in two NHS Hospital Trusts between July 2013 and December 2013. In one study site interviews took place between July and September 2013, whilst in the second site recruitment difficulties extended data collection to end December 2013. The main difference between the study sites was that one site provided a renal psychology service and patient support group to which patients with identified emotional and psychological difficulties could be referred by renal consultants. These support services were not available at the second study site.

The criteria for the patient sample selection were adult patients with end-stage renal disease, on dialysis (HD, PD or HHD) for no more than 12 months, receiving treatment at one of the two Renal Units participating in the study, attending a routine clinical consultation during the fieldwork period, 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 who were clinically unstable or too unwell to be interviewed, or lacked the capacity to give informed consent. Additionally patients were excluded if they were currently accessing psychological support (counselling, psychologist, or psychiatrist).

The criteria for the clinician sample were renal consultants who regularly hold routine clinical consultation for end-stage renal disease patients on dialysis (HD, PD or HHD) at one of the two participating Renal Units, willing to be trained in the use of the two pilot interventions and to then use the interventions in their clinical consultations during the fieldwork period, and willing to be interviewed.

A single telephone interview of 10 to 50 minutes took place with each patient participant. A semi-structured interview schedule was used with 17 open-ended questions. All participants were asked about the recent consultation at the Renal Unit with their consultant, what was discussed, and if there was discussion about any things they felt concerned or worried about in relation to their illness or treatment. Each patient was questioned as to whether their consultant had asked them during the consultation,

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if during the last few weeks they had been feeling down or miserable at all. Patients that said they had been asked this, were then questioned about how they felt, and whether or not they found it helpful. Those participants not asked, were questioned about whether or not they would have found it helpful to have been asked. The patients in the sample given a PI sheet and asked to complete it while they waited in the Renal Unit before their consultation, were additionally questioned about their views of the PI sheet, how and when they used the sheet, what worked well and what could be improved.

Each clinician participating in the study was interviewed in a single, face-to-face interview of 35-75 minutes. A semi-structured interview schedule was used with 22 open-ended questions. In relation to each of the pilot interventions, in rotated order, all the consultants were asked: their general thoughts, how they had used the intervention, how they handled patient responses, how comfortable they were using the intervention, particular likes and dislikes, perceived benefits, and suggested improvements.

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 wished to proceed, they were asked to sign a consent form and asked if they were happy for the interview to be recorded.

## **Study 2**

A total of 9 face-to-face semi-structured individual interviews, and 2 mini-focus groups of 3 patients each were conducted among adult patients with end-stage renal disease. The interviews and mini-focus groups were conducted in two NHS Hospital Trusts (the same study sites as for Study 1) during December 2013. The criteria for the patient sample selection were adult patients with end-stage renal disease at the pre-dialysis stage and with a dialysis plan, or on dialysis (HD, PD or HHD) for no more than 12 months, and receiving treatment at one of the two Renal Units participating in the study, and willing to take part in an interview or focus group. Exclusions put in place ensured there was no participation from among those patients who were clinically unstable or too unwell to be interviewed, or lacked the capacity to give informed consent. Patients were also excluded if they were currently accessing psychological support (counselling, psychologist, or psychiatrist).

A single face-to-face interview of 45-60 minutes or a mini-focus group of 75-90 minutes took place in the home or Renal Unit of each patient participant, dependent on participant choice. A semi-structured interview schedule was used with 14 questions. All participants were asked to briefly describe themselves and about whether they had ever received any support for concerns or issues felt about their illness or treatment. In relation to each of the pilot interventions, in rotated order, all participants were asked: their general feelings, the main thing communicated, particular likes and dislikes, anything difficult to understand, who would benefit most from using and suggested improvements. Participants were also asked which intervention concept they were most interested in using.

Before an interview or mini-focus group commenced, the nature and purpose of the interview was explained and any concerns discussed. It was stressed that the interviews and mini-focus groups were entirely voluntary, questions could be unanswered without explanation and all responses were confidential to the University of Birmingham researchers. If the participant wished to proceed, they were asked to sign a consent form and asked if they were happy for the interview or mini-focus group to be recorded.

### **3.5. Analysis**

To help reduce any possible bias during collection of data, ongoing discussions were held between the study researchers concerning interview procedure and approach to asking questions. All the evaluation interviews and mini-focus groups were recorded and transcribed verbatim.

Separate evaluation frameworks were developed for the study 1 patient interviews, the study 1 consultant interviews and the study 2 interviews and mini-focus groups. The evaluation frameworks were designed on the basis of emerging issues from the first third of the interviews for each participant group. Verbatim data was entered onto separate spreadsheets with fields generated from each research framework. Additional fields were added to reflect new issues emerging from subsequent interviews. Transcripts of the interviews and mini-focus groups were analysed separately before data was inputted into the spreadsheets. Each of the patient and consultant transcripts was read several times by one researcher to identify all super-ordinate or sub-issues. A random selection of 10 per cent of the patient and consultant transcripts were cross-

checked by a second researcher so that the identified issues could be discussed and validated, and to ensure consistency with data selection for entry onto the spreadsheets. Spreadsheet data collected from the interviews was analysed simultaneously with the ongoing conduct of fieldwork. The spreadsheet data and emerging issues were also discussed by the study researchers at several stages during fieldwork, and after fieldwork completion.

## **4. Results**

### **4.1. Introduction**

This section presents a synthesis of the findings from the evaluation, involving two linked studies, designed to answer the following questions:

- Can two simple pilot interventions designed to adjust renal consultant-patient communication in routine consultations encourage consultants to talk explicitly with patients about their emotional feelings and concerns?
- From the patient perspective, what are their views in terms of needs, wants and expectations of interventions to support their lower level emotional and psychological needs?

### **4.2. Participants**

For study 1, a total of 5 renal consultants participated, 3 consultants within one Hospital Trust and 2 consultants in the other Trust. There were a total of 36 patient participants: 27 patients from one Trust and 9 patients from the other Trust. Across the whole sample for the first study, 3 patients were aged less than 40 years, 16 patients aged 40-64 years, and 17 patients were over 65 years. In terms of dialysis treatment type, 21 patients were on PD and 15 patients on in-centre PD. The sample contained 14 participants whose time on any dialysis treatment was less than 3 months, 8 participants who had been dialysing 4-6 months, 5 participants for 7-9 months, 7 participants for 10-12 months. Due to recruitment error, 2 participants in the sample had been dialysing for more than for 12 months. None of the patients was a 'crash lander'.

<b>Table 1: Characteristics of the study participants</b>				
	<b>Study</b>		<b>Total</b>	
	<b>1</b>	<b>2</b>	<b>No.</b>	<b>%</b>
<b>Age group</b>				
18-39	3	2	<b>5</b>	<b>10%</b>
40-64	16	9	<b>25</b>	<b>49%</b>
65+	17	4	<b>21</b>	<b>41%</b>
<b>Gender</b>				
Female	12	6	<b>18</b>	<b>35%</b>
Male	24	9	<b>33</b>	<b>65%</b>
<b>Ethnic Group</b>				
White British	25	12	<b>37</b>	<b>72%</b>
Black British	2	-	<b>2</b>	<b>4%</b>
Asian British	9	3	<b>12</b>	<b>24%</b>
<b>Treatment type</b>				
PD	21	5	<b>26</b>	<b>51%</b>
In-centre HD	15	3	<b>18</b>	<b>35%</b>
Pre-dialysis	-	7	<b>7</b>	<b>14%</b>
<b>Time on dialysis</b>				
0-3 months	14	1	<b>15</b>	<b>29%</b>
4-6 months	8	2	<b>10</b>	<b>20%</b>
7-9 month	5	4	<b>9</b>	<b>17%</b>
10-12 months	7	1	<b>8</b>	<b>16%</b>
12+ months	2	0	<b>2</b>	<b>4%</b>
Pre-dialysis	n/a	7	<b>7</b>	<b>14%</b>

There were 24 males in the sample and 12 females. In terms of ethnicity, 25 patients in the study were White British, 9 participants were Asian British and 2 Black British. Table 1 details the demographic characteristics of the patients, and Appendix 1 the study participants.

Study 2 had a total of 15 participants. 2 participants were aged less than 40 years, 9 were aged 40-64 years, and 4 were over 65 years. 7 patients were at the pre-dialysis stage, 5 patients were on PD treatment and 3 patients on HD. Among the patients on dialysis, the time they had been on any form of treatment ranged from 0-3 months (1 patient), 4-6 months (2 patients), 7-9 months (4 patients) and 10-12 months (1 patient). None of the patients was a 'crash lander'. The sample contained 9 male patients and 6 female patients. There were 12 White British in the sample and 3 Asian British. Table 1 details the demographic characteristics of the patients in the study, and Appendix 2 the study participants.

### 4.3. Findings

The findings are detailed in seven main sections linked to the analytical frameworks used for data analysis. They are presented for the two study sites as whole since there were insufficient patient participants in one study site to make cross-site comparisons. Any notable differences by socio-economic group, dialysis type, or length of time on dialysis are highlighted.

#### 4.3.1. Patients liked the interventions

Patients were predominantly very positive in their responses to both pilot interventions.

##### ***Favourable reactions to the NICE evidence-based intervention***

The NICE evidence-based question prompted favourable reactions from patients who said they had been asked the question during their consultation, as well as from patients not given the intervention but who were read the question and asked their views as part of their research interview. Only one patient thought consultants should not ask their patients the question, whilst two patients were undecided.

A key reason why patients liked the intervention was its capacity to make them feel more emotionally cared for by their consultant (mentioned by 31% of all patients). This was irrespective of whether or not a patient was currently experiencing any emotional issues. Simply by asking the question, consultants were showing there was emotional support available.

*“It shows that somebody cares.”* Patient 36 (Study 1)

An important aspect of the intervention’s capacity to convey emotional care seems to be the reassurance offered that emotional disclosure is acceptable during a consultation. This was particularly pertinent for patients who had experienced negative feelings in the past about their illness or treatment. It was also comforting for patients with no current emotional problems to know that if in future they were feeling down, it was possible to talk about any emotional issues with their consultant.

*“It puts my mind at ease that people are there to help me, guide me, reassure me.”*  
Patient 27 (Study 1)

*“Oh that’s quite alright asking me, yes. I don’t mind that at all... if I was worried then I could tell them how I feel.”* Patient 29 (Study 1)

The second most frequently mentioned reason for liking the NICE evidence-based question was that it encouraged patients to express their emotional worries (mentioned by 28% of all patients). Some patients thought, even if they were experiencing worry and anxiety, they would be unlikely to disclose these feelings without an enabling prompt. By being asked a direct question, patients who lacked confidence or ability to spontaneously express emotional concerns, felt they were being given the opportunity and a helping hand by their consultant to speak out about emotional feelings. For a female HD patient with experience of long waits in the Renal Unit because her consultant was very busy, the intervention gave permission to use consultant time on discussing emotional issues.

*“I mean, I think if you start going on how you’re actually feeling or if I go in and say “well look, I’m feeling a bit depressed” and you’re wondering whether you’re encroaching on their time...I know they haven’t got a lot of time but, I mean, you might feel as though yes you are taking up extra time and they really perhaps don’t want to be bothered so you perhaps don’t talk about it with them.”* Patient 35 (Study 1)

Another key reason for liking the intervention was because it was thought beneficial for consultants to know how their patients feel emotionally, in order to provide appropriate and better care (mentioned by 22% of all patients). Several patients articulated the view that it was an expected and accepted part of the consultant role to care for the general wellbeing of the whole patient. Therefore they viewed the intervention as having positive benefits for both doctor and patient: it would lead to disclosure of emotional issues affecting the patient’s wellbeing, allowing the doctor to do something about that and thereby improve their overall care.

*“I would think it would be helpful for the consultant to know how his patient feels. Then if there are problems he can find means and ways of making this patient less miserable....For the wellbeing of the patient.”* Patient 2 (Study 1)

Significantly, a female PD patient who during her interview mentioned having emotional difficulties in adjusting to being on dialysis, and with whom the intervention was not used, said she would have found it beneficial. She suggested that had she been asked

the NICE evidence-based question, she would have been able share the burden of her emotional concerns.

*“I think I would have found it helpful because sometimes I go to see them and I’m absolutely desperate and I feel as though I want to talk. Do they realise how debilitating it is?”* Patient 14 (Study 1)

The main dislike of the intervention, mentioned by a small minority of patients, was that admittance to feeling down or miserable would imply someone was depressed. For a few patients there was some stigma attached to depression. A female HD patient explained that she might admit to feeling miserable but not to being depressed. Another patient worried that answering the question in the affirmative might lead to him being put on anti-depressants.

There were several patients who thought it personally unnecessary to be asked the NICE evidence-based question. This was because they either had no emotional concerns at the time, or used their own personal support networks to manage any emotional problems. A minority of patients said if they were feeling down or miserable, they would spontaneously mention it to their consultant without needing to be asked. Nonetheless these patients supported general use of the intervention by consultants, recognising many patients do experience emotional difficulties and may not necessarily have good support networks or the confidence to disclose their feelings.

*“Of course, everyone isn’t the same as me. Each and every patient is different, so no doubt some patients get very depressed and very, very upset, and it could be of great importance if they need some further medication or some further consultation or some psychology and some, I don’t know, but yes, of course, I think they should (consultants ask the question).”* Patient 18

Across the total sample, there was only one patient that argued the NICE evidence-based question should not be asked by consultants. He strongly felt that the best approach was to sort out your own personal problems without the support of the consultant.

*“I’m pretty much a firm believer in if you can heal yourself, do it. You’re your own body’s best influence, aren’t you?”* Patient 24 (Study 1)

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### ***Positive responses to the Patient Issues sheet***

The Patient Issues sheet also received an appreciative reaction from patients. The evaluation identified three main reasons why patients liked the sheet. First, it was valued for being a helpful aid memoire (mentioned by 50% of patients who made use of the sheet), enabling patients to recall during their consultation the issues they wanted to discuss. Some patients said that without the sheet they may not have remembered their questions to ask. They gave several different reasons why a memory prompt was necessary: having a poor memory, feeling under pressure or stressed during consultations, and perceived time constraints within which to respond to being asked “do you have any questions?”

*“The sheet helped me because I’d got those three rings round the items I was interested in. I knew what I was going to say and what I was going to ask.....You see, a lot of people don’t ask the right questions. They get muddled in their mind and therefore it affects their health.....I think especially somebody who’s frightened if they just get that little bit of encouragement, I think that’ll go a long way because some people might just suddenly close up or get tongue-tied and then the moment’s gone isn’t it?”* Patient 1 (Study 1)

A second key reason why patients liked the sheet, particularly those who had been on dialysis for less than 6 months, was for being informative about the type and scope of issues that other renal patients might experience (44% of patient users). The information provided useful guidance as to the kind of issues it was possible to ask their consultant about.

*“Basically gives an idea to what to kind of ask.”* Patient 6 (Study1)

Third, the sheet was liked for offering the ‘permission to engage’ (31% of patient users). It was seen as allowing patients themselves to raise questions about issues of personal interest and concern for discussion with their consultant, including emotional issues. Some patients said that without the intervention they would not have felt able to ask their consultant about the issues they did in the consultation. Two younger male patients who had been on PD less than six months claimed use of the PI sheet helped them get more of what they wanted out of the consultation. They viewed this as a positive departure from the standard consultation with a mostly consultant-led agenda.

*“It prompted me to ask the questions. Had I not have had that form, I might not have asked the questions.” Patient 18 (Study 1)*

*“I kind of almost felt I didn’t really have permission to talk about that (prognosis), really, until the yellow sheet.... I think probably without the yellow sheet, I probably wouldn’t have had that conversation about the prognosis.” Patient 16 (Study 1)*

There were several other reasons, although less frequently mentioned, why patients responded favourably to the PI sheet. A few patients gave plaudits for the opportunity and space provided on the sheet to add additional issues. They appreciated the recognition of patients as individuals: that whilst there may be many shared issues experienced in relation to their disease and treatment, patients may also have particular personal issues of concern which need to be raised and discussed.

*“The thing that I liked there was I suppose space to put your own thoughts there as well, plenty of boxes there, and that’s I think quite good because not everything is covered in those and everybody wants something different but it just makes you think doesn’t it?” Patient 26 (Study 1)*

For one male patient, treated on HD for less than 2 months, the main value of the PI sheet was it helped normalise emotional and psychological feelings, including depression, which might be associated with kidney disease. He believed showing such issues on the sheet would reassure patients, new to dialysis like himself, that experiencing negative feelings was to be expected; giving them the confidence to mention such feelings to their consultant.

*“There’s things on there about, you know, some of the circular things are about feelings, depression and stuff like this. That will be, for a lot of people, that’ll be very frightening for them to admit that in that room, but if they see it on a piece of paper issued by the hospital or the consultant, they suddenly start maybe to relax and think, ‘Oh, it’s quite normal to be upset. It’s quite normal to feel depressed. It’s quite normal for that feeling or that feeling or worry about this.’ And therefore it would give them confidence to ask about it, as well.” Patient 13 (Study 1)*

The only dislike expressed about using the PI sheet, voiced by a single participant, was that he felt under pressure to select three specific issues from the sheet to talk about

with his consultant. There was just one issue that he was keen to ask his consultant about, his blood results, which he wrote down on the sheet, yet he thought it was required he mark an additional two issues.

### **4.3.2. How patients used and responded to the interventions**

#### ***The NICE evidence-based question***

##### ***Numbers asked***

As part of the research interview, all patient participants were read out the NICE evidence-based intervention question - *'during the last few weeks have you been feeling down or miserable at all'* - and asked if their consultant had used this question during their consultation. A total of 20 patients (56% of the total study sample) said they had been asked the question, in some form, whilst 2 patients could not remember if they had been asked. The other 14 patients in the study sample said they were not asked the question by their consultant.

##### ***Variations in wording used***

There were variations in the word content of the question that patients recalled being asked. Only a few participants appear to have been asked the complete intervention phrase. Some patients had been asked a shorter, specific question focused on whether they were feeling 'down' or 'depressed'. A larger proportion of patients mentioned being asked a more general question about how they were feeling, or whether they had any worries and concerns.

*"Yes, s/he did...I was fine with it. You know, s/he said, "Have you at all since last time I saw you felt depressed in any way, or stressed?"* Patient 27 (Study 1)

##### ***Different ways patients responded to the question***

Some patients responded with ease and openness when asked the NICE evidence-based question. They were willing to talk about their emotional feelings and did not appear inhibited in expressing emotional concerns and difficulties. For example, a male PD patient in his 70s who had been on dialysis less than 3 months and had described himself during the research interview as being *'lifeless'* and *'someone that finds it difficult to pick himself up'*, in response to being asked the intervention question had talked to his consultant about feeling down as a result of tiredness.

*“They did, they’ve asked me if I’ve felt down, which you do do.....You feel tired and when you’re tired you’re down aren’t you?”* Patient 4 (Study 1)

Another male patient in his 60s, on PD for about 7 months, who mentioned in his interview that he had *‘been feeling a bit down in myself and I got a bit emotional’*, told his consultant about his negative feelings after being asked the intervention question.

*“And I told her/him the truth, that I had, and I mean, what I told her/him, s/he was able to put the matter right.”* Patient 27 (Study 1)

Despite being asked, other participants did not mention any emotional needs even though they recognised the intervention was encouraging them to do so and disclosure might be helpful. A key factor seemed to be negative expectations about how their consultant would react and respond. For example, one patient said he did not want to talk about how he was feeling emotionally to the consultant that asked him the question, because the consultant had previously shown a lack of empathy. Whereas he would have talked in response to the question from his consultant of the last 2-3 years, who always put him at ease, was a good listener, and with whom he had a positive relationship.

*“S/he did ask the question, ‘Is there anything else you want to talk about?’ And you know, whilst I would have talked about certain things with ----, I wasn’t going to discuss them with her/him.”* Patient 13 (Study 1)

A few patients were inhibited by concern about how their consultant would respond to an admittance of feeling down or miserable. For one patient there was worry it might result in being put on anti-depressants. Another patient was uncertain how a consultant would handle an in-depth disclosure of emotional problems.

*“I just think the consultant asking that direct question some people would turn round and say yes, then they’re gonna get anti-depressants or possibly on anti-depressants. I think the general opening question as I’ve said is about how are you feeling rather than are you feeling down.”* Patient 9 (Study 1)

Several patients said they replied to the intervention question about whether they were feeling down or miserable, with a simple rebuttal that they did not have such feelings.

There was only one patient though who said that they had been surprised to be asked the question.

*“I wouldn’t have even thought about that because I haven’t felt down in the last few weeks so it’s a question that I wouldn’t even expected him to ask, if you know what I mean.”* Patient 30 (Study 1)

## **Patient Issues sheet**

### ***Most patients given the sheet used it during their consultation***

A total of 21 patients (58% of the study sample) were given the PI sheet and asked to complete it while waiting in the Renal Unit prior to their consultation. Of these, 19 patients completed the sheet they had been given and 16 patients went on to use the sheet during their consultation.

### ***Issues marked***

‘Tiredness’, ‘worry about the future’ and ‘medicines’ were the issues patients most often mentioned as having marked on their PI sheet. They recalled a broad range of other issues marked: ‘energy levels’, ‘sleeping’, ‘pain’, ‘condition worsening’, ‘diet’, ‘coping’, ‘relationships’, ‘adjustment to dialysis’, ‘kidney function’ and ‘sex life.’ Several patients made use of the space provided on the sheet to write in additional issues they wanted to talk about with their consultant, including: ‘urinating’, ‘kidney transplant’, ‘PD insertion’, ‘blood levels’, ‘nocturnal PD’, and ‘next steps in my treatment plan’.

*“I circled two, one was about the various questions about coping in the future, or coping from now on, and the second one was about the future itself.”* Patient 10 (Study 1)

### ***Different ways patients used the sheet***

The PI sheet was used most actively by patients whose consultant asked them directly what they had marked on the sheet as wanting to discuss. In response some patients read out the issues marked, whilst others showed or handed the sheet to their consultant and the consultant read the issues indicated. A few patients never brought the sheet out to show the consultant, but from memory mentioned the issues they had marked.

*“S/he took the sheet off me and h/she said, you know, ‘What would you like to talk about on here?’ ”* Patient 16 (Study 1)

*“If there was anything I wanted to discuss and what the three items were on the piece of yellow paper.’ S/he didn’t even see the yellow paper.” Patient 1 (Study 1)*

The PI sheet was also put to more use if patients themselves took the initiative, and without prompting gave the sheet to their consultant, thereby generating discussion on the issues that had been marked. However, only a minority of patients acted this way.

*“Well, I just took it in, put it in front of the consultant and s/he looked at it; I looked at it. And the chatting started and s/he said, ‘Anything you want to ask me?’, and I pointed out a couple of items and we went on from there.” Patient 18 (Study 1)*

There were also a few patients who claimed they had asked their consultant about the issues marked on the PI sheet without any reference being made to the sheet itself, either by them or their consultant. Therefore no overt use was made of the sheet in the consultation. For example, one patient who wanted to talk about tiredness, energy levels and urinating explained that whilst he never showed the sheet to his consultant, he had been able to remember marking these issues and could therefore ask questions about them.

*“I never showed it to her/him. I just remembered the ones that I ticked off.” Patient 5 (Study 1)*

A small minority of patients mentioned feeling constrained to bring up certain sensitive or embarrassing issues they had marked on the PI sheet. For example a female patient chose not to discuss issues to do with her sex life because her consultation had been with a male consultant and she preferred to talk about such issues with a female. Whilst a male patient said he did not talk about his sex life, despite having indicated it on the sheet, because as well as the male consultant there had been a female nurse present with whom he had regular contact on the Renal Unit.

### ***Used mainly at the end of consultations***

Most patients who used the PI sheet said this had been done towards the end of their consultation. Even patients who were directly asked by their consultant about the sheet, or had pro-actively given their sheet to the consultant at the outset, found the sheet was not specifically used until later in the consultation. The expected and standard clinical discussion topics constituted the ‘*main part*’ of the consultation. For some patients this

approach gave the impression there was divergence between the main issues of interest to the consultant, and those issues of concern marked on the PI sheet by the patient, with the latter perhaps having lesser importance for the consultant.

*“I filled it in while I was waiting to see the doctor, and then, when I went in, I showed her/him; s/he says, ‘We’ll talk about that towards the end. We’ll go through your blood tests results and everything else, and then we’ll discuss that.’ And that’s how it went. I mean, obviously s/he was more concerned about, you know, my blood test results and how I’m getting on with my dialysis.”* Patient 28 (Study1)

### **Reasons for non-use**

Three patients failed to make any use of the PI sheet they had completed before coming in to the consultation. Lack of encouragement from their consultant was the reason for its non-use by two patients. Responses from these patients suggest they were expecting their consultant to introduce and lead discussion around the issues marked on the sheet. When this did not happen, they just accepted the situation. Another patient explained there had been no need to use the sheet, since the issues they wanted to talk about came up spontaneously for discussion during the consultation.

*“Now, I might have misunderstood it, but I thought s/he was going to ask me for that at some point. S/he never made any reference to it at all....I walked out of there, carrying it still folded up in my hand.”* Patient 13 (Study 1)

### **4.3.3. Patients were generally satisfied with how consultants handled any emotional issues disclosed**

In general, patients who raised any issues for discussion with their consultant in response to use of either intervention were satisfied with how the issues were handled. They felt pleased and comforted by their consultant taking the time to answer their questions. For example, explaining why the patient may be feeling the way they were and what could be done to improve the situation, or to outline what the patient could expect in future in terms of disease progression and treatment.

For some patients, it was the first time their consultant had provided information on an issue of particular emotional concern to them, that might have been troubling them for a

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while. A male PD patient said he had been able to talk for the first time about worries that dialysis treatment might impact on his sexual function; a female PD patient described how she had been suffering from lack of sleep for a while, but as a result of marking 'tiredness' on the PI sheet, the consultant had discussed with her for the first time, possible causes of this problem and suggested how it might best be resolved.

*"S/he kind of reassured me, basically put my mind at ease, that it's kind of OK....The answer was, well it was sufficient basically. I don't really know what else the consultant could have done."* Patient 6 (Study 1)

Several patients clearly experienced a sense of empathy from how their consultant responded when discussing issues they disclosed. This was expressed both in behavioural terms such as friendliness, eye contact, time given, and listening, as well as what was said. It seemed to encourage patients to explain more about how they were feeling.

*"S/he was empathic.....Just in her/his communication skills. Just in, you know, her/his eye contact, her/his tone of voice, etcetera. Things like that. But also, giving me the time to ventilate, you know, what I was thinking, what I was feeling, and listening to what I was saying."* Patient 16 (Study 1)

There were other patients however whose consultants seemed to adopt more of a practical and problem solving response, often focusing solely on the physical symptoms that might be causing the issue raised; giving no consideration to any possible emotional or psychological factors. Certainly for a few patients a practical-focused response alone was not viewed as particularly helpful.

*"Upset after that and worried...because they told me that my weight's too much (in response to issue of 'diet'), get rid of it. So I was very upset....Because I try to lose weight and can't. I've got back problems. I can't exercise I get really upset."* Patient 20 (Study 1)

There were also a few patients who expressed disappointment in how their consultant responded to issues raised. The main reason being the consultant had prevented or closed down any discussion with the patient. For example, a male HD patient who did not use the PI sheet overtly in the consultation, but asked about the issues he had

marked, got the impression his consultant did not want to consider or discuss these issues and preferred to carry on with the normal consultation agenda, possibly because of lack of available time. This was found frustrating and unhelpful by the patient.

*“I don’t know whether s/he actually was pushed for time or something but I got the feeling that s/he didn’t really want to go into discussions about things...when I said about the feeling tired and lack of energy s/he accepted that but didn’t want to go into detail about it....I felt there could have been a bit more time to discuss perhaps the things that I might have wanted to talk about rather than feeling pushed to the idea that s/he wanted to carry on their way and that was it.”* Patient 32 (Study 1)

#### **4.3.4. Mixed but generally favourable consultant reactions to the interventions**

##### ***Reasons for liking the NICE evidence-based question***

Those consultants who held the most positive views about the NICE evidence-based question, particularly liked using the intervention because it ‘opened the door’ to an improved understanding of a patient’s emotional wellbeing – adding to what was already known about their medical health – and enabled them to provide better overall care. For one consultant this benefit was expressed in terms of being in a better position to provide care for the whole patient – *‘we are looking at all their needs, you know, in a holistic manner’*.

*“So there are some patients who have been depressed, as an example, and perhaps it’s never been explored. Obviously, coming to terms with dialysis and all the trauma associated can be overwhelming. But perhaps their coping mechanisms, they haven’t necessarily developed sufficient coping mechanisms, and equally as doctors, perhaps we haven’t helped them because we haven’t actually thought about how they’re managing.....So by asking these obvious questions outright, overtly, has helped to explore those issues.”* Consultant 3

The intervention was also liked by some consultants because it helped them identify patients with emotional support needs whom they might not have expected to have emotional difficulties; it had not always been apparent without the intervention. The consultants had then been able to explore the reasons behind these patients’ emotional problems, and often find a way forward to help, thereby improving the care offered.

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*“Well, I mean sometimes they say ‘no, I’m fine, I’m feeling better, I’m OK doctor, it’s fine, thank you for asking’ and then sometimes they say ‘yes, I’m not feeling great and I am feeling low and life’s not great since I started dialysis’. So you might not always have expected them to say that but then you know it’s a common association with chronic kidney disease. So unless you specifically ask you might not have picked it up.”* Consultant 5

Another positive aspect of the intervention as a whole, emphasised by one consultant, was that it offered a structured way of recognising and responding to patients’ emotional issues. This was found more helpful and effective than asking patients about their emotional feelings in an ad hoc, inconsistent and uncontrolled way. Having a clear structure for asking about patients’ feelings and managing their responses with methods for containment also made it easier to incorporate the intervention into routine consultations.

*“If it has a structure there’s more of a pathway and you know how to proceed, like A, B, C and you could probably put it into your consultation in a more structured way as well. So it’s just a way of how to make it part of your normal working way of practice as opposed to being a bit erratic and haphazard.”* Consultant 5

### **Concerns about the NICE evidence-based question**

There was another consultant who expressed far more ambivalent views about the intervention. Whilst recognising that for some patients it could be beneficial, they nonetheless had serious worries about how it might impact on the mood and tempo of their consultations. The tone of the intervention question was thought ‘*alien*’ to how they liked their consultations to progress; too sad and downbeat whereas they liked to maintain a more positive and upbeat flow. Therefore they found it difficult to introduce the intervention because if ‘*everything is going quite well there’s a sudden change of direction*’ – ‘*it’s a bit like a bomb*’.

*“And that’s the problem I have with the intervention in the sense that if everything is going swimmingly how do you say it without feeling uncomfortable....It’s a bit like a bomb. So we’d be talking about, so to exaggerate we’d say ‘dialysis is going really well, I’m glad you’re feeling fantastic, you’ve got the real hang of this, you’re on the transplant list – oh, you’re back at work that’s great and you’re back to walking 7 miles a day, great’ and then you – how do you stop that and move onto ‘have you been*

*feeling quite down in the last few months or have you been feeling depressed?’ ”*

Consultant 2

### ***Positive views about the Patient Issues sheet***

Clinician views of the PI sheet itself were very favourable. It was considered simple and straightforward for patients to complete. The selection of issues shown was thought relevant and appropriate, covering the key emotional and psychological as well as physical issues that any end-stage renal patient might experience in relation to their disease or treatment. The provision of space for additional personal issues to be written in by the patient was also liked. Furthermore consultants expressed positive views about patients using ‘empty time’ to reflect and then complete the sheet while waiting for their consultation. The process was seen to have the advantage of enabling patients to focus their thoughts on what were their key issues of concern. There were no dislikes expressed by consultants about the sheet itself.

*“I think the good thing with the sheet is it’s simple, it’s one page, A4 size, with the major areas that you would have thought that patients are concerned about.”* Consultant 1

*“I thought the selection of words was brilliant, I thought that it was spaced well....giving it to the patient to think about, allows them to crystallise their thoughts.”* Consultant 2

### ***Mixed views about how the Patient Issues sheet worked***

Opinions were more mixed around how the intervention as a whole worked. For some consultants the intervention failed to live up to their expectations. They had welcomed the PI sheet as a way of enabling patients to formulate questions based on aspects of their emotional care which were unaddressed. It was also seen as a valuable prompt to encourage patients themselves to express emotional issues and concerns which the consultant could then address. In this way the intervention was expected to ease communication between patient and consultant, helping overcome the difficulties consultants often experienced in getting patients to disclose their emotional feelings. However the intervention did not appear to work in this way. Few patients spontaneously used the PI sheet without consultant encouragement and support.

*“It’s a way of raising the issue so you can address it and work through it with the patient.”* Consultant 5

*“I felt uncomfortable because the patients weren’t bringing it to the fore... They’ve got the piece of paper that they’re asked to bring in and if they’ve not put it in front of me and they’ve got it to one side I just felt, because it happened so often I was surprised... I just thought “well”. I was confused to be honest because I thought that, I actually thought it was really well done, the piece of paper.”* Consultant 2

Another consultant really liked the intervention. They found the intervention worked as expected to prompt discussion about issues that patients particularly wanted to discuss and have addressed. It should be noted that this consultant was using the intervention in a two-way manner with their patients, together looking at and responding to the sheet.

*“I find it’s been useful I’m sure that most physicians would find it quite useful as well as a way to prompt discussion, or open up discussion.”* Consultant 1

### **Length of consultations**

The view of most consultants was that use of the pilot interventions had not lengthened their consultations or only by an acceptable few minutes. In large part this was because they had employed strategies, often learnt from the training, to structure and contain the length of any discussion with patients in response to the interventions. Some consultants, if there was likelihood of discussion extending beyond the allotted consultation-time, suggested continuing the conversation around any unresolved issues at the next consultation; usually arranging the appointment sooner than would be routine. Having available referral options was also considered very helpful. Although there was one consultant who emphasised how it was often difficult to establish empathy, encourage discussion and address any issues raised, all within the time constraints of a standard consultation.

*“I will say, ‘Well, on our next visit we’ll talk about whatever else is unresolved.’”*  
Consultant 3

### **4.3.5. Different consultant approaches to using the interventions**

Participating consultants used the two pilot interventions in very different ways. Five different approaches were identified from the study data: empathetic sharing; solution-seeking; patient-led; explanatory; and patient typology-targeted.

### ***Empathetic sharing***

One consultant who described themselves as feeling 'out of their depth' when faced with patients' displays of emotion, and far more comfortable handling medical issues, chose to actively engage with patients in using the PI sheet through a two-way shared process. From the consultant's perspective this worked well in encouraging discussion about the issues patients had marked on the sheet. In order not to disrupt their normal consultation structure this was always done towards the end of the consultation. Whilst they might early on in the consultation acknowledge existence of the sheet, particularly if shown to them, they preferred the sheet be used only after specific medical aspects of their patient's care had been covered.

*"What I normally do is to, I just put them (the PI sheets) aside first and then I go through what I would normally do, you know in a clinic setting, and then come to, towards the latter part of the consultation I will ask 'is there anything in the yellow sheets that you want to discuss?' That's how I start with that. I mean they will just look at the sheets and say these are the areas that I circled or indicated....I just go through the sheets with them."* Consultant 1

Whilst acknowledging general feelings of inadequacy in terms of dealing with emotional problems raised by the PI sheet, this consultant said the training had helped them respond. They had come to realise there was no necessity to provide a solution, it was more about 'just trying to acknowledge the concern and then to look into it if there is anything I can do to help the patient in terms of referring on to an appropriate specialist sort of thing.'

The same consultant expressed initial reservations about using the NICE evidence-based question since it was very specific and direct; preferring to ask more open questions and explore possibilities that might elicit emotional concerns. Therefore they were somewhat taken aback by the depth of emotion the question could evoke. The response from one patient for example, was far more profound than expected.

*"On a particular occasion I just happened to ask that question and it just opened up the flood gates of issues the patient is facing....So we didn't talk about the medicine bit at all we just talked about her tragic events in her life and we just talked about it."* Consultant 1

Again the consultant felt their training had helped in handling patients' responses to the intervention question, particularly using expressions of empathy. They reacted by acknowledging a patient's emotion, trying to show understanding, and encouraging disclosure. In this way they felt their patients were being emotionally supported and their distress reduced. In one case, the consultant thought their empathetic approach had a direct positive impact on their patient's health.

*"I just kept quiet and just let her talk and just use words like 'I see, I understand', sort of reaffirm her emotion and her display and trying to reassure her that you know it's a safe environment for her to talk about it. And it's been very positive, yeah.... because the following few occasions I've seen her I see the blood pressure coming down very nicely...So this is something very unexpected actually happened. Whether you know, all this time I've been seeing her she'd been bottling up all this emotion, fuelling the blood pressure issues or not.'* Consultant 1

### **Solution-seeking**

Another consultant, more confident and at ease about handling patients' emotional concerns, chose to use the NICE evidence-based question at the start of their consultations. This way they ensured the intervention was included and not forgotten amidst the many other issues that needed to be covered in their time-constrained consultations. There was realisation that whilst certain patients could be immediately forthcoming about their emotional concerns, others needed more time and encouragement to emit their feelings – time was needed to build rapport with the patient and for the patient to feel there is sufficient time to explain their feelings.

*They won't necessarily offer it, like some people just say "I feel really miserable" but some people you've got to like ask and give them a bit of time.* Consultant 5

In terms of handling responses to the question, the consultant would try to work with their patients to try to identify the cause of any emotional difficulties - a diagnosis of the problem - so that a solution could be found to hopefully improve the situation. Although it was acknowledged this could be a difficult process since the causes of emotional distress are often multi-factorial.

*"Well, you just talked about it, you know, sort of if there was a problem then yes, you know, what support they had, who was at home, you know, a lot of the time they're*

*elderly and yeah, they don't get out much and they feel all they do is come for dialysis and go home again. So it's relating to sort of, you know, is there any way you can improve that? I mean I didn't tend to put them on any medication but certainly support, but then often it's multi-factorial isn't it? They're elderly, co-morbid and sometimes socially isolated and sometimes it's a money issue.....So it's often multi-factorial. There's no easy answer."* Consultant 5

### **Patient-led**

A consultant with a more patient-led consultation style struggled to effectively incorporate the pilot interventions into their routine consultations. Viewing the PI sheet as a patient-led intervention they preferred not to direct its use by encouraging patients to show them the sheet and say which issues they would like to talk about; it was felt this would be '*invading*'. What they anticipated was that patients would spontaneously present the sheet as they came into the consultation, or specifically reference the sheet and say what issues they had marked; thereby facilitating more patient-initiated discussion of emotional needs. There was surprise and disappointment that in most cases this did not happen. Patients were variously described as putting the sheet to one side, keeping it folded in their hands, or not seen to have the sheet at all. In just a few consultations the patient had taken the initiative in using the PI sheet, which was welcomed by the consultant.

*"With one guy it worked very well. But he was the one that brought it in front of me and had his own hypothesis before he asked me what I thought."* Consultant 2

The consultant also observed that asking patients an abstract, open-ended question to encourage them to talk about what they had marked on the PI sheet, such as '*is there anything else you would like to discuss?*', often failed to get a response. As a result of these experiences it was concluded most patients needed more direct consultant encouragement to make use of the sheet because it was '*alien to the way the people view the consultation.*'

In using the NICE evidence-based intervention, this consultant altered the original wording because, being more direct and specific, it did not accord with their usual question style. They wanted to ask a much more general open-ended question about the wellbeing of their patients, to provide an initial opportunity for disclosure of any emotional problems. If this was not effective then they might progressively use more

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explicit questions about the patient's feelings and moods. This indirect and more cautious approach – *'knocking on the door'* first - was thought much more in keeping with their normal consultation approach.

*"I'd rather have an open question and say 'how have you been?' and then go along – and so that way if – that way at least I'm not intruding onto people's thoughts without giving them a chance."* Consultant 2

They had anticipated that use of the NICE evidence-based intervention would elicit considerable amounts of previously unexpressed emotional concern from across their patient list – *'I was expecting patients to be so forthcoming and just be deluged by all these feelings.'* Instead when asked the intervention question, far fewer patients than expected mentioned having any emotional difficulties. This surprising response was to some extent reassuring for the consultant in that their patients did not seem to have a lot of unresolved emotional issues. Yet it also created some worry that patients might in some way be inhibited about expressing their emotional feelings.

*"In fact I was quite surprised by the fact that a significant number said they didn't have any worries.... The patient would quite often have nothing to say and there would be silence between me and the patient for a little while because obviously I need to let them say something without me saying anymore and the patient would be there going – 'no' and then I would wait and then if not – and then I'd say – and then I would stop because I'm thinking well you want to say 'are you really sure you've not been down?' or do you just leave it at that point?"* Consultant 2

### **Explanatory**

One consultant had used the NICE evidence-based intervention with all their patients. The consultant liked to use an explanation alongside the question, feeling uncomfortable about using such a direct question in isolation. Clarifying to patients why they were being asked whether they had been feeling down or miserable, they believed encouraged disclosure of emotional issues. The explanation given, covered how it was normal for patients with kidney disease to have some emotional concerns and worries, and that talking about such feelings allowed their consultant to help and support them.

*"I have stressed to them, 'Well, it's entirely correct that you are allowed to feel upset about a life-changing event. It is normal to feel depressed. It does happen. So it is*

*important that we talk about it to help you in all its – you know, to deal with all its aspects....It's part of being, you know, being unwell is that you have a reaction to the condition and depression is one component of it, but we have to understand that to make it better, to help the person.' ” Consultant 3*

Their preference was to introduce the NICE evidence-based intervention around the middle of the consultation. They avoided using it at the end of a consultation since if it prompted a response from the patient that they were feeling miserable or depressed, it would need some discussion time and could not simply be dismissed; recognising that for the patient this could be a significant issue.

*“Well, it's in a measured way, obviously. So it's usually in the middle, to be honest, because, to be honest, the end is all the summary and the tidying up..... So, to be honest, you can't really talk about, you know, major issues about their life in the last minute. It's not really appropriate.” Consultant 3*

With those patients who expressed any emotional concerns, the consultant would try to work in a systematic way to identify what was causing the distress, and find a solution that would hopefully lead to improvement. It was nonetheless recognised that sometimes there was no easy answer to resolve a problem and this needed to be explained to the patient.

*“I ask them what are the things that's most upsetting them and therefore then have a systematic way of going through all those issues.... You try and, I guess, as a doctor, you try to find – give them an answer or a solution that will hopefully lead to an improvement. And, clearly, if certain things cannot be resolved, then you have to explain why that is impossible.” Consultant 3*

### **Patient typology-targeted**

A targeted approach was specifically used by one consultant in terms of the patients to whom they chose to ask the NICE evidence-based question; their decision based primarily on whether or not they perceived a patient likely to be feeling down or depressed. Initial trials of the intervention had confirmed their expectation that patients considered to have no emotional difficulties, would be surprised or incredulous to be asked the question. They concluded the intervention was not helpful for this patient typology.

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*“Well, if you’ve got some sort of jovial bloke who’s sort of, you know – he’s not a man to sit down and get angsty about his emotional needs and things like that and he’s always there for a – he’s more interested in a bit of banter and a bit of humour and he’s making gags the entire consultation, and you’re suddenly saying, ‘And have you been feeling down at all?... It didn’t help for those particular patients.’” Consultant 4*

Additionally the consultant expressed worries that some patients with a perceived lack of emotional problems would find use of the intervention question inappropriate and in turn this might impact negatively on the patient-consultant relationship.

*“I didn’t really want to use those questions with those patients because they were just going to look at me funny and it was going to reflect on me and how I interacted with the patient.” Consultant 4*

#### **4.3.6. Training valued by consultants**

Consultants participating in the study only used the two pilot interventions after receiving training from a renal psychologist on how to handle patient responses. In general the training was found helpful, particularly by those consultants who described themselves as feeling less comfortable dealing with patients’ emotional issues. The training was thought to have provided a useful menu of different ways to respond in an empathetic and supportive way to patients’ expressions of emotional concerns. For example, one consultant spoke about learning there was no necessity to always provide a solution and that just listening and acknowledging the concern could sometimes be beneficial.

*“I am capable of handling sort of a mild display of emotion, but when the patient is crying and really upset I find it sort of out of depth. But it was good that - had some training with us and so what I’ve done is I just kept quiet and I just let her talk. And I find that the most useful strategy actually rather than ‘oh, you’ll be alright, see your GP for some sleeping tablets’ and that sort of thing.” Consultant 1*

Another consultant, who seemed rather more confident and experienced in dealing with patient’s expressions of emotion, found the training of value from the perspective of adding new tools to their repertoire.

*“Raising our awareness of how to effectively manage those aspects. And, again, it’s been useful in the clinics, to hopefully be, you know, better in managing the patients’ needs and learning new tricks.” Consultant 3*

The training was also considered beneficial in terms of learning how to better structure and contain discussion of any emotional issues disclosed so reducing the risk that use of the interventions would lengthen consultations. For example, agreeing with the patient to return to discussing the issue during the next consultation. Another consultant mentioned the value of learning about some local referral options so they felt more able to offer tangible support to patients with emotional needs as opposed to listening alone.

*“The most useful thing, actually, was having somebody say, ‘These are the services that seem to be available round here that you may wish to try.’....what you really want to know is not whether you can manage to say something that sounds suitably sympathetic or caring so much as if it comes down to it and they actually want something a bit more, what can you offer? And having that knowledge of ‘these are the services available’ was the most important thing, from my point of view. Consultant 4*

#### **4.3.7. Patient reactions to five evidence-based interventions presented as audio-visual films**

All patients participating in the second study were shown and asked their views about five evidence-based interventions presented as short audio-visual films: physical activity programmes managed and supported by the kidney unit (cycling while on dialysis and walking); clinic time to discuss emotional needs (NICE evidence-based question and Patient Issues Sheet); training in mindfulness; peer support; and, computerised CBT. The film scripts for each of the five interventions are detailed in Appendix 5.

Whilst some interventions were more or less popular than others, there was overall a variable response to each intervention dependent on patients’ emotional status, existing support networks, type of dialysis treatment, perceived ease or difficulty of use; emotional readiness to share feelings with others, and the perceived relevance of communicated benefits.

### **Physical activity programmes managed and supported by the kidney unit (cycling while on dialysis and walking) – the more popular intervention**

A majority of patients reacted positively to this intervention. When patients were asked which intervention they would personally be most interested in using, the physical activity programme, either walking or cycling while on dialysis, received the most first choice mentions (from 62% of study participants)

The most common reason patients gave for liking the intervention is because there are both physical and emotional benefits to be derived from exercising, whether walking or cycling while on dialysis. They liked the premise that through using the exercise programme they could lose weight, improve their blood pressure and achieve a better emotional mood. Several patients said they recognised from personal experience there were positive general wellbeing benefits to be gained from physical activity, often citing examples of activities previously engaged in, but less often nowadays.

*“I think it’s just the exercise and I think, obviously, that lady (in the film), she was saying, you know, she felt a bit down or whatever, then started walking. And it does, I think. It really does make you feel a lot better, especially if you’ve conquered a goal where it’s around walking to there and I feel great getting to that point.”* Patient 15 (Study 2)

Another reason mentioned for liking the intervention was that the exercises, whether walking or cycling while on dialysis, were designed for the individual patient and overseen by a professional. For some patients, this meant they were more likely to keep to the exercise regime, rather than ‘give up’ before the programme was completed.

*“I’m very supportive of that because I don’t do anything like enough exercise. I used to do, as a young man, I was very, very active...but basically I don’t do anything like the exercise I should do. So I need someone to, sort of...impose, not impose the discipline, but encourage the self discipline to do more exercise so, in that sense, that’s very good.”* Patient 7 (Study 2, group)

It was expected that patients of most ages and physical health states could benefit from the intervention, although perhaps more so from walking than cycling while on dialysis. Another perceptual advantage seemed to be there was no explicit association between

the intervention and experiencing depression and therefore it could feel less stigmatising than some of the other interventions. For some male patients in particular, the intervention appealed because it involved something active and positive, as opposed to the more passive interventions focused around thinking or talking.

*“It’s positive, positive thinking, people have got a pastime, to lie there on a bed while you’re dialysing and pedalling, good idea, yeah. That’s more positive, you know, better than just sitting there discussing, you’re doing something to help yourself.”* Patient 6 (Study 2)

Patients generally had personal preferences in terms of walking or cycling on dialysis, irrespective of the type of dialysis they were on. The main reason given for liking the concept of cycling was because it was a convenient way of using ‘empty’ time to gain the benefits of exercise while also relieving the boredom of being on dialysis. HD patients tended to feel time-constrained and this presented an opportunity to use their dialysis time to positive personal effect.

*“But to do that while you’re on dialysis is like – you’re doing it and you haven’t got – you’re not wasting any time anywhere, are you? You’re doing it while you’re there anyway, so to me that’s brilliant.”* Patient 1 (Study 2)

Patients often described the benefits of walking in terms of its social aspects. They liked the group nature of the activity, especially being able to talk with other patients as well as exercise. There were also seen to be emotional support advantages from this activity sharing.

*“Well the other thing is it’s a group thing, if they’re going for a walk and there’s a group of them going for a walk it’s sort of a friendship as well, isn’t it. And you’re probably all in it together.”* Patient 5 (Study 2)

A minority of patients had specific personal reasons for being less keen on the intervention. A female HD patient said walking was not appropriate for her, more so in winter, because since starting dialysis her joints ached and she felt the cold very badly. Another female patient worried that she would not have enough energy to walk. One male HD patient was fearful of cycling while on dialysis because he thought it would damage the neck line he used.

*“I've got a line and my line is temperamental, so if I do any movement, the alarm goes off so for me, so personally, it might not be a good idea, cycling.”* Patient 13 (Study 2)

**Positive reactions to ‘clinic time to discuss emotional needs’ (NICE evidence-based question and Patient Issues sheet)**

Many patients expressed favourable opinions about this intervention. An aspect of the intervention particularly liked was it gave permission to patients to raise and discuss emotional issues of concern with their consultant. The clear impression was that renal consultants were able and willing to listen to and provide support for your emotional as well as medical needs – they were not, as was often thought, ‘*just literally dealing with the kidney side of things*’. The PI sheet was also liked for showing the type of issues other renal patients are concerned about and by association what is therefore acceptable to ask your consultant about.

*“If you’ve got that form in front of you, it gives you a whole broad range of things that you might want to discuss and, you know, somebody might not have – might not want to be up front and talk about it but they see that and think ‘Well actually, yeah, I do feel like that. Perhaps I do need to talk to somebody.’”* Patient 1 (Study 2)

The benefits of using clinic time to discuss emotional needs were widely commented upon. It was generally believed that if a consultant had more knowledge about a patient’s emotional wellbeing they could provide better care. Therefore many patients were attracted to the interventions’ premise that by enabling patients to talk about any emotional concerns they have, consultants could provide support and help in finding a solution to the problem. This was viewed as positive and reassuring, even by a number of patients who said they had no emotional problems. A few patients referred to the benefits of whole-person care that could accrue from use of the intervention.

*“It is a good idea, because the consultant then knows how you’re feeling as well. It’s not just for the medical part of it.”* Patient 11 (Study 2)

Interestingly one patient questioned the type of support and help that a consultant might provide if a patient did raise some emotional problems. Since it was a novel aspect to his learned experience of how consultations were conducted, he was keen to know how the patient-consultant communication might work in practice. He suggested it might be useful to show patients a filmed example.

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*“The bits the doctor and patient tended to be little clips, very tiny clips, which I don’t think gives the full impression of what actually goes on and the level of support you get.”* Patient 7 (Study 2, group)

Some patients described the benefits of the PI sheet in terms of acting as an aide-memoire; a prompt for them of what they wanted to discuss with their doctor during the consultation. For one female PD patient it was seen as a means to make more effective use of the seemingly small opportunity given her in any consultation to raise issues of personal concern.

*“I think that might be good because sometimes you come in and you forget to say some things and then you’ve lost that opportunity then to speak to someone till the next time, haven’t you. So it might help you focus a little bit and jog your memory as to what you want to talk about....And you’ve only got that certain slot with a consultant haven’t you.”* Patient 9 (Study 2, group)

Another reason given by several patients for liking the PI sheet was that it was a helpful tool to disclose any emotional difficulties, for people less confident and able to express emotional feelings in their own words. Instead of having to articulate their thoughts, they could use the sheet to visually show their consultant which particular issues were worrying them.

*“Some people can’t express themselves, or find it difficult to express themselves, so perhaps putting down, well, ‘I’m anxious’, or, ‘I’m nervous about this’, or things of that – and they can see it, you know, to ask the question, then obviously the doctor then can say, ‘Well, you’ve put this down. Shall we, would you like to discuss it?’ And maybe that’ll help alleviate any problems or stress.”* Patient 15 (Study 2)

No one disliked the intervention but some patients felt they did not need the intervention mainly because they had their own personal support network for talking about their emotional concerns. Also one patient described the intervention as not being right for them since they had the confidence and skills to mention of their own volition any concerns they had to their consultant spontaneously

### **Training in mindfulness had appeal for some patients**

Training in how to handle negative thoughts and emotions had particular appeal for

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some participants. The most positive reaction was from patients who were currently experiencing emotional difficulties, several of whom expressed strong interest in using the intervention. They were attracted by the message that mindfulness training helps to calm and relax you by focusing your mind away from what is causing stress and anxiety. For some patients there were parallels with meditation, yoga or praying. In this way it was thought mindfulness could help remove negative feelings about their life and situation, putting them more in control, so they could better cope with preparing for, or being on, dialysis.

*“Being able to control what you think. I mean there’s times when I do, you have some bad thoughts and you try and get rid of them and you can’t. It’s not as easy to cope with as some people make out.”* Patient 14 (Study 2)

A male PD patient who already used self-help relaxation tapes to relax and sleep better at night was very interested in the mindfulness intervention. Since starting PD he had experienced problems with disrupted sleep and had come to appreciate the benefits of relaxing the mind to help him sleep better.

*“See, that interests me because I do, on my phone I’ve got meditation tapes to listen to at night and stuff like that. So that does interest me. So I certainly believe that that would help...and I think it is important to try and relax and, you know, try and to take, as it said, only a few minutes – if you just sit and relax and breathe and different things like that. So yeah, that looks very good.”* Patient 15 (Study 2)

Another important attribute of the intervention was its accessibility. The impression given was that anyone could learn the skills for mindfulness and once learnt could continue to use them. It was not thought difficult to learn; there were no particular skills or qualities required.

There was less interest among patients who claimed not to be feeling any anxiety or stress, although they tended to think the intervention would have appeal and benefit for many of the patients whom they encountered at their Renal Unit who were emotionally distressed. Some patients said they would be reassured to know the support was available if they did experience low moods in future.

Notably a few patients worried that participation in the intervention would signify they were depressed. They worried about the stigma of being seen to have a mental health

problem. This concern led a male HD patient to favour one-to-one training in mindfulness rather than doing the training in a group with other patients; to prevent people he knew from learning he had negative emotions.

*“It might be worth maybe one-to-one rather than in a group unless, because if people know you feel negative and you're depressed and then, you know, if they know who you are, some people do know who you are, they might mention it to their friend or family or something and then, you know, they know that you are.”* Patient 13 (Study 2)

One female HD patient, attracted to using the intervention, mentioned the difficulty of finding time to do a course of one-hour sessions over several weeks. She was already feeling very time-pressured because of having to come into her kidney unit to dialyse three times a week for four hours. It was thought the difficulty of fitting the course into her time-constrained life would cause her more stress than benefit.

### **Mixed responses to peer support**

This intervention concept prompted a variety of different responses. Some patients expressed strong interest in using peer support. The main perceived benefit was being able to share experiences by talking to someone in a similar position so that you feel less isolated. This type of emotional sharing was considered of particular value by several patients on home dialysis therapies, and some patients mentioned it would have been of benefit at the time of diagnosis of end-stage kidney disease. It was thought peer support could help both in adjustment to their illness and to being on dialysis, through the sharing of worries and anxieties and learning how to cope better.

*“It can feel quite lonely at home, can't you, on your own. I know you've got the wards to ring up and the nurses to ring up, but you can feel sort of quite isolated, it doesn't matter how much your family support you, they really don't know what you are going through really. So it is good to have that kind of person to talk to who's experiencing the same issues that you are.”* Patient 9 (Study 2, group)

Choice of timing and format were also cited by as positive aspects of the intervention. One patient mentioned liking the fact they could choose to talk to a peer by phone, face-to-face or online. Another patient mentioned it would be reassuring to know a peer supporter was available to talk to at the times you needed support. They recognised their sense of emotional wellbeing could fluctuate and there would be particular times

when they might need peer support, and at other times not.

*There's always occasions when you feel as if, I do, when I feel as if I want to ask questions of somebody who's in the same situation.* Patient 5 (Study 2, group)

There were, however, some perceived barriers to taking-up peer support even among those who professed a keen interest in using the intervention. A particular worry for some patients was whether they would feel a sense of rapport and understanding with their peer supporter. A male pre-dialysis patient for example, described the negative personas of certain dialysis patients he had talked to informally at the Renal Unit, whom he thought would make very unattractive peer supporters; he would prefer a peer supporter who was more positive and optimistic about their dialysis experience. Another patient was concerned that some peer supporters might benefit more than the patient they were meant to be helping, *'if they weren't having a good day, they'd unload it on you.'*

Patients expressed some polarised views about the value of information and advice given by peer supporters. For example, one pre-dialysis patient thought the peer supporter perspective would be more truthful as the learned experience of being on dialysis, whereas doctors might *'protect you from the worst.'* Conversely another pre-dialysis patient believed clinicians were more likely to provide accurate information because they had more medical knowledge.

*"No, if you want information, you go to the people that know about it, I don't think you should be going to individuals."* Patient 8 (Study 2)

For several patients, peer support was not considered appropriate. They rejected the intervention as having no personal benefit, although they recognised many others might profit from encounters. One male participant said he disliked sharing emotional thoughts and feelings with people he did not know. Several participants said they felt sufficiently well supported by their own family and/or friends to need to engage in peer support. Some HD patients said they got good support from patients they talked to while waiting to dialyse or when on the dialysis machine at the kidney unit. A female patient said she had been offered the option of using peer support when starting on HD treatment, but had not taken it up because she was happy with the support from her family and did not want to talk about her illness.

*“Just not really in a place where I really feel like I want to sit and talk about it. It’s just, I just want to get on and live my life, really.”* Patient 11 (Study 2, group)

### **Computerised CBT was less popular**

Across the study sample, computerised CBT received the least favourable response. One of the most frequently cited reasons by patients for not liking the intervention was lack of expertise and familiarity with computers. Although it was acknowledged that the two patients in the video had clearly communicated there was no need to be ‘a *computer whiz-kid*’, the impression remained that the intervention was more for people ‘*good at computers*’. In part this may be because the course consisted of 8 weekly sessions; suggesting fairly heavy computer usage was required.

*“Well I’m not a computer buff so, no. No, I’m not really a computer buff. I’ve no interest in it at all.”* Patient 6 (Study 2, group)

Female patients in particular said they would prefer to speak to someone face to face if they were feeling low rather than work through a computer course. One patient said the advantage of talking with someone is that you could explore your emotional feelings in more depth than was thought possible online.

*“I think I would rather talk to somebody face to face if I was feeling low about something because I would find that more beneficial than doing an exercise like that...Just asking you questions, dig deeper into how you’re feeling and things like that, whereas you could probably openly talk to somebody in a better way and come out of it feeling well I’ve offloaded that now”.* Patient 9 (Study 2, group)

Some patients were dissuaded by computerised CBT because of the impression it was for people with depression and therefore not for someone like them. The patients in the video may have conveyed this impression by saying they had ‘*been feeling really down*’; communicating depression rather than lower level emotional problems. For a few patients the association with depression was a significant excluding factor.

*“I’m not a depressed person, I don’t get depressed easily and so I don’t think I’d use it, quite frankly.”* Patient 8 (Study 2)

A few men said the intervention was one they might consider using if they were

experiencing low moods mainly because the patients in the video had been so enthusiastic about the emotional benefits, especially understanding and controlling your own feelings so you became less downhearted. However there was some doubt as to how the computer course worked to deliver these benefits. One patient suggested more detail was needed on the course content and the reasons why it was so effective.

*“I’m not sure how a course can make you feel better about yourself....They could go into a bit more depth on what’s actually involved in the course” Patient 12 (Study 2)*

#### **4.3.8. Contextual factors**

The research studies highlighted several significant factors that had a contextual influence on how patients and consultants responded to the evaluated interventions: patients’ emotional and psychological needs; clinicians’ recognition of patients’ emotional and psychological needs; support and coping mechanisms used by patients; and patients’ perceptions of emotional care from clinician communication and behaviour.

##### **Patients’ emotional and psychological needs**

A significant proportion of patients reported emotional and psychological needs, reinforcing the necessity for interventions to support these needs and reflecting evidence identified in the literature review. More than a third of participants across the two studies mentioned existing emotional concerns, or recently experiencing emotional difficulties, linked to their kidney disease or treatment. Certain stages of the renal disease trajectory were found particularly traumatic, notably initial diagnosis and transition to dialysis treatment, although emotional and psychological needs were apparent more widely across the disease pathway.

Several patients described with some strength of feeling the sense of shock, distress and fear experienced when they first received their diagnosis of end-stage renal failure. Even if it was a while since this happened, and they were now well established on dialysis treatment, the memory could still be fairly painful and intense. There were also patients who despite knowing for a number of years in advance that they would require dialysis, nonetheless experienced strong emotions during the transition to end-stage renal failure and dialysis treatment. Lack of adequate preparation for the emotional

feelings that could potentially be experienced during these disease stages, sometimes generated a strong psychological response and consequent support needs.

*“It happened quite quickly. Although I was expecting it, when it did happen it happened quickly. I personally don't think I was prepared for it.... I think some counselling would have been of benefit.....I think it would have made it, it would have just prepared me for the actual – it's as though I've come to a sudden halt.”* Patient 14 (Study 1)

Adjusting to the burden of treatment was a particular problem for some recent starters on HD. They described their dialysis treatment as both physically and emotionally demanding - not only having to dedicate 3 days a week to treatment, with treatment sessions lasting several hours at a time, and requiring regular travel to and from the hospital dialysis unit, but also additional time and effort involved in a succession of clinical appointments. Several patients mentioned experiencing negative psychological feelings in response to the loss of time, freedom, and quality of life.

*“Some days you feel all right and others you don't particularly want to get up.....I'm not suicidal or anything like that, you know, but sometimes I'm a bit depressed, like, you know. You come off (dialysis) and it seems to be not very long before you're on again, you know, it's only a day in between.”* Patient 11 (Study 1)

Whilst some participants reported being accepting of their life on dialysis - just getting on with their treatment and the changes and adaptations they needed to make to their life - this seemingly 'fighting spirit' could sometimes belie more negative feelings. For example, a female HD patient who said she had no hope of a transplant described her situation as 'what it is, it is' and feeling 'there's nothing you can alter so you just get on with it', but later in the interview expressed a sense of hopelessness - 'I've got no hope' - and misery - 'well you do get miserable,' 'it's not much of a life.' A male patient who had only been on HD for just over a month suggested he was coming to terms with the treatment although this required some mental struggle.

*“I just accept it, the position I'm in and take it from there. There's not much I can do about it, now that you're on it. It's your mind, if you can accept what's happening to you then it's trying to put your mind at rest and accepting what's happening to you, what's going on.”* Patient 33 (Study 1)

References and thoughts about dying featured in several interviews. Patients described being more conscious of their own mortality and having to accept that non-maintenance of treatment would result in their death. Two patients mentioned being aware that withdrawal from dialysis was always an option.

*“I’m not really happy but that’s not my choice. I have to have this treatment because if I don’t have this treatment I will end up dead.” Patient 23 (Study 1)*

Some HD patients reported treatment related problems such as decreased energy levels, dietary and fluid constraints, joint pain and impaired sexual activity that had contributed to low mood feelings. For example, one patient described how emotionally upsetting it was to feel constantly cold after recently starting to dialyse. Another patient mentioned sleeping difficulties during the early stages of starting dialysis as the cause of emotional distress.

*“Yes, sometimes, yeah, you do have negative feelings ....because I had initially unable to go to sleep but now kind of settled into the routine of doing it.” Patient 13 (Study 2)*

Early difficulties with their choice of dialysis treatment, sometimes requiring a change in dialysis modality or just the prospect of needing to change, generated emotional issues for some patients. For example a PD patient described having needed three different catheters to be inserted over a period of just a few months, with the concomitant fear that as a result of their failure to work effectively, a transfer to HD might be necessary.

Although emotional and psychological needs were less prevalent among patients interviewed at the pre-dialysis stage, nonetheless some patients at this point in the pathway were experiencing negative emotional and psychological feelings. Uncertainty about the future, fear, worry, low energy and a sense of unfairness all seemed to play a role.

There was recognition among several patients of an interrelationship between their physical and mental wellbeing. They understood negative emotional feelings could impact on physical health, and therefore improvements in emotional wellbeing might have a positive effect on physical outcomes. As a result of this known association, there was also some awareness that emotional and psychological issues might sometimes be confused with the physical aspects of kidney disease.

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*“Because of if you feel down, your body’s going to feel down. So if you feel better in yourself, you should improve your condition.”* Patient 13 (Study 2)

*“I was starting to feel better but you don’t know if that’s psychological or biological.”*  
Patient 26 (Study 1)

Additionally the existence of other chronic diseases could exacerbate physical symptoms, creating emotional stressors or negative feelings linked to patients’ illness and treatment such as uncertainty about the future. Several participants in the study sample mentioned having co-morbidities including stroke, diabetes and cancer. One patient’s emotional stress appeared partly magnified by confusion as to which consultant in the hospital could provide the clinical prognosis he was seeking.

*“I’m not sure whether sometimes that the cancer could come back. And I don’t know who’s possibly is the person to say or look at it, like, or give me an idea, you know.”*  
Patient 8 (Study 2)

### **Clinicians’ recognition of patients’ emotional and psychological needs**

Across the consultant sample there was understanding that many patients with end-stage renal disease experience anxiety and depression. Consultants were also cognisant that at certain stages along the disease pathway, patients’ emotional and psychological needs are likely to be more manifest, notably when patients are initially diagnosed and first start dialysis.

*“It’s very common in patients with end stage kidney failure on dialysis.... people do get low, depressed, frightened, fed up, and it changes their life when they go onto dialysis.”*  
Consultant 5

Consultants expressed divergent views however on the difficulty involved in identifying which patients were experiencing emotional distress. Some consultants were more confident than others about knowing the emotional status of their patients. Whilst one consultant talked with some assurance about being able to tell whether or not a patient is feeling emotionally well, others argued it was much more difficult to ascertain. In this respect renal nurses were often thought to play a valuable role in helping identify patients who may be feeling particularly anxious or depressed; being seen to have a closer relationship with many patients through more regular contact and to therefore be

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in a better position to recognise symptoms of feeling down and miserable. Consultants often used this source of information as an alert to patients needing more emotional and psychological support.

*“We do have a lot of input from nurses who do home visits, who know their carers very well – you do get a sense of their emotional wellbeing.”* Consultant 1

In addition to the problem of recognition, encouraging patients to disclose and discuss any emotional and psychological needs was acknowledged by all consultants to be complex and difficult. In particular several consultants highlighted the problem that a patient feeling miserable or depressed does not always want to talk about those feelings, or not necessarily at the time of a consultation. Most consultants said they had favourite open-ended phrases they used when necessary to try to elicit patient's emotional concerns - for example, *‘how are you feeling today?’*, *‘is there anything we haven't talked about?’*, and *‘is there anything else troubling you?’* - although they admitted such efforts were infrequently used and often failed to prompt patients to discuss emotional issues. The result, as described by one consultant, was that *“perhaps sometimes we skated round the issue about the emotions”*.

Continuity of care was considered beneficial in that patients are more likely to open up if they know their consultant well. Yet even long-standing patients were known to not always be forthcoming about emotional issues. One consultant, whilst drawing attention to the importance of a patient feeling, *‘they have some rapport or some connection or have some relationship’* with their consultant, described how difficult it can be even with a familiar patient, to understand a patient's emotional needs when they do not want to open-up and express their emotional concerns.

*“I had a man...he had problems...we had three meetings within about a two month period and eventually it all came out, he was frustrated, but I had to really dig deep for that.”* Consultant 2

Another consultant talked about how difficult it could be to identify the cause of a patient's depression in order to provide an appropriate solution. The socio-economic characteristics of their patient catchment area meant there could be multi-faceted causal factors – unemployment, cuts in benefits, poor living conditions, relational problems – although starting dialysis could often be a compounding issue.

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*“It’s often complex. And it might not just be that they’re feeling depressed because they’re starting on dialysis, it might be because, you know, the relationship with their partner’s not good, but it’s probably got worse since they’ve gone onto dialysis, you know, so things that weren’t quite right beforehand aren’t going to get any better once you go onto dialysis, things that weren’t quite right beforehand are probably going to get worse.”* Consultant 5

Time available within the consultation appears to be a significant inhibitor for consultants in terms of capacity to identify and address end-stage renal patient’s emotional and psychological needs. This seems to stem from two interrelated factors: perception it is a time-consuming process; and belief the focus of a consultation should be on physical health aspects. As a consequence some consultants acknowledged they might sometimes be dismissive, or not give emotional issues consideration unless made very apparent to them.

*“You may be, in a busy clinic, you may be worrying about the physical aspects of dialysis and then time quickly runs out, potentially, and you haven’t necessarily come to talk about their feelings about their treatment or explored any of their difficulties, because of time constraints.”* Consultant 2

### **Support and coping mechanisms used by patients**

Patients mostly sought support from within their own personal networks of family and friends for any emotional difficulties associated with their kidney disease and treatment. In general patients using this coping mechanism appeared content with the support they received, but for several patients it was found insufficient in addressing their emotional needs. There was also reluctance among some patients to expose the true extent of their emotional concerns; not wanting to burden those most close to them or fearing the impact on their personal relationships. The perceived social stigma of suffering from depression troubled a few patients and made them hesitant about expressing their real feelings. Others had poor social support networks and were unsure where they would turn for emotional support if needed, which left them feeling isolated.

*“I would come home upset and just have a word with my family member and just be upset, like I always do.....it doesn’t help because the next day I think ‘oh God, I’m going*

*to go up another day' and you know I'll be really upset when I'm about to go to dialysis, that doesn't help."* Patient 23 (Study 1)

It was notable that only one study participant mentioned talking to their renal consultant as their usual coping strategy if they were feeling down or miserable. Key factors inhibiting patients appear to be the perception that consultations are about physical health issues, and that consultants are too busy to start talking about emotional concerns.

*"When you go in to see the consultant the first thing they want to talk about is your medication, your dialysis. I mean, I think if you start going on how you're actually feeling or if I go in and say 'well look, I'm feeling a bit depressed' and you're wondering whether you're encroaching on their time. I mean, as I say, I mean, I know they haven't got a lot of time but, I mean, you might feel as though yes you are taking up extra time and they really perhaps don't want to be bothered, so you perhaps don't talk about it with them."* Patient 35 (Study 1)

Nurses by contrast had been used as a support resource by several patients. They were often thought easier to talk to about emotional issues because of being better known and more familiar to patients as a result of more frequent contacts through the Renal Unit. There were many plaudits for how accessible, caring and empathetic the renal nurses were and how encouraging they were that patients should ask for their support and advice. Nonetheless some patients mentioned being hesitant about troubling the nurses with their emotional concerns since talking about such issues takes time and the nurses always appeared overly busy and time-pressured.

In general patients' experiences of talking with nurses about any emotional concerns were very positive and the interaction found supportive. Nonetheless when patients mention physical symptoms of dialysis treatment that are causing emotional stress, for example feeling really tired, the tendency can be for the nurse's response to focus on the medical, not emotional aspects of the issue.

*"I say 'Well, I've been really, really tired for the last couple of weeks and it's getting me down.' So while we're doing what we have to do, s/he'll (nurse) say different things – you know: 'Have you been thinking about what you've been eating or you've been drinking? 'Cause this can affect this and can affect that.' So s/he talks you through it in*

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*a very nice way. You'll come up with a little bit of a plan... And sometimes it's not an answer but it's a suggestion that, you know, if you try this, it might work for you."*  
Patient 13 (Study 1)

This type of response may be judged to some extent helpful by the patient but might also forestall or inhibit further discussion and exploration of any underlying emotional issues. Several patients mentioned they would have liked more information on the psychosocial aspects of dialysis treatment prior to starting on their dialysis modality. There was some criticism that preparation and training provided by clinical staff concentrated too much on the physical consequences of dialysis treatment with insufficient attention to the potential emotional impacts. It was suggested better preparation for psychological treatment effects could result in improved coping.

*"The process you go through in terms of setting up the dialysis, is all very focused on the mechanics of getting it done rather than the emotional aspects of it."* Patient 26 (Study 1)

Use of 'tried and tested' personal coping strategies were mentioned by some participants, particularly to relax and calm their mind and reduce feelings of stress. Such strategies included doing housework, reading, and listening to meditation tapes at night.

*"Oh I feel low.... Yeah, I do get low now and again but it's a doing thing, isn't it, you know, you're doing an activity, you're doing something, it's just pulling the Hoover around or something like that, just takes something off your mind and I think that's the key word."* Patient 10 (Study 2)

Anti-depressants had been taken by a few patients in the past to treat their depression. Whilst generally finding the medication beneficial, they were not keen to remain on pharmacological support. One patient mentioned being offered medication for his depression, but had rejected the suggestion because of his already high level of medication.

*Well I've felt a bit depressed just recently and doctor - was interested to know if I would take some pills, in effect pills geared to improve my general feeling. I said I didn't want*

*to because I thought I was taking enough tablets already. So I'm a bit down.'* Patient 31 (Study 1)

A small minority of patients had previously used the support of a renal psychologist at one of the Hospital Trusts involved in the study. Others were aware of the renal psychology service but had not felt they needed such 'high level' support at the time it was offered; they nevertheless emphasised how emotionally reassuring it was to know the support was available if and when required.

*"If you've got any real issues they offer the psychologist services as well. If you really needed to speak to somebody you can....well they offered it me and I haven't been. I'm not ready to really discuss transplants yet. But I know that if I wanted to it would be there..... It's good that I know that it's there if I need it."* Patient 7 (Study 1)

Very few patients were aware of any interventions offered by their Renal Unit to support lower level emotional and psychological needs; those known were peer support and a patient support group. None of the research participants had made use of these services. The offer of support where made to patients was not felt necessary at the time when it was given. One patient, unaware of any available interventions, described her personal need of low level emotional support and how it might have helped relieve feelings of anxiety and uncertainty experienced during her transition to dialysis. She did not consider these emotional difficulties appropriate for discussion with either the renal nurses, because of their more practical focus, or a renal psychologist whose remit would be helping people with the most serious psychological problems.

*"I don't feel I ever needed a psychologist, you know, to be quite honest.....I, perhaps, do just need some sort of, like, pastoral support sort of like within the department, but I don't know who would provide that...But there were times, you know, where I was a little bit anxious, a little bit, you know, down about sort of like the prospects of the future, a little bit concerned and whatnot, and it might have been nice to have somebody to talk to about that."* Patient 16 (Study 1)

### **Emotional care from clinician behaviours and communications**

Patients can feel more cared for emotionally as a result of certain behaviours and communications by their renal consultants. Whilst such approaches are unlikely to directly address specific mild to moderate emotional and psychological difficulties they can play a significant moderating role in relation to some of the trauma and distress

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effects and provide a valuable sense of emotional support. What is important in making a patient feel emotionally cared for is very individual. Nonetheless some approaches were more frequently mentioned.

Feeling they have a personal relationship with their consultant in which they are treated and respected as an individual was considered important by patients across the research sample. Even if a consultant is unfamiliar to a patient, simple behavioural traits such as direct eye contact, smiling, a friendly greeting and some obvious knowledge of the patient's history, can engender a sense for the patient of being personally valued. Conversely when a consultant clearly shows no personal regard or knowledge of an individual patient, and fails to communicate on a personal level, creating an impression there is no relationship, a patient can feel emotionally distressed and personally rejected.

*"I'm under -- and s/he's brilliant...they give the impression, I mean, this is good psychology from their point of view, they give the impression that you're the most important patient that they've got....their bedside manner is extremely good, at least in my experience....and that gives you a lot of confidence. You get the feeling that they are concerned to help you as much as they can."* Patient 5 (Study 2 - group)

*"The last consultation I had with her/him I felt very out of it, if you will. I felt very much I was just, you know, 'Next.' Another patient, another day, go through the process, move on....And I felt at that time s/he didn't understand my case.....I actually felt worse when I came out of that than when I went in."* Patient 13 (Study 1)

Within the context of the patient-consultant relationship there is expectation for some patients of an ongoing conversation from consultation to consultation. They may feel less emotionally cared for when their consultant does not continue this conversation, for example by failing to reference previously communicated emotional issues.

*"Well the thing is I've got a background of problems, various problems with my chest and prostrate and such like and also I've got a wife who's very depressed at home and she suffers from depression.....mentioned that on the first visit but s/he never followed it up at all on the second....I would have expected her/him to ask a few questions on that basis....I just felt that a little bit more personal involvement might have been acceptable."* Patient 32 (Study 1)

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A continuous relationship between consultant and patient is particularly valued. Over time a consultant is thought to build a fuller, more rounded knowledge picture of the patient. Some patients believed this should enable their consultant to recognise when they were feeling down or not their normal self. For other patients it meant they felt more confident about asking questions. One patient mentioned how emotionally disruptive it had been to see a succession of different consultants after starting dialysis, and not the consultant with whom they had become familiar with pre-dialysis.

*“If you see one doctor one week, one doctor the next week and they don’t know you, they don’t know your personality and how can they make a judgement if you’re down?”*

Patient 9 (Study 1)

Being seen to have done something beyond or outside the normal consultant role was also thought to demonstrate emotional care. For example, a female HD patient described how her consultant had gone out of their way in the Renal Unit to ask how she was feeling, even though attending to another patient not her, and clearly very busy. This unprompted gesture of care made her feel more emotionally supported.

*“During the time when s/he was supposed to be seeing another patient next door, but basically after s/he finished talking to that other patient s/he came over to have a check on me as well. That kind of thing is very nice for the consultant to do.”*

Patient 6  
(Study 1)

The perception for the patient of being in a caring relationship can also be communicated by a consultant noticing and commenting on positive individual aspects relating to the patient’s treatment or condition:

*“S/he said ‘You look so much better since I last saw you’ and I said I feel better.”*

Patient 1 (Study 1)

Providing clear, understandable explanations about their condition and treatment was thought by many patients to be an integral element of emotional care. Many patients stressed their appreciation for consultants who gave explanations in plain, straightforward layman’s terms without use of jargon; communicating in a humane not

official manner. Also a consultant taking the time to repeat more complex statements and ensuring the patient fully understands what is being communicated.

*“You know, s/he knows how much I’m concerned and s/he’s able to put me at ease. S/he’s able to relax me....Just by the way s/he talks and the way s/he explains things. I mean, you know, in laymen’s terms, you know, there’s no bull.”* Patient 27 (Study 1)

The way a consultant communicates bad news was often mentioned as being indicative of how emotionally caring a consultant is about their patients. Some of the strongest criticism of consultants perceived to be uncaring was in reference to how they first communicated a diagnosis of end-stage renal failure to a patient. In particular a lack of kindness, sympathy and recognition for how the patient might be feeling on immediately hearing news that is both shocking and frightening.

There were notable differences though in patients’ preferences for how bad news is communicated in terms of information content. Some patients said they always want to have the reality of the situation clearly laid out whereas others want to be left with a sense of hope and optimism.

*“I liked her/him because s/he was straightforward, didn’t beat about the bush. I said ‘well, what happens if it doesn’t work?’ S/he said ‘you lose the use of your hand’. Now I prefer that than being fobbed off, and you know, told proper.”* Patient 6 (Study 2 – group)

*“The doctor who I’ve got now, s/he just tends to think about what s/he’s saying, the way that s/he’s saying it so that it comes across in a kind way..... S/he tries to put a positive spin on it and I suppose that puts you in a positive mind frame as well.”* Patient 7 (Study 1)

Emotional care was also felt to be demonstrated by a consultant encouraging a patient to ask questions about how they feel, and how the consultant then reacts and responds to those questions: listening attentively, communicating empathetically, showing the patient has been heard and understood. In turn this can encourage a patient to disclose more of their emotional feelings.

*“If I ask her/him a question s/he can explain me very good with a smile, you know, I don’t feel afraid or feel ashamed to ask her/him a question.”* Patient 12 (Study 1)

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## 5. Discussion

This section of the report discusses the findings from the two linked studies of the evaluation, in relation to the key aims of the evaluation and evidence from the literature review.

### **Impact on clinicians explicitly talking with patients about their emotional feelings and concerns**

The research findings identified that both pilot interventions, the NICE evidence-based question and the PI sheet, could impact positively on what was talked about in consultations. The form, manner and context in which consultants and patients used each intervention tended to determine how effective it was in encouraging explicit discussion about emotional feelings and concerns.

There were two aspects of the NICE evidence-based intervention that seemed to provide the means to encourage emotional disclosure by patients. First, its capacity to make patients feel more emotionally cared for by their consultant; simply by asking the question consultants were showing emotional support was available. This provided reassurance of the acceptability of disclosure. The importance of perceived emotional care and empathy in encouraging emotional response is well documented in the literature on emotional support in consultations for cancer patients (Maguire, 1985; Ryan et al, 2005; Pollack et al, 2007; Suchman et al, 1997; Anderson et al, 2008)

Second its role as an enabling prompt. By asking a direct question, patients who lacked confidence or ability to spontaneously express emotional concerns felt they were being given the opportunity and a helping hand by their consultant to speak out. Whilst some consultants were uncomfortable about using such a direct, specific question, most patients liked and supported its use. It appeared to encourage disclosure by patients with emotional difficulties, and potential anticipated use by patients who felt they might need emotional support in future. These patient responses are congruent with the findings of Maguire et al (1996), that active clinician enquiry through use of direct leading questions facilitates discussion about cancer patients' concerns and feelings. Although Ryan et al (2005) argued that use of direct questions has varied effects depending on the general style of the consultation. When asked in an appropriate context they could lead to disclosure, but could also have the opposite effect when

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inserted out of context. Consultant adaptation of the intervention to individual consultation style may therefore be apposite.

The evaluation revealed that the PI sheet intervention successfully overcame some of the cognitive and affective disabling barriers first identified by Roter et al (1977) as inhibiting patient question-asking in consultations; in particular, patients perceiving it unacceptable to ask questions, and forgetting the questions they want to ask. However our study also identified some important enabling factors requiring consultant support, notably the ability and confidence to ask questions, before many patients would use the PI sheet as a tool to raise issues they wanted to discuss.

Our study suggests that patients willing and able to spontaneously introduce the PI sheet into the consultation without consultant prompting and support tended to have higher levels of self-efficacy, in line with Bandura's model (1995). They seemed confident in their capacity and skills to master the task of using the new intervention without assistance. There were many other patients in this study who appeared to have lower levels of self-efficacy, although we did not specifically measure this dimension. For them use of the intervention involved a shift from more of a sick role as described by Parsons (1951), with a focus on passivity and dependency, to an active and empowered role. Study findings suggested they need consultant support to make this transition. The intervention seemed to work best in having an impact on what was talked about when used in a two-way communication process between patient and consultant and as an integral part of the consultation. Since the intervention involved change to the learned consultation structure, and patient expectations of what happens in a consultation, effective use was more likely if there was active consultant encouragement. This reflects the social support model first identified by Cobb (1976), which showed that mastery of a new patient task as well as any role change is best undertaken under emotionally supportive conditions. Interestingly a study by Brown et al (1999, 2001) found that cancer patients asked more questions in consultations when given a question prompt sheet, but without oncologist endorsement of the sheet, their anxiety levels increased.

In general, patients who raised any issues for discussion with their consultant in response to use of either intervention were satisfied with how the issues were handled. Several patients clearly experienced a sense of empathy from how their consultant responded when discussing issues disclosed. It seemed to encourage patients to

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

explain more about how they were feeling. Research with cancer patients by Maguire et al (1996) also found that patients whose clinicians are empathetic and invite discussion, seem to disclose more concerns. In our study there were also patients however, whose consultants seemed to adopt more of practical and problem-solving response, often focusing solely on the physical symptoms that might be causing the issue raised. Whilst some of these patients expressed satisfaction their consultant had discussed the issue, it is also possible that a practical response, without discussion of any emotional aspects, or any expression of empathy by the consultant, might have prevented a patient's emotional needs from being supported. In this respect Maguire (1985) found cancer patients could be discouraged from mentioning emotional and psychological needs when clinicians concentrate on the physical aspects of the disease.

### **Patient needs, wants and expectations of emotional support interventions**

The evaluation has achieved a better understanding of what patients need, want and expect from interventions to support their lower level emotional and psychological needs and identified how these can be better met. A considerable level of unmet emotional need was revealed among patients participating in the evaluation. Whilst more than a third of patients across the two studies mentioned existing emotional concerns, or recently experiencing emotional difficulties, only a small minority had used a support intervention. Very few patients were aware of any available interventions to meet lower level emotional and psychological needs. Only one patient mentioned talking to their renal consultant as their usual coping strategy. The findings suggest that existing renal services are not set up to look for or support patients' lower level emotional needs. Specific consultation-focused interventions appear necessary to encourage patients' disclosure of emotional needs; disclosure does not seem to happen ad hoc as a result of patients having got to know their consultant. These findings reinforce those from the literature that end-stage renal disease patients experience considerable emotional and psychological difficulties, not responded to or supported by their clinicians (Watnick et al, 2003; Hedayati et al, 2008; Combes et al, 2013).

Most patients in this evaluation wanted improved emotional and psychological support particularly in terms of help with accepting their diagnosis and life on dialysis, adjusting to the burden of dialysis treatment, dealing with uncertainty, and handling treatment related problems. This is in line with existing evidence that highlights patients want help with adjustment, coping and maintaining control (Tong et al, 2008; Schipper and Abma,

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

2011). Nonetheless receptivity to the evidence-based interventions shown as audio-visual films varied across the study sample, dependent on a complex mix of emotional status, anticipated self-efficacy, existing support networks, type of dialysis treatment, emotional readiness to share feelings with others, and relevance of perceived benefits. It was also apparent that motivation to take-up an intervention offering emotional support can vary over time. Yet patients in general felt reassured and better supported emotionally simply by knowing that consultant-endorsed support was available, if and when required. This would suggest there is value in patient awareness-raising of interventions offering emotional and psychological support, with some choice and flexibility in terms of format and timing across the pathway from diagnosis to the early stages of being on dialysis.

This evaluation revealed that for many patients with emotional difficulties, fear of the stigma of being perceived as suffering from depression, is a significant psychological barrier to taking-up a support intervention. Any perceived association with depression tended to make an intervention unattractive. Conversely, interventions perceived as inclusive and suitable for any renal patient were generally found more motivating. Wuerth et al (2005) similarly found that a key reason dialysis patients with emotional concerns did not want to receive support is denial of being depressed, with some feeling they would be stigmatised if they were to acknowledge symptoms of depression. This suggests use of the NICE evidence-based intervention is likely to be encouraged by the approach taken by one consultant of providing an explanation to normalise its introduction; explaining it is normal for kidney patients to have some emotional concerns.

The two studies also identified that patients can feel more cared for emotionally as a result of certain behaviour and communications by their renal consultants including: treating and respecting patients as individuals in a personal relationship with their consultant; having an on-going conversation from consultation to consultation which constitutes part of a continuous relationship; aspects of a patients' behaviour or condition being positively commented upon; providing clear and understandable explanations in layman's language; and, encouraging questions and responding by listening attentively and communicating empathetically. Several studies among cancer patients have identified similar findings (Maguire et al, 1996; Roter et al, 1997; Suchman et al, 1997; Pollack et al, 2007)

Whilst such approaches are unlikely to directly address emotional and psychological difficulties they can play a significant moderating role in relation to some of the trauma and distress effects and provide a valuable sense of emotional support. Whether or not a patient felt emotionally cared for was also shown to play a role in the facilitation of emotional disclosure in relation to use of the two pilot interventions. These responses are congruent with findings from the literature on long term conditions and cancer in particular, indicating that patients who feel empathised with and supported have lower levels of distress (Suchman et al, 1997; Pollack et al, 2007) and clinicians who acknowledge patients' emotions and encourage discussion through listening skills and empathy create the opportunity for greater expression of emotional feelings and concerns (Roter et al, 1995; Del Piccolo et al, 2000; Ryan et al, 2003; Anderson et al 2008).

### **Limitations of the evaluation**

The evaluation had a number of limitations which should be noted when considering the findings. First, based on initial consultant estimates of potential numbers of eligible patients in each Hospital Trust, the original intention had been to recruit a purposively selected sample for study 1, based on the study inclusion criteria and to give maximum variation of dialysis type, age, gender and ethnicity. However when actual numbers of eligible patients were collected by Renal Unit staff, these were only around a third of the initial estimates in each Trust. Therefore all eligible patients were included in the potential sample and purposive sampling was not feasible. This meant that some sub-groups were under-represented, for example only 35% of participants were females, or not represented – there were no HHD patients recruited.

Second, it was not possible to directly compare findings as intended between the two Hospital Unit sites for study 1 given the relative and absolute low number of patients recruited in one of the study sites. Only 9 patients were recruited to the study in one site, representing 22% of all eligible patients. Whilst in the second site, 27 patients were recruited (82% of eligible patients).

Third, given the low numbers of patients recruited in one Hospital Unit site for study 1, the participating consultants in that site had limited experience of using the pilot interventions, especially the PI sheet.

Fourth, there are limitations arising from there being only two study sites and sites which were not selected to be representative of Renal Units either locally, regionally or

nationally. Whilst acceptable for a pilot study, it is not possible to generalise the findings.

### **Strengths of the evaluation**

The evaluation also had some notable strengths, worth highlighting. First, consultants from one study site were closely involved in the development and design of the two pilot interventions and this seemed to encourage stronger clinician ownership of the interventions at that site. It may also have helped the patient recruitment process.

Second, use of audio-visual films to communicate the five intervention concepts helped make the unknown interventions more 'real' for patients than if they had to use their imaginations alone. They were better able to understand how each intervention would work in practice and the perceived relative benefits and disadvantages.

Third, use of mini-focus groups as well as individual interviews enabled better exploration of patients' needs, wants and expectations in relation to interventions providing emotional and psychological support. Whilst individual interviews allowed in-depth examination of personal attitudes, behaviours and motivations, mini-focus groups provided different insights through discussion around alternative ideas and opinions.

## **6. Recommendations**

**The two pilot interventions, the NICE evidence-based question and the Patient Issues sheet, look promising from a patient perspective and consultants should consider incorporating them into routine consultations to help address patients' low level emotional needs.** Patients liked both interventions and there appeared to be no significant negative reactions.

**Interventions are necessary to encourage disclosure and to support patients' emotional and psychological needs.** The evaluation findings indicated that the status quo does not work for most patients. They are not asked about and do not disclose their emotional concerns on an ad hoc basis in consultations and without interventions.

**Interventions are likely to work best when consultants also promote emotional disclosure and ease discussion.** Patients felt less supported if the consultant used practical or problem-solving approaches rather than listening or empathy. Some

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

patients expressed dissatisfaction if their consultant closed down discussion of an emotional issue quickly or stuck to their usual agenda.

**Renal consultants should record in their patients' notes** any disclosure and discussion of emotional issues by patients. These emotional issues can then be followed-up in future consultations.

**There is potential for a larger-scale study to see if the interventions result in better outcomes for patients.** This might include measurement of impact on patient disclosure and discussion of emotional needs in consultations, and effects on emotional and psychological wellbeing and anxiety levels. Additionally measurement of effect of patient attributes such as self-efficacy and emotional status on acceptability and use of the interventions, might be helpful.

**Training of renal consultants is necessary** prior to their use of the pilot interventions. In particular to help consultants respond appropriately to any emotional issues raised by patients and to contain discussion so as not to lengthen consultations.

**Any of the interventions shown to patients as audio-visual films, have the potential to provide beneficial emotional and psychological support for patients.** A key requirement is that an intervention clearly be promoted by clinicians as being 'normal' support for renal patients, and not be associated with depression.

## 7. References

Alam R, Sturt J, Lall R, Winkley K. An updated meta-analysis to assess the effectiveness of psychological interventions delivered by psychological specialists and generalist clinicians on glycaemic control and on psychological status. *Patient Educ Couns* 2009; **75**(1):25-36.

American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders 4<sup>th</sup> edn.* American Psychiatric Association, Washington DC, 1994

Anand S, Johansen KL, Grimes B *et al.* Physical activity and self-reported symptoms of insomnia, restless legs syndrome, and depression: The comprehensive dialysis study. *Hemodial Int* July 20 2012: 1542-4758

Anderson RJ *et al.* (2001) The prevalence of comorbid depression in adults with diabetes: a meta-analysis. *Diabetes Care* 2001; **24**:1069-78

Anderson WG, Alexander SC, Rodriguez KL *et al.* "What concerns me is . . ." Expression of emotion by advanced cancer patients during outpatient visits. *Support Care Cancer* 2008; **16**(7):803-811

Arrol B, Goodyear-Smith F, Kerse, N *et al* Effect of the addition of a "help" question to two screening questions on specificity for diagnosis of depression in general practice: diagnostic validity study. *BMJ* 2005;**331**: 884

Baer RA Mindfulness Training as a Clinical Intervention: A Conceptual and Empirical Review *Clinical Psychology: Science and Practice* 2003; **10**(2):125-143

Bandura A *Self-efficacy in changing societies.* Cambridge: Cambridge University Press, 1995

Barnett K, Mercer SW, Norbury M *et al.* Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross sectional study. *The Lancet* 2012; **380**:37-43

Bass EB, Jenckes MW, Fink NE *et al.* Use of Focus Groups to Identify Concerns about Dialysis. *Med Decis Making* 1999; **19**:287-295

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Beaver K, Craven O, Witham G *et al.* Patient participation in decision-making: views of health professionals caring for people with colorectal cancer. *Journal of Clinical Nursing*, 2007;**16**: 725-733.

Bekker H, Thornton JG, Aieray CM *et al.* Informed decision making: an annotated bibliography and systematic review. *Health Technology Assessment* 1999; **3**(1)

Bertrand LJ, Schiller B, Burkart JM *et al.* Impact of Short Daily Hemodialysis on Restless Legs Symptoms and Sleep Disturbances. *Clin J Am Soc Nephrol* 2011; **6**(5):1049-1056

Billington E, Simpson J, Unwin J *et al.* Does hope predict adjustment to end-stage renal failure and consequent dialysis? *British Journal of Health Psychology* 2008; **13**:683-699

Birmele B, Le Gall A, Sautenet B *et al.* Clinical, Sociodemographic, and Psychological Correlates of Health-Related Quality of Life in Chronic Hemodialysis Patients. *Psychosomatics* 2012; **53**(1):30-37

Bohlmeijer E, Prenger R, Taal E, Cuijpers P. The effects of mindfulness-based stress reduction therapy on mental health of adults with a chronic medical disease: A meta-analysis. *Journal of Psychomatic Research*, 2010;**68**: 539-544

Boulware LE, Liu Y, Fink NE *et al.* Temporal relation among depression symptoms, cardiovascular disease events, and mortality in end-stage renal disease: contribution of reverse causality. *Clin J Am Soc Nephrol* 2006; **1**: 496–504.

British Renal Society *The Renal Team. A multi-professional renal workforce plan for adults and children with renal disease. Recommendations of the National Renal Workforce Planning Group 2002.* [http://www.britishrenal.org/getattachment/Workforce-Planning/WFP\\_Renal\\_Book1.pdf.aspx](http://www.britishrenal.org/getattachment/Workforce-Planning/WFP_Renal_Book1.pdf.aspx) (last accessed 14/04/14)

Brown EA, Johansson L, Farrington K *et al.* Broadening Options for Long-Term Dialysis in the Elderly (BOLDE): differences in quality of life on peritoneal dialysis compared to haemodialysis for older patients. *Nephrol Dial Transplant* 2010; **25**:3755-3763

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Brown RF, Butow PN, Boyer MJ, Tattersall MHN. Promoting patient participation in the cancer consultation: evaluation of a prompt sheet and coaching in question-asking. *British Journal of Cancer* 1999;**80**: 242–248

Brown RF, Butow PN, Dunn SM and Tattersall MHN. Promoting patient participation and shortening cancer consultations: a randomised trial. *British Journal of Cancer* 2001;**85**: 1273-1279

Burnard P. *Counselling Skills for Health Professionals 3<sup>rd</sup> edn.* Stanley Thomas, 1999

Butow PN, Dunn SM, Tattersall MHN and Jones QL. Patient participation in the cancer consultation: Evaluation of a question prompt sheet. *Annals of Oncology* 1994; **5**:199-204

Butow PN, Brown RF, Cogar S, Tattersall MH, Dunn SM. Oncologists' reactions to cancer patients' verbal cues. *Psychooncology*, 2002;**11**:47–58.

Byrne A, Ellershaw J, Holcombe C, Salmon P. Patients' experience of cancer: evidence of the role of 'fighting' in collusive clinical communication. *Patient Education and Counseling*, 2002;**48**(1): 15–21

Campbell H S, Phaneuf M R, Deane K. Cancer peer support programs: do they work? *Patient Education and Counseling* 2004; **55**(1): 3-15

Carkhuff RR. *The Art of Helping* 6<sup>th</sup> edn. Amherst MA: Human Resource Development Press, 1987

Carmack CL, Amarel-Melendez M, Boudreaux E *et al.* Exercise as a component of the physical and psychological rehabilitation of hemodialysis patients. *International Journal of Rehabilitation and Health* 1995; **1**(1):13-23

Chan R, Brooks R, Erlich J *et al.* The Effects of Kidney-Disease-Related Loss on Long-Term Dialysis Patients' Depression and Quality of Life. *Clin J Am Soc Nephrol* 2009; **4**(1): 160-167

Chilcot J, Wellsted D, Da Silva-Gane M, Farrington K. Depression on Dialysis. *Nephron Clin Pract* 2008; **108**:c256-264

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Christians CG., (2000). Ethics and politics in qualitative research. In Denzin, N.K., Lincoln, Y.S. (Eds.) (2000) *Handbook of Qualitative Research*. London, Sage Publications

Cobb S. Social Support as a Moderator of Life Stress. *Psychosomatic Medicine* 1976; **38**:300-314

Cohen LM, Dobscha SK, Hails KC *et al.* Depression and suicidal ideation in patients who discontinue the life-support treatment of dialysis. *Psychosomatic Medicine* 2002; **64**:889–896.

Cooney GB, Dwan K, Greig CA *et al.* Exercise for depression. *The Cochrane Library*, Issue 9, 2013

Combes G, Allen K, Sein K. *Evaluation of case study sites for home therapies for people with chronic kidney disease*, West Midlands Central Health Innovation and Education Cluster, Birmingham, University of Birmingham, 2013 <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC>(last accessed 14/04/14)

Craven JL, Rodin GM, Littlefield C. The BDI as a screening device for major depression in renal dialysis patients. *Int J Psychiatry Med* 1988; **18**:365–374

Cukor D. Use of CBT to Treat Depression Among Patients on Hemodialysis. *Psychiatric Services* May 2007; **58**(5):711-712

Cukor D, Coplan J, Brown C *et al.* Anxiety Disorder in Adults Treated by Hemodialysis: A Single-Center Study. *American Journal of Kidney Disease* 2008a; **52**(1):128-136

Cukor D, Coplan J, Brown C *et al.* Course of Depression and Anxiety Diagnosis in Patients with Hemodialysis: A 16-month Follow-up. *Clin J Am Soc Nephrol* 2008b; **3**:1752-1758

Cukor D, Rosenthal DS, Jindal RM *et al.* Depression is an important contributor to low medication adherence in hemodialysed patients and transplant recipients *Kidney*

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Curtin RB, Bultman DC, Thomas-Hawkins C *et al.* Hemodialysis Patients' Symptom Experience: Effects on Physical and Mental Functioning. *Nephrology Nursing Journal* 2002; **29**(6):562-574

Cvengros JA, Christensen AJ, Lawton WJ. Health locus of control and depression in chronic kidney disease: A dynamic perspective. *J Health Psychol* 2005; **10**:677-86.

Dennis CL. Peer support within a health care context: a concept analysis *Int J Nurs Stud* 2003; **40**(3):321-332

Department of Health. *The National Service Framework for Renal Services Part 1: Dialysis and transplantation*. Department of Health, London, 2004 Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/199001/National\\_Service\\_Framework\\_for\\_Renal\\_Services\\_Part\\_One\\_-\\_Dialysis\\_and\\_Transplantation.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199001/National_Service_Framework_for_Renal_Services_Part_One_-_Dialysis_and_Transplantation.pdf) (last accessed 14/04/14)

Department of Health. *The National Service Framework for Renal Services Part 2: Chronic kidney disease, acute renal failure and end of life care*. Department of Health, London, 2005 Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/199002/National\\_Service\\_Framework\\_for\\_Renal\\_Services\\_Part\\_Two\\_-\\_Chronic\\_Kidney\\_Disease\\_\\_Acute\\_Renal\\_Failure\\_and\\_End\\_of\\_Life\\_Care.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/199002/National_Service_Framework_for_Renal_Services_Part_Two_-_Chronic_Kidney_Disease__Acute_Renal_Failure_and_End_of_Life_Care.pdf) (last accessed 14/04/14)

Department of Health *Long Term Conditions Compendium of Information Third Edition* London, Department of Health, 2012a Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216528/dh\\_134486.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216528/dh_134486.pdf) (last accessed 14/04/14)

Department of Health. *Understanding personal health budgets* Department of Health, London, 2012b Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/216813/Understanding-personal-health-budgets-2012.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216813/Understanding-personal-health-budgets-2012.pdf) (last accessed 14/04/14)

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Department of Health *Closing the gap: priorities for essential change in mental health*  
London, Department of Health, 2014 Available at:  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/281250/  
Closing\\_the\\_gap\\_V2\\_-\\_17\\_Feb\\_2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/281250/Closing_the_gap_V2_-_17_Feb_2014.pdf) (last accessed at 14/04/14)

Detmar SB, Muller MJ, Wever LD, Schornagel JH, Aaronson NK. The patient- physician relationship. Patient-physician communication during outpatient palliative treatment visits: an observational study. *JAMA* 2001; **285**(10):1351-1357.

Drayer RA, Piraino B, Reynolds III CF *et al.* Characteristics of depression in hemodialysis patients: symptoms, quality of life, and mortality risk. *Gen Hosp Psychiatry* 2006; **28**: 306–312.

Duarte PS, Miyazaki MC, Blay SL and Sesso R *et al.* Cognitive-behavioural group therapy is an effective treatment for major depression in hemodialysis patients. *Kidney International* 2009; **76**:414-421

Egan G. *The Skilled Helper: A Problem-management and Opportunity-developing Approach to Helping*. 7<sup>th</sup> edn. California: Brooks/Cole, 2002

Fallowfield L, Ratcliffe D, Jenkins V, Saul J. Psychiatric morbidity and its recognition by doctors in patients with cancer. *Br J Cancer* 2001;**84**(8):1011–5

Feroze U, Martin D, Kalantar-Zadeh K. Anxiety and Depression in Maintenance Dialysis Patients: Preliminary Data of a Cross-Sectional Study and Brief Literature Review. *Journal of Renal Nutrition* 2012; **22**(1) 207-210

Finkelstein FO, Finkelstein SH. Depression in chronic dialysis patients: assessment and treatment. *Nephrol Dial Transplant* 2000; **15**:1911-1913

Fjorback CO, Arendt M, Ornbol E *et al.* Mindfulness-Based Stress Reduction and Mindfulness-Based Cognitive Therapy – a systematic review of randomized controlled trials *Acta Psychiatr Scand*, 2011;**124**: 102-119

Ford S, Fallowfield L, Lewis S. Can oncologists detect distress in their out-patients and how satisfied are they with their performance during bad news consultations? *Br J Cancer* 1994; **70**(4):767-770.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Foroushani PS, Schnieder J and Assareh N Meta-review of the effectiveness of computerised CBT in treating depression *BMC Psychiatry* 2011; **11**:131-136

Foster G, Taylor SJC, Eldridge S *et al.* Self-management education programmes by lay leaders for people with chronic conditions. *The Cochrane Library* Issue 1, 2009

Gilbody S, Sheldon T, Wessely S. Should we screen for depression? *BMJ* 2006;**332**: 1027-1030.

Gottlieb B, Wachala E. Cancer support groups: a critical review of empirical studies. *Psycho-Oncology* 2007; **16**:379-400

Green JA, Mor MK, Shields AM *et al.* Renal provider perceptions and practice patterns regarding the management of pain, sexual dysfunction, and depression in hemodialysis patients. *J Palliat Med* Feb 2012;**15**(2):163-7

Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. *Ann Intern Med* 1985; **102**:520-528.

Greenfield S, Kaplan SH, Ware JE Jr *et al.* Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. *J Gen Intern Med.* 1988; **3**:448-457.

Greenwood SA, Lindup H, Taylor K *et al.* Evaluation of a pragmatic exercise rehabilitation programme in chronic kidney disease. *Nephrol Dial Transplant* 2012; **26** (Suppl 3):26-34

Gregory DM, Way CY, Hutchinson TA *et al* Patients' Perceptions of their Experiences with ESRD and Hemodialysis Treatment *Qual Health Res* 1998;**8**:764-783

Griffin SJ, Kinmouth AL, Veltman MWM *et al.* Effect on Health-Related Outcomes of Interactions to Alter the Interaction Between Patients and Practitioners: A Systematic Review of Trials *Annals of Family Medicine* 2004; **2**(6):595-608

Grigsby AB, Anderson RJ, Freedland KE *et al.* Prevalence of anxiety in adults with CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

diabetes: a systematic review. *J. Psychosom Res* 2002; **53**:1053-1060.

HM Government No health without mental health. *A cross-government mental health outcomes strategy for people of all ages* COI, London, 2011 Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213761/dh\\_124058.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf) (last accessed 14/04/14)

Haiwe S, Jacobsen H. Exercise training for adults with chronic kidney disease (Review). *The Cochrane Library* Issue 10, 2011

Hedayati SS, Grambow SC, Szczech LA *et al.* Physician-diagnosed depression as a correlate of hospitalizations in patients receiving long-term hemodialysis. *Am J Kidney Dis* 2005; **46**: 642–649

Hedayati SS, Bosworth HB, Kuchibhatla M *et al.* The predictive value of self-report scales compared with physician diagnosis of depression in hemodialysis patients. *Kidney International* 2006; **69**:1662-1668

Hedayati SS, Bosworth HB, Briley LP. Death or hospitalization of patients on chronic hemodialysis is associated with a physician-based diagnosis of depression. *Kidney International* 2008; **74**:930-936

Hedayati S, Minhajuddin AT, Toto RD *et al.* Validation of Depression Screening Scales in Patients with CKD. *Am J Kidney Dis* 2009; **54**(3):433-439

Hedayati SS, Minhajuddin AT, Afshar M *et al.* Association Between Major Depressive Episodes in Patients With Chronic Kidney Disease and Initiation of Dialysis, Hospitalization, or Death. *JAMA* 2010; **303**(19):1946-1953

Hedayati SS, Yalamanchili V and Finkelstein FO. A practical approach to the treatment of depression in patients with chronic kidney disease and end-stage renal disease. *Kidney international* 2012; **81**:247-255

Heine S and Tollin H. Patients' perceptions on the implementation of intra-dialytic cycling – a phenomenographic study. *Implementation Science*, 2012;**7**: 68-76

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Hoey L, Leropoli S, White V, Jefford M. Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling* 2008; **70**: 315-337

Hofmann SG, Sawyer AT, Witt AA, Oh D. The effect of mindfulness-based therapy on anxiety and depression: A meta-analytic review. *J Consult Clin Psychol* 2010; **78**(2):169-183

Hughes J, Wood E, Smith G. Exploring kidney patients' experiences of receiving individual peer support. *Health Expectations* 2009; **12**:396-406

Husebye DG, Westliel L, Styrvoky TJ *et al.* Psychological, social and somatic prognostic indicators in old patients undergoing long-term dialysis. *Arch Intern Med* 1987; **177**:1921-1924

Ismail K, Maissi E, Thomas S *et al.* A randomised controlled trial of cognitive behaviour therapy and motivational interviewing for people with Type 1 diabetes mellitus with persistent sub-optimal glycaemic control: a Diabetes and Psychological Therapies (ADaPT) study. *Health Technology Assessment* May 2010; **14** (22):1-101, iii-iv.

Jiang W, Alexander J, Christopher E *et al.* Relationship of depression to increased risk of mortality and rehospitalization in patients with congestive heart failure. *Arch Intern Med* 2001; **161**:1849-1856

Kaltenthaker E, Parry G and Beverley C Computerised cognitive-behavioural therapy for depression: systematic review *The British Journal of Psychiatry* 2008; **193**:818-184

Kaplan SH, Greenfield MD and Ware JE. Assessing the Effects of Physician-Patient Interactions on the Outcomes of Chronic Disease *Medical Care* 1989; **27**(3): Spl.

Kenardy J, Mensch M, Bowen K *et al.* Disordered eating behaviours in women with Type 2 diabetes mellitus. *Eating Behaviour* 2001; **2**(2):183-92.

Kendrick T, Peveler R. Guidelines for the management of depression: NICE work? *The British Journal of Psychiatry*, 2010; **197**:345-347

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Kennedy A, Reeves D, Bower P *et al.* The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. *J Epidemiol Community Health* 2007; **61**:254-261

Khoury B, Lecompte T, Fortin G *et al.* Mindfulness-based therapy: A comprehensive meta-analysis *Clinical Psychology Review*, 2013;**33**: 763-771

Kidd J, Marteau TM, Robinson S *et al.* Promoting patient participation in consultations: a randomised controlled trial to evaluate the effectiveness of three patient-focused interventions. *Patient Education & Counseling* 2004; **52**:107-112

Kimmel PL, Weis K and Peterson RA. Survival in Hemodialysis Patients: The Role of Depression. *Journal of the American Society of Nephrology* 1993; **3**:12-27

Kimmel PL, Peterson RA, Weihs KL. Behavioural Compliance With Dialysis Prescription in Hemodialysis Patients. *Journal of the American Society of Nephrology* 1995; **5**:1826-1834

Kimmel PL, Boyle DH, Umana WO. Psychologic Functioning, Quality of Life, and Behavioural Compliance in Patients Beginning Hemodialysis. *Journal of the American Society of Nephrology* 1996; **7**(10):2152-2159

Kimmel PL, Peterson RA, Weihs KL. Psychosocial factors, behavioural compliance and survival in urban hemodialysis patients. *Kidney International* 1998; **54**:245-254

Kimmel PL, Peterson RA, Weihs KL. Multiple measurements of depression predict mortality in a longitudinal study of chronic hemodialysis outpatients *Kidney International* 2000; **57**:2093-2098

Kimmel PL. Psychosocial factors in dialysis patients. *Kidney International* 2001; **59**:1599-1613

Kimmel PL. Depression in patients with chronic renal disease. What we know and what we need to know. *Journal of Psychosomatic Research* 2002; **53**:951-956

Kimmel PL and Peterson RA. Depression in End-Stage Renal Disease Patients Treated  
CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

with Hemodialysis: Tools, Correlates, Outcomes and Needs. *Seminars in Dialysis* 2005; **18**(2):91-97

Kroenke K, Spitzer RL and Williams JB. The Patient Health Questionnaire-2: Validity of a two-item depression screener. *Medical Care* 2003;**41**(11): 1284-1292

Kübler-Ross E. *On Death and Dying*. Toronto, Macmillan, 1969

Kurella M, Kimmel PL, Young BS, Chertow GM. Suicide in the US End-Stage Renal Disease Program. *J Am Soc Nephrol* 2005; **16**:774-781

Kutner NG, Fair PL and Kutner MH. Assessing Depression and Anxiety in Chronic Dialysis Patients. *Journal of Psychosomatic Research* 1985; **29**(1):23-31

Leake R, Friend R and Wadhwa N. Improving Adjustment to Chronic Illness Through Strategic Self-Presentation: An Experimental Study on a Renal Dialysis Unit. *Health Psychology* 1999; **18**(1):54-62

Lopes AA, Bragg J, Young E *et al*. Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney International* 2002; **62**:199-207

Lopes AA, Albert JM, Young EW *et al*. Screening for depression in hemodialysis patients: associations with diagnosis, treatment, and outcomes in the DOPPS. *Kidney International* 2004; **66**:2047–2053.

Lopez KR, Lopez FJG, de Alvaro FM and Alonso J. Perceived mental health at the start of dialysis as a predictor of morbidity and mortality in patients with end-stage renal disorder (CALVIDIA Study). *Nephrol Dial Transplant* 2004; **19**:2347-2353

Maguire P. Improving the detection of psychiatric problems in cancer patients. *Soc Sci Med*, 1985; **20**: 819–823.

Maguire P, Faulkner A, Booth K, Elliott C, Hillier V. Helping cancer patients disclose their concerns. *Eur J Cancer*, 1996;**32**: 78–81.

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Major B and Glass D. Common psychological problems experienced by renal patients. *Journal of Renal Nursing* July 2010; **2**(4):172-177

McMurchie W, Macleod F, Power K et al Computerised cognitive behavioural therapy for depression and anxiety with older people: A pilot study to examine patient acceptability and treatment outcome *International Journal of Geriatric Psychiatry* 2013; **28**(11):1147-1156

Martin CR and Thompson DR. Prediction of quality of life in patients with end-stage renal disease. *British Journal of Health Psychology* 2000; 5:41-55

McDade-Montez EA, Christensen AJ, Cvengros JA and Lawton WJ. The Role of Depression Symptoms in Dialysis Withdrawal *Health Psychology* 2006; 25(2):198-204

Miller WR, Rollnick S. *Motivational Interviewing: Helping People Change*. 3rd edn. New York: The Guildford Press, 2012

Molyneux PJ, Jones C and Brooks A. Local service evaluation of psychological distress in a renal population. *Renal Association Abstract*, 2010

Morton RL, Tong A, Howard K *et al*. The views of patients and carers in treatment decision making for chronic kidney disease; systematic review and thematic synthesis of qualitative studies. *BMJ* 2010; **340**:c112

Murtagh FEM, Addington-Hall J and Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Advances in Chronic Kidney Diseases* 2007; **14**(1):82-99

National Collaborating Centre for Mental Health. *Depression: Management of Depression in Primary and Secondary Care*. Clinical Guideline 23. National Institute for Health and Clinical Excellence, 2004

National Collaborating Centre for Mental Health. *Depression in adults with a chronic physical health problem. The NICE guidance on the treatment and management*. Leicester and London: The British Psychological Society and The Royal College of Psychiatrists, 2010a

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

National Collaborating Centre for Mental Health. *Depression. The treatment and management of depression in adults. Updated edition.* Leicester and London: The British Psychological Society and The Royal College of Psychiatrists, 2010b

National Institute for Health and Clinical Excellence. *The treatment and management of depression in adults with chronic physical health problems: CG91 Depression with a chronic physical health problem, 2009* <http://guidance.nice.org.uk/CG91> (last accessed 14/04/14)

National Institute for Health and Clinical Excellence. *GS5 Chronic kidney disease quality standard, 2011* <http://www.nice.org.uk/GS5> (last accessed 14/04/14)

NHS Confederation and the Association of Directors of Social Services *Joint personal budgets: A new solution to the problem of integrated care* NHS Confederation, 2012 <http://www.nhsconfed.org> (last accessed 14/04/14)

NHS Evidence *Depression in adults with a chronic physical health problem: Evidence Update March 2012* Manchester: National Institute for Health and Clinical Excellence, 2012 Available at: <https://www.evidence.nhs.uk/evidence-update-12> (last accessed 14/04/14)

O'Donnell K and Chung JY. The diagnosis of major depression in end-stage renal disease. *Psychotherapy and Psychosomatics* 1997; **66**(1):38-43

Olsson B, Olsson B, Tibblin G. Effect of patients' expectations on recovery from acute tonsillitis. *Fam Pract* 1989; **6**:188-192.

Ong LM, De Haes JCJM, Hoos AM and Lammes FB Doctor-patient communication: A review of the literature *Soc Sci Med*, 1995;**40**(7): 903-918

Ormandy P, Hulme C, Caress AL *et al. Identifying chronic kidney disease patients' preferences for information topics.* University of Salford, 2007

Ouzouni S, Kouidi E, Sioulis A *et al* Effects of intradialytic exercise training on health-related quality of life indices in haemodialysis patients. *Clin Rehabil* 2009; **23**:53

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Palmer S, Vecchio M, Criag JC *et al* Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies *Kidney International*, 2013;**84**: 179-191

Pibernik-Okanovic M, Grgureric M, Begic D *et al*. Interaction of depressive symptoms and diabetes-related distress with glycaemic control in Type 2 diabetic patients. *Diabetic Medicine* 2008; **25**(10):1252-1254.

Polonsky WH *et al*. Assessment of diabetes related distress. *Diabetes Care* 1995; **18**: 754-760

Pollack KI, Arnold RM, Jeffreys AS *et al*. Oncologist Communication About Emotion During Visits With Patients With Advanced Cancer. *Journal of Clinical Oncology* 2007; **25**(26):5748-5752

Proudfoot J, Ryden C, Everitt B *et al* Clinical efficacy of computerised cognitive-behavioural therapy for anxiety and depression in primary care: randomised controlled trial *British Journal of Psychiatry* 2004; **185**:46-54

Rabindranath KS, Daly C, Butler J *et al*. *Psychosocial interventions for depression in dialysis patients (Review)*. The Cochrane Library, 2009

Roter DL Patient Participation in the Patient-Provider Interaction: The Effects of Patient Question Asking on the Quality of Interaction, Satisfaction and Compliance. *Health Education and Behaviour*. 1977; **5**:281-315

Roter DL, Hall JA, Kern DE *et al*. Improving Physicians' Interviewing Skills and Reducing Patients' Emotional Distress. A Randomized Clinical Trial. *Archives of Internal Medicine*. 1995; **155**(17):1877-1884

Ryan H, Schofield P, Cockburn J *et al*. How to recognize and manage psychological distress in cancer patients. *Eur J Cancer Care (Engl)*. 2005; **14**(1):7-15.

Schell JO, Patel UD, Steinhauser PD. Discussions of the Kidney Disease Trajectory by Elderly Patients and Nephrologists: A Qualitative Study. *Am J Kidney Dis* 2012; **59**(4):495-503

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Schipper K and Abma TA. Coping, family and mastery: top priorities for social science research by patients with chronic kidney disease. *Nephrol Dial Transplant* 2011; **26**:3189-3195

Schofield PE and Butow PN. Towards better communication in cancer care: a framework for developing evidence-based interventions *Patient Education and Counseling* 2004;**55**: 32-39

Smith M, Hopkins D, Peveler RC *et al.* First- v. second-generation antipsychotics and risk for diabetes in schizophrenia: systematic review and meta-analysis. *The British Journal of Psychiatry* 2008; **192**:406-11.

Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;**282**(18): 1737-1744.

Srippoli, G *et al.* The Number, Quality and Coverage of Randomized Controlled Trials in Nephrology. *Journal of the American Society of Nephrology* 2004; **15**:411-419

Suchman AL, Markakis K, Beckman HB, Frankel R. A model of empathetic communication in medical interview *JAMA* 1997; **277**(8):678-682

Szeifert L, Bragg-Gresham JL, Thumma J *et al.* Psychosocial variables are associated with being wait-listed, but not with receiving a kidney transplant in the dialysis outcomes and practice patterns study (DOPPS). *Nephrol Dial Transplant* 2012; **27**(5):2107-2113

Taskapan H, Ales F, Kaya B *et al.* Psychiatric disorders and large interdialytic weight gain in patients on chronic hemodialysis *Nephrology* 2005; **10**:15-20

Taylor F, Gutteridge R. *Overcoming barriers and facilitating access to peer support for CKD patients and carers*, West Midlands Central Health Innovation and Education Cluster, Birmingham, University of Birmingham, 2013 <http://www.birmingham.ac.uk/research/activity/mds/projects/WMC-HIEC>(last accessed 14/04/14)

The Kidney Advisory Group *Kidney Health: Delivering Excellence. A Kidney Health* CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Report, The Kidney Advisory Group, 2013 Available at: <http://www.britishrenal.org/getattachment/NewsLinks/Kidney-Health-Delivering-Excellence/Kidney-Health-Delivering-Excellence.pdf.aspx> (last accessed 14/04/14)

The Renal Association *Renal Association Home Haemodialysis Working Party Report*, The Renal Association, 2010 [http://www.renal.org/docs/default-source/what-we-do/RA\\_Home\\_HD\\_Working\\_Party\\_Report\\_January\\_2010.pdf?sfvrsn=0](http://www.renal.org/docs/default-source/what-we-do/RA_Home_HD_Working_Party_Report_January_2010.pdf?sfvrsn=0) (last accessed 14/04/14)

The Royal College of Physicians. *Chronic kidney disease. National clinical guideline for early identification and management in adults in primary and secondary care*. Royal College of Physicians, London, 2008

Theofilou P. Medication Adherence in Greek Hemodialysis Patients: The Contribution of Depression and Health Cognitions. *Int J Behav Med* March 2012; DOI 10.1007/s12529-012-9231-8

Thomas KB. General practice consultations: is there any point in being positive? *BMJ*. 1987; **294**:1200-1202.

Tong A, Sainsbury P, Carter SM *et al*. Patients' priorities for health research: focus group study of patients with chronic kidney disease. *Nephrol Dial Transplant* 2008; **23**:3206-3214

Tong A, Sainsbury P, Chadblan S *et al*. Patients' Experiences and Perspectives of Living with CKD. *Am J Kidney Disease* 2009; **53**:689-700

Trigwell P *et al*. *Minding the Gap. The provision of psychological support and care for people with diabetes in the UK*. Diabetes UK, 2008 Available at: [http://www.diabetes.org.uk/Documents/Reports/Minding\\_the\\_Gap\\_psychological\\_report.pdf](http://www.diabetes.org.uk/Documents/Reports/Minding_the_Gap_psychological_report.pdf) (last accessed 14/04/14)

Tsay S-L, Hung L-O. Empowerment of patients with end-stage renal disease – a randomized controlled trial International. *Journal of Nursing Studies* 2004; **41**:59-65

Van Bastelaar KMP, Pouwer F, Cuijpers P *et al* Web-based depression treatment for CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

- type 1 and type 2 diabetic patients: a randomized controlled trial *Diabetes Care* 2011; **34**:320-325
- van Vilsteren MCBA, de Greef MHG, Huisman RM. The effects of a low-to-moderate intensity pre-conditioning exercise programme linked with exercise counselling for sedentary hemodialysis patients in The Netherlands: results of a randomized clinical trial. *Nephrol Dial Transplant* 2005; **20**:141-146.
- van Bastelaar KMP, Pouwer F, Cuijpers P *et al.* Web-based depression treatment for type 1 and type 2 diabetic patients: a randomized controlled trial. *Diabetes Care*, 2011; **34**: 320–5
- Walters BAJ, Hays RD, Spritzer KL *et al.* Health-Related Quality of Life, Depressive Symptoms, Anemia, and Malnutrition at Hemodialysis Initiation. *Am J Kid Dis* 2002; **40**(6):1185-1194
- Watnick S, Kirwin P, Mahnensmith R, Concato J. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003; **41**(1):105-10
- Watnick S, Wang PL, Demadura T and Ganzini L. Validation of 2 depression screening tools in dialysis patients. *Am J Kidney Dis* 2005; **46**:919–24
- Weisbord SD, Fried LF, Unruh ML *et al.* Associations of race with depression and symptoms in patients for maintenance haemodialysis. *Nephrol Dial Transplant* 2007a; **22**:203-208
- Weisbord SD, Fried LF, Mor MK *et al.* Renal Provider Recognition of Symptoms in Patients on Maintenance Hemodialysis. *Clin J Am Soc Nephrol* 2007b; **2**:960-967
- White Y and Grenyer BFS. The biopsychosocial impact of end-stage renal disease: the experiences of dialysis patients and their partners. *Journal of Advanced Nursing* 1999; **30**(6):1312-1320
- White M, White PW, Russell CS. Multiple Sclerosis Patients Talking with Healthcare Providers About Emotions. *Journal of Neuroscience Nursing* 2007; **39**(2):89-101
- CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

Wright SJ and Kirby A. Deconstructing Conceptualizations of 'Adjustment' To Chronic Illness. A proposed framework. *Journal of Health Psychology* 1999; **4**:259

Wuerth, Finkelstein SH and Finkelstein FO. The Identification and Treatment of Depression in Patients Maintained on Dialysis. *Seminars in Dialysis* 2005; **18**(2):142-146

Zabalegui A, Sanchez S, Sancez P, Juando C. Nursing and Cancer Support Groups. *Journal of Advanced Nursing* 2005; **51**(4):36

## 8. Appendices

### Appendix 1: Details of Study 1 patient participants

	Gender	Age	Ethnicity	Current treatment	Time on any dialysis (months)	Patient Issues Sheet
P1	Female	87	White British	HD	4	Yes
P2	Male	64	Black British	PD	11.5	No
P3	Male	43	Asian British	PD	2	Yes
P4	Male	77	White British	PD	2.5	No
P5	Male	65	Asian British	PD	3.5	No
P6	Female	54	Asian British	PD	2	Yes
P7	Female	51	White British	PD	Under 0.5	No
P8	Male	70	White British	PD	4.5	Yes
P9	Male	45	White British	PD	8	Yes
P10	Male	77	Asian British	PD	4	Yes
P11	Male	74	White British	HD	8.5	No
P12	Male	57	Asian British	PD	10	No
P13	Male	58	White British	PD	12	Yes
P14	Female	59	White British	PD	2.5	No
P15	Female	22	Black British	HD	11	Yes
P16	Male	43	White British	PD	4	Yes
P17	Female	73	White British	PD	2.5	No
P18	Male	87	White British	PD	12	Yes
P19	Male	43	White British	PD	2	No
P20	Female	42	Asian British	PD	11.5	Yes
P21	Female	49	Asian British	HD	7	No
P22	Male	74	White British	HD	3	No
P23	Female	29	Asian British	HD	4	Yes
P24	Male	59	White British	PD	12	Yes
P25	Male	73	Asian British	PD	2	No
P26	Male	53	White British	PD	1.5	Yes
P27	Male	66	White British	PD	7.5	Yes
P28	Female	72	White British	HD	9.5	Yes
P29	Female	83	White British	HD	6	No
P30	Male	65	White British	HD	6.5	Yes
P31	Male	78	White British	HD	12+	No
P32	Male	77	White British	HD	2.5	Yes
P33	Male	66	White British	HD	1.5	No
P34	Male	38	White British	HD	2.5	Yes
P35	Female	62	White British	HD	12+	Yes
P36	Male	56	White British	HD	1.5	Yes

### Appendix 2: Details of Study 2 patient participants

	Gender	Age	Ethnicity	Current treatment	Time on any dialysis (months)	Research Method	Venue
P1	Female	43	White British	HD	7.5	Interview	Home
P2	Female	56	White British	Pre-dialysis	-	Interview	Home
P3	Male	68	Asian British	Pre-dialysis	-	Interview	Home
P4	Male	57	Asian British	Pre-dialysis	-	Interview	Home
P5	Female	64	White British	PD	9	Focus group	Hospital
P6	Male	81	White British	Pre-dialysis	-	Focus group	Hospital
P7	Male	76	White British	Pre-dialysis	-	Focus group	Hospital
P8	Male	77	White British	Pre-dialysis	-	Interview	Hospital
P9	Female	59	White British	PD	8.5	Focus group	Hospital
P10	Female	60	White British	PD	12	Focus group	Hospital
P11	Female	33	White British	HD	0.5	Focus group	Hospital
P12	Male	31	White British	PD	6	Interview	Hospital
P13	Male	62	Asian British	HD	6	Interview	Hospital
P14	Male	54	White British	Pre-dialysis	-	Interview	Home
P15	Male	52	White British	PD	9	Interview	Home

PD = Peritoneal dialysis      HD = Haemodialysis

CLAHRC-WMC: Supporting the emotional and psychological needs of renal patients. Study Report.

**Appendix 3: Patient Issues Sheet**

*Below are some issues that other people with your illness have said they wanted to talk about with their renal clinicians.*

*Please mark the 2 or 3 issues you would **most** like to talk about with your clinician during your consultation today. There is space for you to add any other issues you would like to talk about.*

The form consists of 28 oval-shaped bubbles arranged in a grid-like pattern. Each bubble contains a text label representing a patient issue. The labels are: Sleeping, Diet, Hope, Sadness, Enjoying life, Coping, Worry about the future, Side effects of treatment, Nervous, Kidney function, Tiredness, Energy levels, Sex life, Condition worsening, Adjustment to dialysis, Relationships, Acceptance, Medicines, Maintaining control, Pain, Feeling down, and three empty bubbles at the bottom.

**Please have this sheet with you during your consultation**

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## **Appendix 4**

### **Training for Renal Consultants – A Reflective Summary**

**Dr Jennifer Hare (Registered Health Psychologist)**

#### **Why train?**

As alluded to within the main body of the report (pp. 13-14), there is much research to suggest that enhanced clinician communication and exploration of the psychosocial issues associated with physical illness, can positively impact the health-related outcomes of patients. Nonetheless, as the research team identified from discussions with the renal clinicians involved in this project; there was a hesitancy to explore the wider emotional and psychological issues within routine clinic appointments. This is consistent with the literature identified in the main report. The reasons postulated for this hesitancy were discussed and included a lack of confidence in being able to manage patients' responses, in addition to the amount of time that such exploration might add to the clinical consultation. Therefore it was suggested that additional training may be appropriate to enhance clinicians' self-efficacy in adopting the proposed intervention in study 1.

One of the proposed interventions in study 1 was to employ the question endorsed by the National Institute for Health and Clinical Excellence (NICE, 2009) in their Clinical Guideline 91, for the treatment and management of depression among adults with a chronic physical health problem. Specifically, these questions were extrapolated from the PHQ-9 ("Patient Health Questionnaire") (Spitzer et al., 1999), which also constitute the PHQ-2 (Kroenke et al., 2003). While there is a recognition that these new guidelines (NICE, 2009) are a welcome extension of the original guideline published in 2004 (NICE, 2004), in that they emphasise the individual experience of depression; Kendrick and Peveler (2010) note their implementation still assumes a medical model. Furthermore, there is little detail within the guidance about the implementation of the question and handling patient's response; beyond recognising practitioner competency in conducting a "mental health assessment" (pp. 18, NICE, 2009) and general measures or interventions recommended if sub-threshold depressive symptoms or mild to moderate depression are identified. Indeed, there have been considerations of the paucity of evidence as to how well such guidelines are adopted by clinicians beyond practice trials (Arrol et al, 2005; Gilbody et al, 2006). Recognising this as a relevant issue in various discussions with the research team, a potential gap between guideline recommendation and implementation was highlighted. Additionally, concerns were

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raised regarding the over-identification of depression among patients, with a potential over-reliance to consider higher level interventions unsuitable for patients with lower levels of need. Therefore, a one-off interactive training session to cover “Communication, Asking about Feelings and Handling Responses” was arranged with the renal consultants. Follow-up observations of clinic sessions were scheduled to provide immediate feedback of the implementation of the agreed intervention question.

### **Content of training**

The learning outcomes of the training and clinic observation were:

- To increase understanding and practice of core communication skills to facilitate patient engagement
- To increase confidence in asking patients about their emotional needs, feelings and concerns
- To increase confidence and skills in handling emotional responses
- To enhance awareness of actions that could be taken to improve patients’ psychological well-being
- To increase reflective practice in patient engagement

The training session was divided into three core topics:

#### **1) *Engaging with the patient***

The content of this was based on communication training, with an emphasis on facilitating patient engagement via the processes endorsed in the recent advances of Motivational Interviewing (MI) (Miller & Rollnick, 2012). Communication styles, empathy and active listening were discussed, with specific reference to the concept of “OARS” (Miller & Rollnick, 2012), these techniques being: open questions, affirmations, reflections and summaries. Specific training examples relating to renal patients were provided and practiced.

#### **2) *Asking about feelings***

Using the communication skills discussed, the aim of the second topic was to see how these skills could be used to explore patients’ emotional difficulties. This topic was structured around a three stage model of counselling (Carkhuff , 1987; Egan, 2002) to describe the essential elements of the counselling process: Exploration, Understanding and Action. It was made clear that such a model provides useful techniques for health professionals and non-counsellors.

The training session also encouraged a reflective discussion about how the NICE (2009) question could be asked AND how the Patient Issues Sheet be used, in relation to the communication styles of the consultants. Issues such as question wording, timing and further exploratory questions were covered, with reflections on how these would best fit *realistically* into consultant's current practice.

### **3) Handling responses**

The final topic explored consultants' concerns about patients' responses and how they may deal with these effectively. This involved, managing patient's emotional release, exploring whether action and/or further intervention was necessary, means to identify patient-led solutions, providing information on evidence-based low-level interventions and services offering higher level support/interventions were all included. Critically, the training also covered recognition of when the patient may need a higher level intervention or service.

Final consideration was made to the consultant's own emotional wellbeing, where time was spent discussing methods to strengthen their own inner resources; in order to manage their own stress, to be in a better position to support patients.

### **Consultant confidence and concerns following training**

At the end of each training session, clinician's confidence and concerns with the intervention and areas covered within the training were explored. Overall, fairly high confidence levels were reported in being able to "pick-up" on patients' feelings. Additionally, they felt able to question more widely into areas outside of the renal condition and reported that this was a frequent occurrence in their practice. They also indicated openness for discussion of such wider issues, as they recognised how these were not easily separable from overall adjustment.

In terms of concerns, the most frequently cited concern for all clinicians was the lack of time available in a consultation to explore wider emotional issues for the patient, with a fear of "opening the floodgates". Although these concerns were addressed within the training, there was a tendency to worry that these potential solutions would be insufficient. Similarly, concerns were raised about how consultants' priorities for the consultation, or rather their concerns related to the patient's physiological wellbeing, could be addressed adequately in the time available. Interestingly, some comments

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were made regarding the consultant's own emotional wellbeing; in relation to the balance of exploring patients' emotional needs versus finding solutions to the "solvable" issues. Finally, a key concern for all involved was the wording of the question; with views that it did not fit their language or style, or that it seemed quite mechanised. Ideas were shared across the consultants involved, and more suitable wording was agreed upon to make the question as easily embedded into their consultations as possible.

### **Reflective Practice opportunity**

To conclude the training, consultants were provided with a reflective practice worksheet, which they were encouraged to complete for a handful of patients after each consultation. This reflective worksheet was designed to remind the consultants of the core skills covered in the training, with opportunities to reflect on what went well, what they would do differently next time and any issues that needed revisiting in follow-up training.

The same reflective practice sheets were used as an evaluative framework for the observations of clinical consultations.

Before clinic observation, the use of the reflective practice sheets was explored with the consultants involved. It was reported across the group that these proformas acted as a memory prompt for internal reflection of consultations, rather than being completed formally. However, the areas of consideration were described to be helpful in linking back to the training provided.

### **Clinic Observation, Feedback and Follow-up Support**

Each consultant involved in the research project consented to be observed within their routine clinics with renal patients. Patient consent for observation was obtained verbally and it was made explicitly aware that the observation was on the consultation, not the patient; as both hospitals were involved with medical teaching, observation was not uncommon. After each patient consultation, consultants were provided with immediate feedback on the observed interaction and key points or pertinent issues identified were discussed. A summary of these observations is provided below:

**1) *Inconsistent wording of the "NICE" question:*** all of the participating consultants had their own way of approaching the question. Additionally, there was inconsistency in the way the question was asked among patients of the same consultant. The wordings

used were in line with the consultant's own terminology and styles. Examples included: "how've you been feeling?", "have you been feeling down or low at all recently/the last two weeks", "have you been feeling fed-up at all", "I'm guessing you've not been feeling down or fed-up". For a small number of patients, the question wasn't asked at all. These observations were few, however reasons for not exploring the question was that it was unnecessary in patients presenting as very buoyant. Conversely, for patients that appeared low at presentation, the consultants used more exploratory open-ended questions, rather than "stating the obvious" with the NICE question.

**2) Timing of the question varied among consultants:** some asked at a "natural" opening, some explored the issue at the beginning, and some waited until the end. There was no "right" way endorsed, rather that whenever the questions was explored, there was sufficient time to engage in a meaningful conversation.

**3) Engagement:** generally good patient engagement techniques were observed, including use of eye contact, positioning and creating an environment of empathy. There were some instances where questions were asked without good eye-contact or body language, for example whilst looking at the computer screen. These occasions were fed-back and identified. Although such observations may be unavoidable in a busy clinic where electronic patient notes are used, there are means to reduce the impact it may have on a consultation; for example, by offering patients an explanation as to what is on the screen, or by not exploring the issue of emotional wellbeing whilst it is necessary to look at additional information.

In the main, patient displays of emotion were well responded to and for a patient to feel able to show emotion and talk about the issues of concern for them, speaks volumes for the trust and empathy demonstrated.

**4) Generally there was good use of OARS skills:** many open-questions were observed, which really augmented the use of NICE question, which typically lends itself to a yes or no response. Further questions were used to explore and reflect what consultants were hearing from their patients, i.e. "what do you mean by things going around in your head". There were occasions when "good listening" was taken almost too literally, and patients veered off on tangents completely unrelated to their health or emotional wellbeing (or of any relevance to the consultation); while others heavily relied on closed-questions, creating stumbling blocks for further exploration of the issue. Both of these instances were fed-back with solutions for such scenarios arising in future.

**5) Exploration of emotional wellbeing:** there were mixed observations for exploring the issue of emotional wellbeing. Some consultants appeared to be more comfortable with emotional release and sitting with silence/reflection, while others were keen to explore further by questioning, or quickly find a solution to the cause of concern.

When carers were present in the consultation, there was an inclusion of their thoughts as well; one patient's partner used the word "depressed" and the consultant explored this with both of them, asking what it meant to them, to gather a greater understanding of the issue.

**6) Understanding of the issue:** possible reasons for identified low mood or emotional issues were explored well in the main and the conversations appeared to be well received by the patients.

A good use of normalising and affirming patients' concerns was observed; where consultants recognised and validated patient's difficulties. This is understood to be most important in reducing feelings of stigmatisation. Some consultants were seen to respond well with reflections and summaries such as: "it's normal to feel XYZ", however this was not done consistently. There were also some missed opportunities identified, where exploration of certain psychosocial issues may have been discussed to understand their impact on patient's overall adjustment, i.e. bereavement issues.

**7) Cues to action:** although the training emphasised that "action" was not always necessary, observations revealed a tendency to find and offer solutions fairly quickly, as opposed to further exploration and understanding of the issue raised. In providing feedback and discussion, it was not uncommon for clinicians to feel a 'need to fix or solve'. It was reflected that for some patients, one could argue that all they wanted was to be heard and understood, as some concerns unfortunately don't have solutions or answers. It is often this feeling of uncertainty that creates an uncomfortable feeling to simply sit and listen to what is being heard; and to counteract this, one's natural instinct is to problem-solve.

Nonetheless, feedback from the consultants revealed a greater sense of awareness of this issue and the natural role of "problem-solver". Distinctions were made on when to offer advice on more formalised services offering high-level intervention, when low-level interventions may be appropriate and how these could be patient-led if possible. It was appreciated that some patients prefer a more direct communication style, whilst others prefer to be empowered to find solutions for themselves.

**8) Time spent on exploring emotional wellbeing:** although there were no observable issues seen in the clinics, consultants related their concerns about how the discussion of emotional wellbeing may impact the clinic time in covering the routine medical aspects. Containing and managing patient responses were covered in both the main training and in follow-up training, to give the consultants' confidence in exploring emotional issues. While there is evidence to suggest that time spent in effective patient engagement and listening can actually reduce the consultation time and enhance patient outcomes (as referenced in the main report), reassurance was offered in how as professionals, we all have "identifiers" or "labels". Patients recognise they are coming for a medical consultation with their consultant; therefore there is an implicit understanding that an hour's counselling session is not being offered. However, means to overcome these concerns were explored and suggestions on how to re-focus the consultation were discussed; such as parking the issue until the next appointment or opening up the discussion early on to allow for exploration time and prioritisation of patient issues.

### **Follow-up Support**

At the end of the trial period, a follow-up session or contact opportunity was made available to troubleshoot the issues identified above. All of the training, individual observations and follow-up discussions/training were well received by the consultants, with good engagement in the process.

The issues highlighted here allude to potential difficulties in the implementation of guidelines within the practicalities and constraints of the clinical environment and the concerns and self-efficacy of the clinicians. This emphasises the need for specific training or support in the implementation of any guidelines or low-level intervention exploring emotional wellbeing; and the role of psychologists in bridging the gap from recommendation to implementation.

## **Appendix 5: Intervention audio-visual film scripts**

### **Training in Mindfulness**

You can be given training in how to handle any negative thoughts and emotions you might have, so you feel calmer and more accepting of your situation. You will learn how to concentrate and how to focus your mind. This will help you deal with any unnecessary and unpleasant thoughts. As a result you will feel less worried.

Anyone can learn the skills to make their mind feel more at peace. You can do the training with other patients in a group led by a professional teacher or on your own with a professional teacher. Or you might prefer to learn online using a CD. The training involves a one-hour session each week, over 6 to 8 weeks.

Between each session, it will be helpful to set aside some time each day, even if it's only a minute, to practice the skills you have been taught. This might, for example, involve doing a breathing exercise, or sitting in a certain way.

After you've done the training, you'll be able to use the skills you've learnt to calm your mind and make it feel more at peace; whenever you need to. This can help reduce stress, help you sleep better and improve your general mood and wellbeing.

### **Clinic time to discuss emotional needs**

When you attend a regular clinic appointment with your consultant at the hospital, as well as talking about your kidneys, you could be given some time to discuss how you are in general.

During your regular appointment your consultant could simply ask, whether during the last few weeks you had been feeling down or miserable at all.

To help you prepare for this discussion, while you wait in the renal unit before your appointment, you might like to look at a sheet of paper showing issues that other people with your illness have said they want to talk about. You could mark on this sheet of paper the issues that you would most like to talk about with your consultant. You could then take this sheet of paper with you into the appointment.

It would be up to you whether or not you wanted to discuss such issues. You would have the choice.

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But it's good to talk. Discussing any things you're worried about with your consultant can help reduce worry and stress. It gives your consultant a better idea of what is going on for you and what can be done to help. Together you can find solutions you may not have thought of before, to the things troubling you.

### **Physical activity programmes managed and supported by the kidney unit**

You could have your own personal activity programme designed for you by the hospital physiotherapist. Based on your individual situation and health, they will work out what is the best for you.

There are two main choices of activity, both especially designed for kidney patients. You do not have to be especially fit or active to do either of them.

One choice is cycling while on dialysis. This involves using a specially designed bike. It's fun and easy to do, and makes good use of time while you are dialysing. You can cycle for as long as you want. But most patients will cycle for about 30 minutes during each dialysis session.

The other choice of activity is walking. You can join in regular walks with small groups of other patients. The walks have a trained leader and follow safe and easy routes. The walking is fun and easy to manage, even if you are not feeling your best. You can choose to walk as much as you like, gradually building up how often you walk each week. You can fit the walks in around your personal life.

The hospital physiotherapist will regularly check how your activity programme is going. And make sure it is meeting your needs. Staff in the kidney unit will also support and encourage you in doing your chosen activities.

Cycling on dialysis or walking can make you feel better. Doing these activities will help reduce any feelings of stress you have and improve your mood. You will also benefit from increased muscle strength and better blood pressure.

### **Peer support**

You can have a friendly one-to-one chat and share thoughts and experiences with a

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kidney patient who is in a similar situation to you. They will have experience of kidney disease and dialysis treatment. And they are also an unpaid volunteer, trained to provide support and guidance to other kidney patients.

You can choose to talk either over the telephone, face-to-face, or online.

If you would like to talk with another kidney patient in this way, your nurse or consultant will try to make sure that you are matched to an appropriate person.

Although each patient's experience is unique, many kidney patients find it helpful to talk to someone who really understands what they are going through. Often one session of talking is enough. But some patients choose to have further contact with their supporter.

There are many benefits from talking with another, more experienced kidney patient. It can help reduce feelings of anxiety and isolation, increase confidence, and give you a greater sense of control.

### **Computerised cognitive behaviour therapy**

You can do a training course online that will help you learn how to manage your feelings and mood. It will teach you ways to deal with the problems that might be making you feel down. For example you can learn how to relax more, or how to better plan all the tasks and activities you have to do.

The course consists of 8 weekly sessions. Each session lasts about 50 minutes. You can do the course at anytime of the day you choose. And you can go at the speed that best suits you.

It is also helpful to practice the skills you have learnt between each of the weekly training sessions.

You will need to be able to use a computer to do the course. But you do not have to be a computer expert. And there is support available to help you. If you have any questions, you can contact a trained professional by phone. They can help you with any advice you might need or answer any questions you might have. If you would like them to, they can also assess how you are doing both during and after the course.

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