NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Renal replacement therapy (RRT) services

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 3 April 2014

Contents

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for renal replacement therapy services. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development sources referenced in this briefing paper is:

Peritoneal dialysis. NICE clinical guideline 125 (2011).

Clinical practice guideline: vascular access for haemodialysis. The Renal Association (2011).

Clinical practice guideline: post-operative care of the Kidney Transplant Recipient. The Renal Association (2011)

Clinical practice guideline: assessment of the potential kidney transplant recipient. The Renal Association (2010).

Clinical practice guideline: peritoneal dialysis. The Renal Association (2010).

Clinical practice guideline: haemodialysis. The Renal Association (2009).

Clinical practice guideline: peritoneal access. The Renal Association (2009).

Clinical practice guideline: Planning, initiating and withdrawal of renal replacement therapy. The Renal Association (2009).

2 Overview

2.1 Focus of quality standard

This quality standard will cover renal replacement therapy services for renal failure in adults, young people and children.

2.2 Definition

Renal replacement therapy services for renal failure in adults, young people and children covers the following choices:

- Conservative care and symptom control.
- Dialysis (either peritoneal dialysis or haemodialysis).
- Kidney transplant (from a living or cadaveric donor)

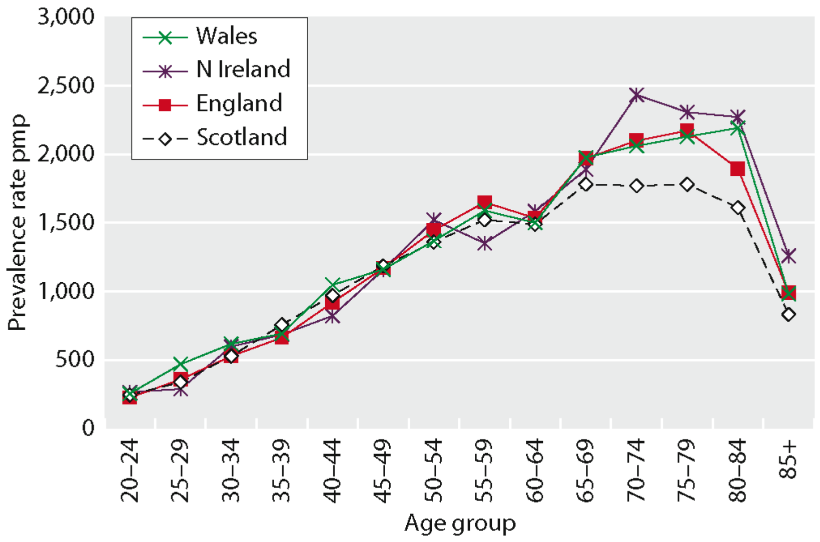
2.3 Incidence and prevalence

At any one time in the UK, 400–800 people per million of the population need renal replacement in the form of dialysis. The prevalence of dialysis in the UK is highly age dependent – for adults aged 70–80 years it is between 1600 and 2000 people per million. Dialysis is needed to sustain life for patients with chronic kidney disease (CKD). For about 40% of adults on dialysis a kidney transplant is the treatment of choice; this percentage is higher in children. If patients do not have a kidney transplant, dialysis is needed for the rest of the patient's life.

UK Renal Registry Report 2013

The UK Renal Registry reports that there were 54,824 adult patients receiving renal replacement therapy (RRT) in the UK on 31st December 2012, an absolute increase of 3.7% from 2011. The UK adult prevalence of RRT was 861 per million population (pmp). The reported prevalence in 2000 was 523 pmp. There were national, regional and dialysis centre level variations in prevalence rates. A significant factor in this variation was the ethnic mix of local populations, but a large amount of the variation remains unexplained.

Prevalence rates per million population by age group and UK country on 31/12/2012 (UK Renal Registry Report 2013, figure 2.1)



2.4 Management

More than 2% of the NHS budget is spent on renal replacement therapy (dialysis and transplants) for people with established renal failure[1]. The main goal of renal transplantation is to improve the life expectancy and quality of life of patients with established renal failure.

The Renal Association has stated that most patients with advanced kidney failure, regardless of age and co-morbidity, are now considered as potential candidates for RRT. This has meant that the question of whether or not such treatment is the most appropriate option for the individual patient, has assumed increasing importance.

Kidney transplant is accepted as the most successful or optimal modality of RRT treatment for people with established renal failure in whom it is suitable, offering better quality of life and life expectancy than dialysis.

Two main types of dialysis are available, haemodialysis and peritoneal dialysis. The main factors that determine what type of dialysis people have are patient preferences about which treatment fits best within their lifestyle, availability of options within a service and clinical contraindications. Not all patients receiving dialysis are suitable for kidney transplantation.

2.5 National Outcome Frameworks

Tables 1–2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Table 1 NHS Outcomes Framework 2014–15

Domain	**Overarching indicators and improvement areas**
1 Preventing people from dying prematurely	*Overarching indicator* 1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare i Adults ii Children and young people 1b Life expectancy at 75 i Males ii Females
2 Enhancing quality of life for people with long-term conditions	*Overarching indicator* 2 Health-related quality of life for people with long-term conditions** *Improvement areas* Ensuring people feel supported to manage their condition 2.1 Proportion of people feeling supported to manage their condition Reducing time spent in hospital by people with long-term conditions 2.3i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)
4 Ensuring that people have	*Overarching indicator*

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[1] CG125 Peritoneal dialysis: costing report (2011)

a positive experience of care	4b Patient experience of hospital care *Improvement areas* Improving hospitals’ responsiveness to personal needs 4.2 Responsiveness to in-patients’ personal needs Improving people’s experience of accident and emergency services 4.3 Patient experience of A&E services
5 Treating and caring for people in a safe environment and protecting them from avoidable harm	*Overarching indicator* 5a Patient safety incidents reported 5b Safety incidents involving severe harm or death 5c Hospital deaths attributable to problems in care *Improvement areas* Reducing the incidence of avoidable harm 5.4 Incidence of medication errors causing serious harm
Alignment across the health and social care system ** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF)	

3 Summary of suggestions

3.1 Responses

In total 13 stakeholders responded to the 2-week engagement exercise 3 -17 February 2014.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee. Full details on the suggestions provided are given in appendix 3 for information.

Table 3 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Information, education and support	BKPA, BH Ltd
Transplantation	NHS England, CRGRD, SCM
Access to the range of dialysis options	CRGRD
Changing treatment modalities	BH Ltd
Transport	BKPA, NKF, SCM
Multidisciplinary teams (MDT)	BH Ltd, BKPA, SCM
Patient safety	NHS England, NHSEPSD
Vascular access	NHS England, SCM
Additional areas • **Data capture** • **Conservative management** • **Psychological/social patient support** • **Patient care plan** • **Communication between primary and secondary care** • **Quality measures (PROMs and PREMs)** • **Medication review**	BH Ltd BH Ltd NKF BKPA, SCM BKPA SCM NHS England, CRGRD SCM
ARI, Association of Renal Industries BH Ltd, Baxter Healthcare Ltd BKPA, British Kidney Patient Association CRGRD, Clinical Reference Group for Renal Dialysis NHS England, NHS England NHSEPSD, NHS England Patient Safety Division NKF, National Kidney Federation RCN, Royal College of Nursing RCP, Royal College of Pathologists SCM, Specialist Committee Member	

4 Suggested improvement areas

4.1 Information, education and support

4.1.1 Summary of suggestions

Stakeholders highlighted the need for informed discussion of treatment options for people requiring for RRT which should emphasise, where relevant, a longer term approach. It was noted that treatment types should be seen as complementary rather than competitive.

Patients requiring RRT should be supported by regular information provision and education on the best possible treatment depending upon their kidney failure stage and the specific short and long term clinical benefits of RRT options. Information support should occur regularly, along the whole patient pathway, preferably at routine clinic appointments and for patients who have started dialysis in an unplanned manner.

The role of ‘expert patients’ was also highlighted to help support the patient decision-making process. Patients engaging with peers who have first-hand experience of the various treatments was raised as vital to ensure not only that the ‘expert patients’ are qualified to offer the support, but the patients themselves are supported in the process. Peer support for newer patients was supported by a stakeholder as being very important and helpful.

It was emphasised that patients with early stage renal disease who are referred late to renal services must not be disadvantaged and provided with appropriate information compared with those referred early.

Relevant statements within CKD quality standard (QS5)

Quality statement 9: Preparing for renal replacement therapy

- *People with progressive CKD whose eGFR is less than 20 ml/min/1.73 m2, and/or who are likely to progress to established kidney failure within 12 months, receive unbiased personalised information on established kidney failure and renal replacement therapy options.*

Quality statement 10: Psychosocial support

- *People with established renal failure have access to psychosocial support (which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances.*

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full below table 4 to help inform the Committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Information, education and support	**Information and support** NICE CG125 Recommendations 1.1.2, 1.1.3, 1.1.6-1.1.8 **Preparing patients for RRT** Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.1 and 3.2) **Educating patients and carers for RRT** Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (4.1 – 4.3)

Information and support

NICE CG125 Recommendation 1.1.2

Offer patients and their families and carers oral and written information about pre-emptive transplant, dialysis, and conservative care to allow them to make informed decisions about their treatment.

NICE CG125 Recommendation 1.1.3

To enable patients to make informed decisions, offer balanced and accurate information about all dialysis options. The information should include:

- a description of treatment modalities (assisted automated peritoneal dialysis aAPD], automated peritoneal dialysis [APD], continuous ambulatory peritoneal dialysis [CAPD], and home or in-centre haemodialysis) including:
  - efficacy
  - risks
  - potential benefits, based on the person's prognosis
  - potential side effects and their severity

  - changing the modality of dialysis and the possible consequences (that is, the impact on the person's life or how this may affect future treatment or outcomes)
- a discussion about how treatment fits into people's lives, including:
  - the patient's and/or carer's ability to carry out and adjust the treatment themselves
  - integration with daily activities such as work, school, hobbies, family commitments and travel for work or leisure
  - opportunities to maintain social interaction
  - the impact on body image
  - how the dialysis access point on the body may restrict physical activity
  - if their home will need to be modified to accommodate treatment
  - distance and time spent travelling for treatment
  - flexibility of treatment regimen
  - any additional support or services that might be needed from others.

NICE CG125 Recommendation 1.1.6

Make sure that healthcare professionals offering information have specialist knowledge about CKD and the necessary skills to support decision-making.

This may include training in:

- using decision aids to help patients make decisions about their care and treatment
- presenting information to children in a form suitable for their developmental stage, such as play therapies.

NICE CG125 Recommendation 1.1.7

Trained healthcare professionals (see recommendation 1.1.6) should be available to discuss the information provided both before and after the start of dialysis.

NICE CG125 Recommendation 1.1.8

Offer all patients who have presented late, or started dialysis treatment urgently, an enhanced programme of information, at an appropriate time, that offers the same information and choices as those who present at an earlier stage of chronic kidney disease.

Preparing patients for RRT

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.1)

We recommend that most patients whose eGFR is <30ml/min/1.73m$_2$ and declining should receive timely and personalised information regarding established kidney failure and renal replacement therapy options so they can make an informed decision about treatment.

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.2)

We recommend that patients who present with advanced kidney failure and are likely to need RRT within 3 months should be able to access an accelerated care pathway to deliver education, information and prepare for RRT.

Educating patients and carers for RRT

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (4.1)

We recommend that all patients with severe CKD (stage 5 and progressive stage 4), together with their families and carers, should be offered an appropriate education programme aimed at improving their knowledge and understanding of their condition, and of the options for treatment.

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (4.2)

We suggest that education programmes should be multidisciplinary, multifaceted, tailored to the needs of the individual, and based on the principles of adult learning. A variety of approaches should be available including individual conversations, group work, written materials, DVD/CDs, access to expert patients. There should be opportunities for informal follow up. The information imparted should be relevant to the person, with the method, scale, pace and scope of the delivery being suited to the individual's learning style, capacity and preferences. The programme should also include provision for the education of patients who present late, and initiate dialysis in an unplanned fashion.

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (4.3)

We suggest that pre-renal replacement therapy education programmes for patients and their families and carers should be continued into the treatment phase, with the aims of optimising patient involvement in their own care, improving treatment adherence, and fostering good communication and collaborative relationships with caregivers.

4.1.3 Current UK practice

Stakeholders reported that people often start RRT with too little involvement in their care. A report by the All-Party Parliamentary Kidney Group highlighted that in-centre haemodialysis is frequently the default treatment for patients starting dialysis which may be symptomatic of a lack of informed discussion and education of patients. The uptake of shared decision making aids is also reported to vary between centres.

4.2 *Transplantation*

4.2.1 Summary of suggestions

Pre-emptive transplantation

Stakeholders highlighted that pre-emptive transplantation should be the preferred treatment of choice for all suitable patients.

Criteria for acceptance

One stakeholder highlighted that appropriate and timely access to the kidney transplant list is important. Earlier transplantation reduces time on dialysis which impacts upon how long the patient will live and their quality of life.

Post-operative care – acute rejection

One stakeholder stated that the diagnosis of the cause of renal transplant rejection depends on the access to a specialised histopathology service that allows rapid diagnosis of the cause of transplant dysfunction. Treatment for acute rejection needs to be started as rapidly as possible and if this is to be guided by the transplant biopsy results there needs to be access to a histopathology service 7 days a week.

Relevant statements within CKD quality standard (QS5)

Quality statement 11: Transplantation – pre-emptive

- *People with CKD are supported to receive a pre-emptive kidney transplant before they need dialysis, if they are medically suitable*

Quality statement 12: Transplantation – on dialysis

- *People with CKD on dialysis are supported to receive a kidney transplant, if they are medically suitable.*

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full below table 5 to help inform the Committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Pre-emptive transplantation	**Preparing patients for RRT** Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.3 and 3.4)

	Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (5.1) **Access to renal transplantation** Renal Association Guidelines: Assessment of the potential kidney transplant recipient- Access to renal transplantation (1.1 – 1.3)
Criteria for acceptance	**Access to renal transplantation** Renal Association Guidelines: Assessment of the potential kidney transplant recipient- Access to renal transplantation (1.6)
Post-operative care – acute rejection	**Diagnosis of acute rejection** Renal Association Guidelines: Post-operative Care of the Kidney Transplant Recipient- Acute rejection (4.1)

Preparing patients for RRT

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.3)

We recommend that all medically suitable patients should be informed about the advantages of pre-emptive living kidney transplantation and efforts made to identify a potential donor to allow pre-emptive transplantation before the need for renal replacement therapy.

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.4)

We recommend that all suitable patients should be listed for cadaveric transplantation six months before the anticipated start of renal replacement therapy.

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (5.1)

We recommend that patients known to nephrology services for 3 months or more and who are planned to have renal support should start renal replacement therapy in a controlled manner, without the need for hospital admission and using an established access (arteriovenous fistula [AVF], arteriovenous [AV] graft, PD catheter) or by pre-emptive renal transplantation.

Access to renal transplantation

Renal Association Guidelines: Assessment of the potential kidney transplant recipient- Access to renal transplantation (1.1)

We recommend that kidney transplantation should be the renal replacement therapy of choice for the patient with chronic kidney disease stage 5 who is considered fit for major surgery and for chronic immunosuppression. All patients predicted to have an increased life expectancy post-transplantation should be assessed for transplantation. Placement on the transplant waiting list will be limited by individual co-morbidity and prognosis.

Renal Association Guidelines: Assessment of the potential kidney transplant recipient- Access to renal transplantation (1.2)

We recommend that living donor transplantation should be considered the treatment of choice for all patients suitable for renal transplantation when there is an appropriate donor.

Renal Association Guidelines: Assessment of the potential kidney transplant recipient- Access to renal transplantation (1.3)

We recommend that patients with progressive deterioration in renal function suitable for transplantation should be placed on the national transplant list within six months of their anticipated dialysis start date. Pre-emptive transplantation should be the treatment of choice for all suitable patients whenever a living donor is available.

Access to renal transplantation – criteria for acceptance

Renal Association Guidelines: Assessment of the potential kidney transplant recipient- Access to renal transplantation (1.6)

We recommend that all transplant units should have written criteria for acceptance on to the waiting list. The benefits and potential risks associated with transplantation should be fully explained both verbally and in writing. Potential transplant recipients should be informed of all donor options including living related and unrelated donation and the NHSBT/BTS guidelines for consent for solid organ donation should be followed.

Diagnosis of acute rejection

Renal Association Guidelines: Post-operative Care of the Kidney Transplant Recipient- Acute rejection (4.1)

We recommend that a transplant renal biopsy should be carried out before treating an acute rejection episode unless this will substantially delay treatment or pose a significant risk to the patient.

4.2.3 Current UK practice

Transplantation rates and acceptance criteria

UK Renal Registry 16th Annual Report

The UK prevalence by treatment modality since 1997 shows a steady increase in the numbers of transplants, as shown below in relation to other treatment modalities

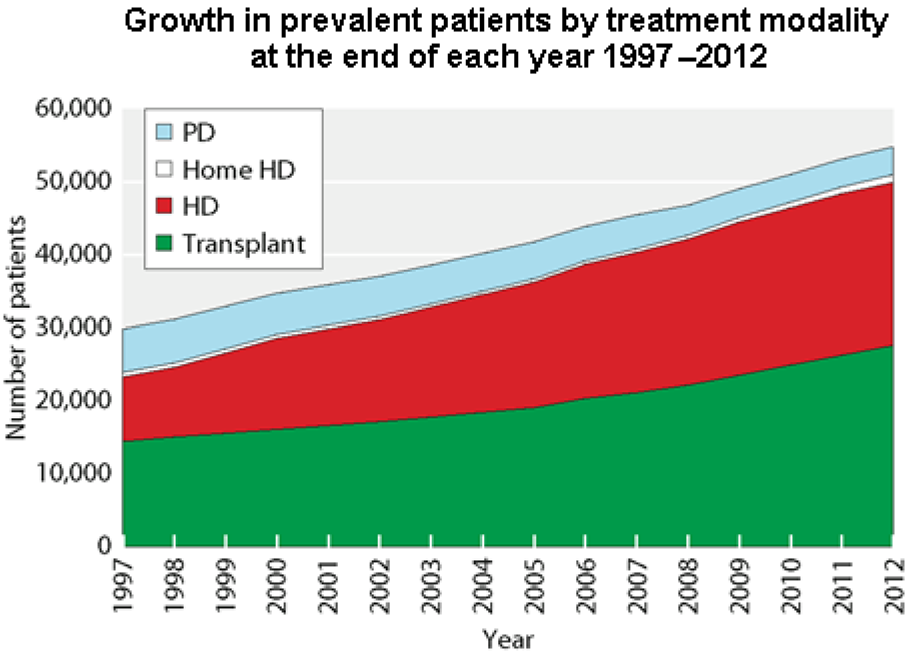

Figure taken from UK Renal Registry 16th Annual Report (figure 2.2)

The Renal Registry has reported inter-centre variation exists in the number of patients waiting for a transplant (both pre-emptively and after commencing dialysis) and in the proportion listed across different ethnic groups, age and blood groups.

This may reflect differences in geography, local population density, age distribution, ethnic composition, prevalence of diseases predisposing to kidney disease and the social deprivation index of that population as well as individual centre practice patterns. However, significant unexplained inter-centre variation may also be evident.

A longitudinal study of variation between centres in access to renal transplantation in the UK concluded that there is significant variation in access to renal transplantation between centres that cannot be explained by differences in the characteristics of the populations.[2]

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[2] Ravanan et al. (2010) Variation between centres in access to renal transplantation in the UK; longitudinal cohort study. BMJ: 341

The Renal Association has reported that this reflects variation in the selection or acceptance criteria for donor organs used across the UK, according to the NHSBT/BTS guidelines.

Post-operative care – acute rejection

No routine data were identified for this report; this is based on stakeholder expert opinion. It was reported that provision of same day and weekend biopsy service is variable.

4.3 Access to the range of dialysis options

4.3.1 Summary of suggestions

Home based dialysis was supported as the initial treatment choice. It was noted that whilst choice is an important factor in the decision making process, it is essential that the choice is informed by the best available clinical evidence and that this is combined with patient lifestyle needs and preferences.

Stakeholders highlighted NICE clinical guideline 125 which recommends offering a choice of peritoneal dialysis or haemodialysis (HD), if appropriate, and peritoneal dialysis (PD) as the first choice treatment modality for certain people with significant residual kidney function without significant co-morbidities and those wanting to remain independent and not wanting HD.

Stakeholders highlighted research indicating that given appropriate education, 50% of patients who are deemed able to choose a dialysis modality will opt for PD and up to 80% will select home dialysis (PD and home HD). This is however not reflected in the actual number of patients receiving dialysis at home.

It was also highlighted that all appropriate treatments must be available to all patients irrespective of where they live, so that they can select the option that best meets their clinical and lifestyle needs.

Relevant statements within CKD quality standard (QS5)

Quality statement 14: Best possible dialysis

- *People on long-term dialysis receive the best possible therapy, incorporating regular and frequent application of dialysis and ideally home-based or self-care dialysis.*

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full below table 6 to help inform the Committee’s discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Access to the range of dialysis options	**Choosing dialysis** NICE CG125 Recommendations 1.1.9, 1.1.10 and 1.1.11 **Preparing patients for RRT** Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.5 and 3.6)

Choosing dialysis

NICE CG125 Recommendation 1.1.9

Offer all people with stage 5 CKD a choice of peritoneal dialysis or haemodialysis, if appropriate, but consider peritoneal dialysis as the first choice of treatment modality for:

- children 2 years old or younger
- people with residual renal function
- adults without significant associated comorbidities.

NICE CG125 Recommendation 1.1.10

When discussing choice of treatment modalities, healthcare professionals should take into account that people's priorities are not necessarily the same as their own clinical priorities.

NICE CG125 Recommendation 1.1.11

Before starting peritoneal dialysis, offer all patients a choice, if appropriate, between CAPD and APD (or aAPD if necessary).

Preparing patients for RRT

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.5)

We suggest that all patients should be encouraged to perform home dialysis therapy where possible, as part of an integrated approach to renal replacement therapy.

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Preparing patients for RRT (3.6)

We suggest that, where home dialysis is not possible, patients and their carers/partners should be actively involved in their dialysis treatment, be encouraged to perform as much self-care as possible and be engaged in all aspects of their treatment including medicines management and changes in diet and lifestyle.

4.3.3 Current UK practice

UK Renal Registry 16th Annual Report

In 2012, transplantation was the most common treatment modality (50.4%) for prevalent RRT patients followed closely by centre-based HD (40.7%) in either hospital centre (19.4%) or satellite unit (21.3%). The remaining 8.9% was home therapies, which was largely PD in its different treatment types of APD and CAPD (6.9%). This proportion was similar to 2011. Significantly for the first time in 2012, satellite based haemodialysis was reported as more prevalent than hospital centre haemodialysis.

Treatment modality in prevalent RRT patients on 31/12/2012

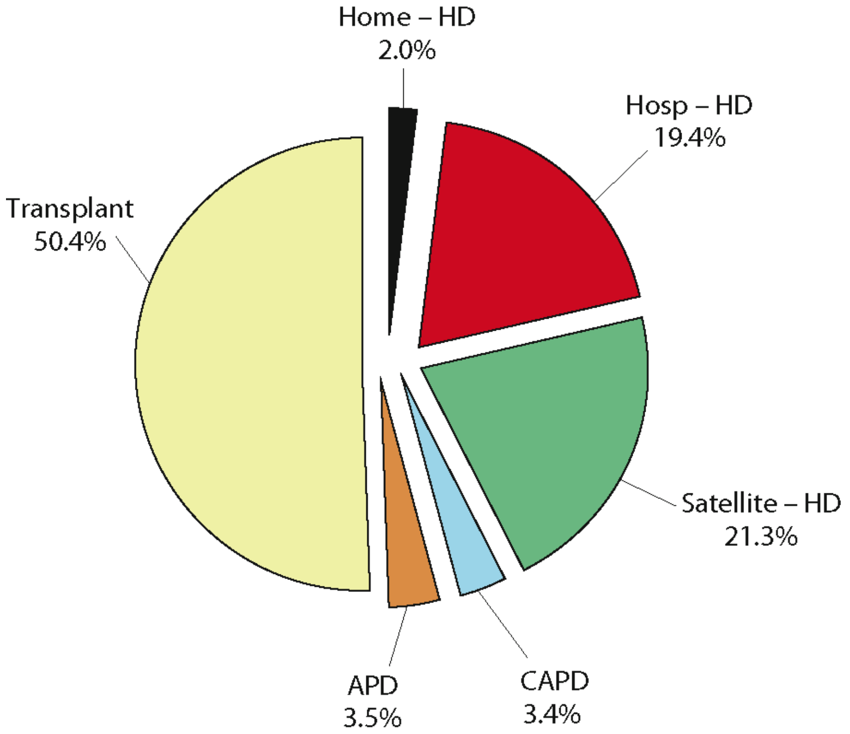

Figure taken from UK Renal Registry 16th Annual Report (figure 2.6)

The relative proportion of RRT modalities has changed dramatically over the past decade with a reported decrease in the proportion of prevalent RRT patients treated by PD after 2000. However, this decline may have now started to plateau with some small increases in the absolute numbers of patients commencing PD as the first established modality.

Modality changes in prevalent RRT patients from 1997–2012

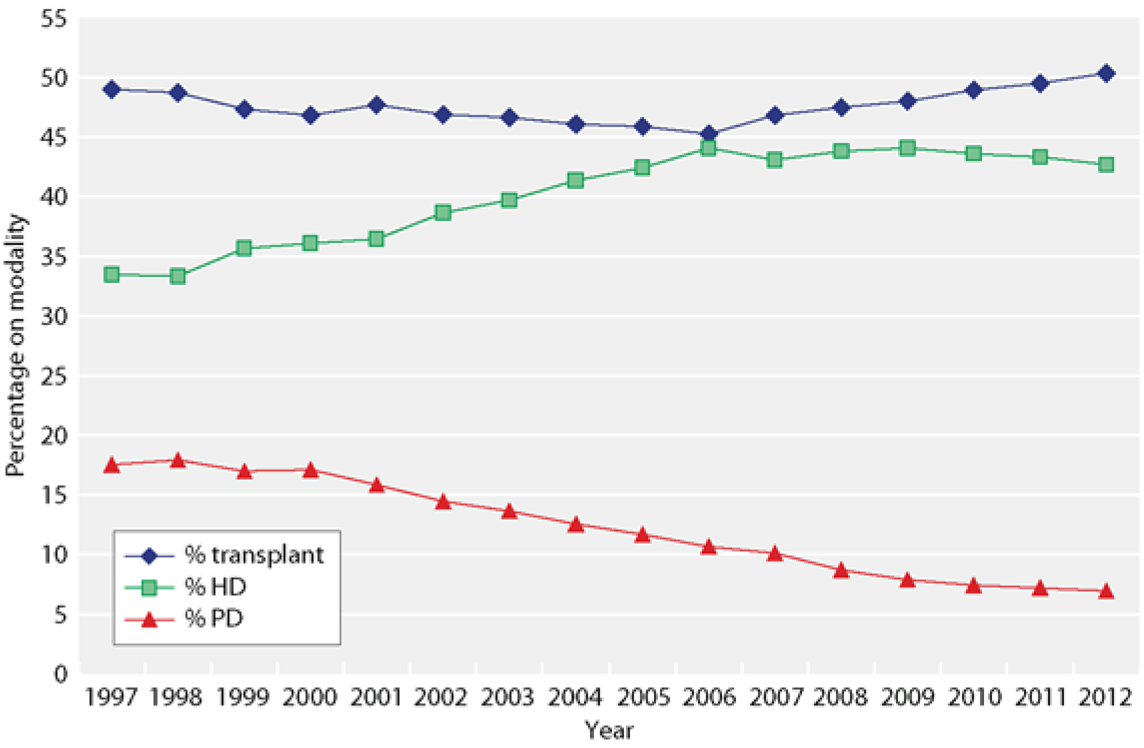

Figure taken from UK Renal Registry 16th Annual Report (figure 2.9)

All-Party Parliamentary Kidney Group – Home Dialysis Summit (Increasing uptake of home dialysis in the UK to benefit patients and the NHS) (2013)

The authors highlighted low uptake of home dialysis, noting that home HD and PD should be better supported within the NHS as they offer improved clinical outcomes for suitable patients.

Various barriers to home dialysis uptake was reported which included:-

- clinical bias against home dialysis
- lack of patient awareness of the availability and advantages of home dialysis
- absence of a coordinated national approach to home dialysis.

The report also noted that in-centre haemodialysis is frequently the default treatment for patients starting dialysis, particularly for those who present late or who start dialysis in an unplanned way.

In addition, it was reported that patients were not given the option to change their dialysis modality after initiating in-centre treatment. This can result in patients remaining on in-centre HD when home HD or PD may be a more effective modality.

4.4 Changing treatment modalities

4.4.1 Summary of suggestions

Stakeholders highlighted the importance of effective switching between treatment modalities, temporary transfers and the management of failing transplant patients' transition to dialysis. Patients changing modality should also be as planned as possible to avoid the requirement to start dialysis without adequate preparation.

This is also appropriate to patients with transplant failure when an expected requirement for an alternative RRT is anticipated within 12 months.

4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Changing treatment modalities	**Switching treatment modalities** NICE CG125 Recommendations 1.1.13 – 1.1.16

Switching treatment modalities

NICE CG125 Recommendation 1.1.13

Do not routinely switch patients on peritoneal dialysis to a different treatment modality in anticipation of potential future complications such as encapsulating peritoneal sclerosis. However, healthcare professionals should monitor risk factors such as loss of ultrafiltration and discuss with patients regularly the efficacy of all aspects of their treatment.

NICE CG125 Recommendation 1.1.14

Consider switching treatment modality if the patient, their family or carer asks.

NICE CG125 Recommendation 1.1.15

When considering switching treatment modality, offer information on treatment options described in recommendations 1.1.1–1.1.8. This should also include how any decision to switch may affect future treatment options.

NICE CG125 Recommendation 1.1.16

Switching between treatment modalities should be planned if possible.

4.4.3 Current UK practice

No routine data were identified for this report; this is based on stakeholder expert opinion.

4.5 Transport

4.5.1 Summary of suggestions

Stakeholders highlighted that patient transport is an essential part of patient experience and integral to dialysis care. It must be organised in a patient-focused way as poor transport can undermine good dialysis care resulting in treatment delays. For example, delayed access to haemodialysis can lead to extra costs in staff time and have a major impact on the patient's quality of life.

Relevant statements within CKD quality standard (QS5)
Quality statement 15: Patient transport

- *People with CKD receiving haemodialysis or training for home therapies who are eligible for transport, have access to an effective and efficient transport service.*

4.5.2 Selected recommendations from development source

Table 8 Specific areas for quality improvement

Table 8 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Transport	**Haemodialysis facilities** Renal Association Guidelines: Haemodialysis (1.3 and 1.4) Planning, Initiating & Withdrawal of RRT- Initiating RRT (Guideline 5.4)

Haemodialysis facilities

Renal Association Guidelines: Haemodialysis- Haemodialysis facilities (1.3)

We recommend that, except in remote geographical areas, the travel time to a haemodialysis facility should be less than 30 minutes or a haemodialysis facility should be located with 25 miles of the patient's home. In inner city areas travel times over short distances may exceed 30 minutes at peak traffic flow periods during the day.

Renal Association Guidelines: Haemodialysis- Haemodialysis facilities (1.4)

We suggest that haemodialysis patients who require transport should be collected from home within 30 minutes of the allotted time and be collected to return home within 30 minutes of finishing dialysis.

4.5.3 Current UK practice

2012 Kidney Patient Transport Audit

The 2012 Kidney Patient Transport Audit reported that two-thirds of patients who travelled for haemodialysis did so using hospital transport. While it indicated improvements in transport arrangements since the previous audit in 2010, around one-third of users reported delays of more than 30 minutes in pick-up times on outward and return journeys and journey times of over 30 minutes each way, caused by multiple pick-ups or drop-offs. In some cases, 45 minute journeys could take up to two hours.

4.6 Multidisciplinary teams (MDT)

4.6.1 Summary of suggestions

Stakeholders highlighted the important role of multidisciplinary teams (MDTs) for people requiring RRT. MDTs also have an important role in ensuring that any transitions of care experienced by kidney patients are streamlined as patients are at their most vulnerable when moving from one treatment type to another.

In addition, the importance of high quality patient information and education received from MDTs was highlighted. The involvement of specialist members within the MDT was supported as it would improve the holistic care and quality of life of the patient.

Two main issues highlighted are as follows:

<u>MDT composition and function</u>

These teams can include a dietician, psychologist, pharmacist, doctor nurse social worker, peer support and patient. Management should be regularly reviewed by the team to help optimise treatments and proactively manage conditions associated with RRT in order to improve the patient’s quality of life.

<u>Training and specialist skills of MDTs</u>

A stakeholder raised the importance of training MDTs; the MDT members should have specialist knowledge and the necessary skills to support decision-making and patient education. It was noted that there is no formal training requirement for MDT members. It was therefore suggested that all education should be delivered through nationally accredited programmes.

4.6.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 9 to help inform the Committee’s discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
MDTs	**Nephrology follow-up** Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT-Nephrology follow-up (2.2) **Haemodialysis facilities** Renal Association Guidelines: Haemodialysis-Haemodialysis equipment

	and disposables (1.2) **Information and support** NICE CG125 Recommendations 1.1.6 and 1.1.17

RRT: Nephrology follow-up

Renal Association Guidelines: Planning, Initiating & Withdrawal of RRT- Nephrology follow-up (2.2)

We recommend that these patients [patients whose eGFR is <30ml/min/1.73m2 and declining] should be managed in a dedicated clinic by a multidisciplinary team.

Haemodialysis facilities

Renal Association Guidelines: Haemodialysis: Haemodialysis equipment and disposables (1.2)

We recommend that the haemodialysis facility should have sufficient specialist support staff to fulfil the criteria listed by the Renal Workforce Planning Group 2002.

Information and support

NICE CG125 Recommendation 1.1.6

Make sure that healthcare professionals offering information have specialist knowledge about CKD and the necessary skills to support decision-making.

This may include training in:

- using decision aids to help patients make decisions about their care and treatment
- presenting information to children in a form suitable for their developmental stage, such as play therapies.

NICE CG125 Recommendation 1.1.7

Trained healthcare professionals (see recommendation 1.1.6) should be available to discuss the information provided both before and after the start of dialysis

4.6.3 Current UK practice

No routine data were identified for this report; this is based on stakeholder expert opinion.

One stakeholder reported current UK variation on MDT approach and access as not all patients have contact with specialist pharmacists, dieticians, physiotherapists, social workers, and counsellors.

It was highlighted that the British Renal Society (BRS) are helping with content development of the renal section of the Skills for Health workforce planning website. There is a joint project between the Department of Health and Skills for Health to look at the workforce planning issues within renal services[3].

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[3] British Renal Society- Workforce planning

4.7 Patient safety

4.7.1 Summary of suggestions

Stakeholders reported a need to develop a wider suite of safety measures within renal centres as RRT are potentially complicated procedures involving risk to the patient. It was highlighted that patient safety requires special consideration in the commissioning of dialysis services.

Examples of RRT safety measures highlighted include:

- Infection control
- Risks to haemodialysis patients from water supply (hydrogen peroxide)
- Risk of hypothermia in Continuous Renal Replacement Therapy (CRRT) used in intensive care settings for patients critically ill with acute kidney injury.

4.7.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 10 to help inform the Committee's discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Patient safety	**Haemodialysis equipment and disposables** Renal Association Guidelines: Haemodialysis- Haemodialysis equipment and disposables (2.1) **Monitoring of feed and dialysis water for haemodialysis** Renal Association Guidelines: Haemodialysis- equipment and disposables (3.7) **Prevention and detection of venous fistula needle or venous line disconnection** Renal Association Guidelines: Haemodialysis Prevention and detection of venous fistula needle or venous line disconnection (8.4)

Haemodialysis equipment and disposables

Renal Association Guidelines: Haemodialysis- Haemodialysis equipment and disposables (2.1)

We recommend that all equipment used in the delivery and monitoring of haemodialysis should be CE marked and approved to ensure compliance with the relevant safety standards BS EN 60601-1:2006 General safety standards for electrical equipment in clinical use (currently under revision with the revised version being available in 2010) and BS EN 60601-2-16:2008 Particular requirements for basic safety and essential performance of haemodialysis, haemodiafiltration and haemofiltration equipment.

Monitoring of feed and dialysis water for haemodialysis

Renal Association Guidelines: Haemodialysis- Monitoring of feed and dialysis water for haemodialysis (3.7)

We recommend that a routine testing procedure for water for dialysis should form part of the renal unit policy. Each unit should have standard operating procedures in place for sampling, monitoring and recording of feed and product water quality. The operating procedures should include details of the procedures to be followed if the prescribed limits are exceeded.

Prevention and detection of venous fistula needle or venous line disconnection

Renal Association Guidelines: Haemodialysis- Prevention and detection of venous fistula needle or venous line disconnection (8.4)

We suggest that all haemodialysis staff should follow standard operating procedures to minimize the risk of accidental venous needle/line disconnection. In patients who are restless or undergoing haemodialysis at home consideration should be given to the use of commercially available monitoring systems.

4.7.3 Current UK practice

The National Patient Safety Agency (NPSA) now known as NHS England Patient Safety Division produced a 2008 Rapid Response Report[4] on water supply safety in haemodialysis units as a hospital trust had reported a cluster of incidents of haemodialysis patients being re-admitted to the hospital 2-7 days after treatment with acute haemolysis (destruction of red blood cells leading to anaemia and risk of severe hyperkalaemia).

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[4] Risks to haemodialysis patients from water supply (hydrogen peroxide) (NPSA, 2008)

The NHS England Patient Safety Division has also recently (February 2014) produced a Patient Safety Alert[5] on the risk of hypothermia in Continuous Renal Replacement Therapy (CRRT) used in intensive care settings for patients critically ill with acute kidney injury.

Both reports highlight the importance of safety as well as effectiveness in the delivery of high quality care for RRT patients.

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[5] Risk of hypothermia for patients on continuous renal replacement therapy (Patient Safety Alert, 2014)

4.8 Vascular access

4.8.1 Summary of suggestions

Vascular access is a fundamental aspect of haemodialysis treatment. The ideal vascular access should provide safe and effective therapy by enabling the removal and return of blood via an extracorporeal circuit[6].

Stakeholders reported wide variation in the care and survival rates of vascular access in haemodialysis patients in terms of interventions and their timeliness and the timely identification of complications. Standardisation of care (needling techniques) and appropriate placement of patients (on Renal wards as opposed to General wards) was also highlighted as crucial to ensure high quality care with no current specific competencies reported in most centres.

Stakeholders raised the need for an advanced service for definitive vascular access. In particular, it was suggested that haemodialysis nurses should have their competency assessed to ensure standardisation of practice and better access survival rates.

Relevant statements within CKD quality standard (QS5)

Quality statement 13: Dialysis access

- *People with established kidney failure start dialysis with a functioning arteriovenous fistula or peritoneal dialysis catheter in situ.*

Safety of vascular access

A stakeholder highlighted the importance of safety in line with the 2013/14 NHS Standard Contract for Renal Dialysis: Hospital and satellite (adult). This states the need of safety of dialysis patients while hospitalised with vascular complications of their disease. This requires special consideration in the commissioning of dialysis services.[7]

Maintenance of vascular access

A stakeholder highlighted that buttonhole technique is not available in some centres in which cases a fistula's life cannot be extended.

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[6] Renal Association Guidelines- Vascular access for haemodialysis (2011)

[7] 2013/14 NHS Standard Contract for Renal Dialysis: Hospital and satellite (audit)

Complications of vascular access

A stakeholder reported that fistula infections are controlled badly as a new fistula in a different area is not an option.

4.8.2 Selected recommendations from development source

Table 11 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 11 to help inform the Committee’s discussion.

Table 11 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Safety of vascular access	No specific recommendations are included as this area requires further discussion.
Maintenance of vascular access	Renal Association Guidelines: Vascular access for haemodialysis: Needling technique (4.2)
Complications of vascular access	Renal Association Guidelines: Vascular access for haemodialysis: Prevention of arteriovenous aneurysmal formation (6.2)

Maintenance of vascular access

Renal Association Guidelines: Vascular access for haemodialysis: Needling technique (4.2)

We suggest that buttonhole is the preferred needling technique.

Complications of vascular access

Renal Association Guidelines: Vascular access for haemodialysis: Prevention of arteriovenous aneurysmal formation (6.2)

We suggest that prevention of aneurysmal formation with good needling technique is appropriate and is the cornerstone for preserving arteriovenous fistulae

4.8.3 Current UK practice

No routine data were identified for this report; this is based on stakeholder expert opinion.

Stakeholders highlighted evidence which shows outcomes are less good in patients starting haemodialysis via a central venous catheter. However in 2011, only 43% of patients commenced haemodialysis with definitive vascular access. Significant variation between centres was reported.

4.9 Additional areas

4.9.1 Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise however these felt either to be outside the remit of the quality standard referral and the development source (NICE guidance) or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 3 April 2014.

4.4.4 Data capture

One stakeholder raised the importance of regular and frequent data capture for all dialysis patients including those that are outside of the acute setting (telehealth).

4.4.5 Conservative management

A stakeholder emphasised that it should be acknowledged that conservative management does not replace renal function and is therefore not a RRT. Conservative management should be more highly regulated, well defined and patients should be accurately informed before opting out of active treatment regimes. It was noted that there is no agreed definition of conservative care with minimal data collection.

4.4.6 Psychological/social patient support (as per CKD statement 10)

One stakeholder highlighted that for chronic kidney disease (CKD) patients requiring RRT, managing existing comorbidities, managing finances and even consequentially loosing employment and then applying for benefits can be extremely difficult. Also living with a long term health condition is very hard both mentally and financially for many patients. These two issues are very much interrelated.

4.4.7 Patient care plan (as per CKD statement 3)

Patients requiring RRT will have an agreed care plan and are supported to receive a kidney transplant if they are medically suitable.

4.4.8 Communication between primary and secondary care

Closer working and better communication between primary and secondary care was supported by a stakeholder to help minimise avoidable late referrals and reduce unnecessary geographic variation. It was emphasised that renal units must ensure that effective handover systems are in place as the clinical team providing the care within the kidney unit may change simultaneously. Patients should also be informed who their key points of contact and support are.

4.5.6 Quality measures (PROMs and PREMs)

Stakeholders highlighted the need for wider adoption of patient reported outcome measures to ensure RRT patients are informed and involved in their care as evidence demonstrates that clinical outcomes are improved in many areas of care when the more patients are involved in managing their chronic illness. Proxy indicators of “patient engagement” were reported as varied in England.

4.5.7 Medication review

A stakeholder highlighted the need for RRT patients to have their medications reviewed and updated on a regular basis and are given support to ensure that their medicines are optimised to suit their individual needs. They reported that satellite dialysis patients are often neglected in terms of medication review. It was suggested that healthcare professions working in renal medicine could act as a liaison between the GPs, community pharmacists and consultants to optimise the medication treatment regimens in this “outpatient setting”. This would improve adherence, and communication as well as ensuring cost effective use of medicines.

Appendix 1: Chronic kidney disease Quality Standard (QS5) (2011)

Statement 1. People with risk factors for CKD are offered testing, and people with CKD are correctly identified.

Statement 2. People with CKD who may benefit from specialist care are referred for specialist assessment in accordance with NICE guidance.

Statement 3. People with CKD have a current agreed care plan appropriate to the stage and rate of progression of CKD.

Statement 4. People with CKD are assessed for cardiovascular risk.

Statement 5. People with higher levels of proteinuria, and people with diabetes and microalbuminuria, are enabled to safely maintain their systolic blood pressure within a target range 120–129 mmHg and their diastolic blood pressure below 80 mmHg.

Statement 6. People with CKD are assessed for disease progression.

Statement 7. People with CKD who become acutely unwell have their medication reviewed, and receive an assessment of volume status and renal function.

Statement 8**.** People with anaemia of CKD have access to and receive anaemia treatment in accordance with NICE guidance.

Statement 9. People with progressive CKD whose eGFR is less than 20 ml/min/1.73m^2, and/or who are likely to progress to established kidney failure within 12 months, receive unbiased personalised information on established kidney failure and renal replacement therapy options.

Statement 10. People with established renal failure have access to psychosocial support (which may include support with personal, family, financial, employment and/or social needs) appropriate to their circumstances.

Statement 11**.** People with CKD are supported to receive a pre-emptive kidney transplant before they need dialysis, if they are medically suitable.

Statement 12. People with CKD on dialysis are supported to receive a kidney transplant, if they are medically suitable.

Statement 13. People with established kidney failure start dialysis with a functioning arteriovenous fistula or peritoneal dialysis catheter in situ.

Statement 14. People on long-term dialysis receive the best possible therapy, incorporating regular and frequent application of dialysis and ideally home-based or self-care dialysis.

Statement 15. People with CKD receiving haemodialysis or training for home therapies who are eligible for transport, have access to an effective and efficient transport service.

Appendix 2: Glossary

APD automated peritoneal dialysis

Allograft A graft of tissue obtained from a donor genetically different from, though of the same species as the recipient.

CAPD Continuous ambulatory peritoneal

Conservative management Treatment without having dialysis or transplantation

Haemodialysis (HD) A type of dialysis usually done in hospital, blood is taken out of the body and passed through a machine to be cleaned.

Peritoneal dialysis (PD) A type of dialysis which is usually done at home, the blood is cleaned inside the body. It uses special fluid that is drained in and out of the space inside the abdomen called the 'peritoneal space'

Pre-emptive transplantation Pre-emptive transplantation may be from a cadaveric or living donor; living donor is preferred.

PREMS Patient reported experience measures

PROMS Patient reported outcome measures

Telehealth The delivery of health-related services and information via telecommunications technologies.

Appendix 3: Suggestions from stakeholder engagement exercise

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
01	Royal College of Pathologists	Provision of out-of hours reporting service for renal transplant biopsies	Diagnosis of the cause of renal transplant rejection depends on renal biopsy. Treatment for acute rejection needs to started as rapidly as possible and if this is to be guided by the results of the transplant biopsy there needs to be access to a histopathology service 7 days a week	Optimum care for patients with renal transplants depends on access to a specialised histopathology service that allows rapid diagnosis of the cause of transplant dysfunction. At present the provision of same day and weekend biopsy services is variable with some hospitals where a 7 day biopsy service is not provided. A standard UK policy with regional provision of such a service would improve care	The Renal Association Guidelines for post-operative care of the renal transplant recipient say: 'We recommend that a transplant renal biopsy should be carried out before treating an acute rejection episode unless this will substantially delay treatment or pose a significant risk to the patient' Guideline 4.1 http://www.renal.org/guidelines/modules/post-operative-care-of-the-kidney-transplant-recipient#sthash.3BJ6orNp.dpbs Evidence collected at the meeting of UK Renal Pathologists in Oxford in 2013 established that not all renal biopsy centres were providing a 7 day on call service
02	Association of Renal Industries		The management of patients on renal replacement therapy is highly complex requiring input from specialist teams with expertise in many areas. This encompassed such varied areas as water quality to anaemia and phosphate management. To help define the key areas we would suggest an examination is made of the various guidelines already in place (many of which are listed in the topic overview) and use these as the basis for formulating the standards.	The key areas for improvement will be identified by the process described in column one of comparing the existing guidelines with data showing what is currently achieved as taken from the renal registry data. This should enable the identification of those areas of provision that would benefit most from inclusion as a quality standard.	The renal registry web site: http://www.renalreg.com/ Improving the management of renal replacement using quality standards will be helpful and the list of suggested resources in the topic overview is wide ranging. The list includes a number of guidelines from NICE which are currently in the process of being updated (CKD, and anaemia management). It is likely that some of the content will be changed and it is important that only the most up to date

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			A vital tool in the formulation of the quality standards will be those data from the renal registry which does not seem to be listed in the topic overview. A comparison of the existing standards with registry will show the variance in achievement and serve to highlight the key areas where a quality standard would be of value and help to improve care. The use of the existing standards and registry data will though be unable to pick up on many areas that may be great importance to patients, their carers and wider family. We would suggest consultation with as wide a range of stakeholders as possible including all members of the multi-disciplinary team and most importantly patients and carers.		guidelines are used. The topic overview would benefit from being widened as currently no mention is made of such areas as the importance of nutritional support, the provision of support by social workers, the need for assistance for patients in terms of coping with the provision of benefits, etc.
03	Baxter Healthcare Ltd	Robust implementation of all relevant NICE Guidelines, NICE Quality Standards, Renal Association Guidelines and NHS England's Service Specifications to ensure that all patients have equity of access to all RRT services, regardless of where	It is now more than ten years since NICE first recognised the benefits of home dialysis, stating that between 10-15% of patients would be on home haemodialysis (HHD) if given the choice (*NICE TA 48, 2002*). More recently, NICE has also stated that the optimum level for peritoneal dialysis (PD), which is also administered at home, would be 39% (*NICE Clinical Guideline 125 Costing report 2011*). Despite this fewer than 14% of dialysis patients are currently receiving PD at home and only 4% are having HHD (Renal Registry	In addition to the NICE Home HD and PD Guidance, a plethora of other publications have been issued. In 2006 the Renal Association Working Party on PD stated that a minimum 25% of dialysis patients should receive dialysis at home. In the same year, NHS Kidney Care published the commissioning of PD pathway which stated its purpose was "*to be used by patients and commissioners as a guide to services they should be able to access; by providers to offer*	UK Renal Registry 16th Annual Report: Chapter 2 UK RRT Prevalence in 2012: National and Centre-specific Analyses NICE TA 48, Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure 2002 NICE Clinical Guideline 125 Costing report, 2011 NICE Quality Standard for Chronic Kidney Disease, 2011 Specification for the Commissioning of Peritoneal Dialysis Pathway, NHS Kidney Care, 2009 Renal Association Working Party on

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		they live	Report 2013). It is vital therefore that reimbursement mechanisms are implemented in line with guidance and standards to drive patient choice of modality rather than capacity issues	*patients genuine modality choice; and by procurement departments to gain high quality, cost-effective services and supplies. Their work aimed to achieve equity of patient access, consistent pricing and a full range of product availability in a competitive market, leading to an increase in home therapy, with all patients offered a real choice*". In 2010 NICE published the CKD Quality Standards which stated; Where clinically indicated, people with established kidney failure start dialysis with a functioning arteriovenous fistula or peritoneal dialysis catheter in situ and; People on long-term dialysis receive the best possible therapy, incorporating regular and frequent application of dialysis and ideally home-based or self-care dialysis. Despite this, and the introduction of best practice tariffs that were ostensibly designed to support these guidelines, the UK has seen a steady decline in the number of patients treated at home from 5923 patients in 2002 to 4872 in 2012. This is despite a modest rise in the number of patients receiving haemodialysis at home but a huge growth in the total number of patients receiving dialysis from 19,904 to 27,203 during the same time period (Renal Registry Report	Peritoneal Dialysis Final Report 18.11.09 (Appendix 1 page 13)

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				2013). It is therefore of paramount importance that any further guidance or quality standards that are issued are not only taken seriously and implemented in clinical practice, but the performance of the providers of dialysis services are routinely measured and monitored against these standards.	
04	Baxter Healthcare Ltd	Self-managed therapies should be the default renal replacement therapy. This should include transplantation (if clinically appropriate), home based, self-care or minimal care dialysis.	In addition to the wealth of evidence cited above, the Kings Fund have also identified the positive impact that self-management can have for patients with long-term conditions. These include; the potential to improve health outcomes, with some patients reporting increases in physical functioning improvements in patient experience, with patients reporting benefits in terms of greater confidence and reduced anxiety a reduction in unplanned hospital admissions and improvements in adherence to treatment and medication.	As outlined above, those patients who manage their own dialysis are currently in the minority despite recognised cost and clinical benefits.	Transforming our Health Care System. 10 Priorities for Commissioners. The Kings Fund, 2011 (Revised 2013) NICE Clinical Guideline 125 Costing report, 2011
05	Baxter Healthcare Ltd	Patients requiring RRT should be supported to have the best possible treatment depending upon their stage of	There is a growing body of evidence and support for ensuring that patients have the best possible RRT, depending on their individual clinical and personal situation. Pre-emptive transplantation is recommended in the NICE Quality	Anecdotal evidence suggests that clinicians believe that they offer patients a choice of RRT in the Pre-Dialysis phase. However, research studies show that with appropriate education, 50% of patients who are deemed able to choose a dialysis	NICE Quality Standard for Chronic Kidney Disease, 2011 Renal Association Guideline, Assessment of the potential kidney transplant recipient, 2011 NICE Clinical Guideline 125 Peritoneal Dialysis 2011

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		kidney failure. This should include the regular provision of information and education regarding the particular short term and long term clinical benefits of renal replacement therapy options. This should occur regularly, along the whole patient pathway, preferably at routine clinic appointments and for patients who have started dialysis in an unplanned manner. All patients should be educated and offered a choice, if appropriate, between Home HD done for longer hours or more frequently, Individualised Quality assured HD in-centre, self-care HD, minimal care HD, CAPD and APD and assisted home dialysis if necessary.	Standard for Chronic Kidney Disease, 2011 and by the Renal Association who state in their Kidney Transplant Guidelines 2011 "*Pre-emptive transplantation should be the treatment of choice for all suitable patients whenever a living donor is available*." The NICE Clinical Guidelines for PD state that "*Peritoneal Dialysis is the preferred initial treatment option for children 2 years old or younger, people with residual renal function and adults without significant associated comorbidities*". The use of PD as a first dialysis modality will also enable the preservation of vascular access for those patients who are likely to require haemodialysis at a later date. Evidence also suggests that compared with haemodialysis, patients treated with PD before transplantation had lower mortality. Evidence for longer duration or more frequent (or "High Dose") haemodialysis without a 2 day gap (which is more easily performed at home) demonstrates a number of clinical and lifestyle benefits. These include survival similar to survival after cadaveric kidney transplantation reduction of the impact of kidney disease on patient's lives compared to conventional HD and increases	modality will opt for PD and up to 80% will select home dialysis (peritoneal and home HD). This is not reflected in the actual number of patients receiving dialysis at home. Whilst choice is an important factor in the decision making process, it is essential that the choice is informed by the best available clinical evidence and that this is combined with patient lifestyle needs and preferences. It should also be acknowledged that conservative management does not replace renal function and is therefore not a Renal Replacement Therapy. This option should be more highly regulated, well defined and patients should be accurately informed before opting out of active treatment regimes. High quality dialysis should recognise the need to use bicarbonate based dialysis solutions, Icodextrin for patients on PD with fluid and sodium management issues and low glucose fluids in PD, particularly for people with diabetes.	Molnar et al. Clin J Am Soc Nephrol 7: 332–341, 2012. doi: 10.2215/CJN.07110711 Renal Association Working Party on Peritoneal Dialysis Final Report 18.11.09 Pauly RP, Gill JS, Rose CL, et al. Survival among nocturnal home haemodialysis patients compared to kidney transplant recipients. Nephrol Dial Transplant. 2009;24:2915-2919. Chertow GM, Levin NW, Beck GJ, et al. In-centre haemodialysis six times per week versus three times per week. N Engl J Med. 2010;363:2287-2300. Culleton BF, Walsh M, Klarenbach SW, et al. Effect of frequent nocturnal haemodialysis vs conventional haemodialysis on left ventricular mass and quality of life: a randomized controlled trial. JAMA. 2007;298:1291-1299 Li P. K.T. et al. Randomized, Controlled Trial of Glucose-Sparing Peritoneal Dialysis in Diabetic Patients J Am Soc Nephrol 24: 2013 Han SH. Et al, Mortality and Technique Failure in Peritoneal Dialysis Patients Using Advanced Peritoneal Dialysis Solutions. Am J Kidney Dis. 2009 Oct;54(4):711-20. doi:10.1053/j.ajkd.2009.05.014. Takatori Y et al. Icodextrin Increases Technique Survival Rate in Peritoneal Dialysis Patients with Diabetic Nephropathy by Improving Body Fluid

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			patient's general health		Management: A Randomized Controlled Trial CJASN ePress. April 14, 2011 as doi: 10.2215/CJN.10041110 Marshall J. et al. Glycemic control in diabetic CAPD patients assessed by continuous glucose monitoring system (CGMS). Kidney International, Vol. 64 (2003), pp. 1480–1486 Li FK et al. A 3-Year, Prospective, Randomized, Controlled Study on Amino Acid Dialysate in Patients on CAPD. American Journal of Kidney Diseases, Vol 42, No 1 (July), 2003: pp 173-183 Davies et al. and the EAPOS Group. Longitudinal membrane function in functionally anuric patients treated with APD: Data from EAPOS on the effects of glucose and icodextrin prescription. Kidney International, Vol. 67 (2005), pp. 1609–1615 Davies S. Longitudinal relationship between solute transport and ultrafiltration capacity in peritoneal dialysis patients Kidney International, Vol. 66 (2004), pp. 2437–2445 Hon-Yen Wu et al. Safety Issues of Long-Term Glucose Load in Patients on Peritoneal Dialysis—A 7-Year Cohort Study Ahn S V et al Survival Advantage of Icodextrin Peritoneal Dialysis Solution in a Time-Dependent Model (letter to the editor). Am J Kidney Dis. 2012;
06	Baxter Healthcare Ltd	All multidisciplinary team healthcare	The quality of information and education that patients receive can	There is currently no formal training requirement for those members of	The importance of patient preferences in treatment decisions—challenges for

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		professionals (MDT) who are involved in the care of patients on RRT have both the specialist knowledge and the necessary skills to support decision-making and patient education.	have a major impact on their treatment choice and thus their quality of life and treatment satisfaction.	the MDT who are involved in treatment options education and shared decision making. All education should be delivered through nationally accredited programmes.	doctors BMJ 2003;327:542–5
07	Baxter Healthcare Ltd	Support and training for patients providing peer support and education for other patients	When a patient is undergoing treatment options education, experiential learning is not possible, particularly if they are new to RRT. Thus the individual must rely on vicarious learning strategies by engaging with peers who have first-hand experience of the various treatments. Support for such people is vital to ensure not only that they are qualified to offer the support, but they themselves are supported in the process.	The use of "Expert Patients" to help support the decision making process for patients. NHS Kidney Care developed a package for training peer support volunteers. Since NHS Kidney Care dissolved, this package has become obsolete, despite its value.	The psychological well-being of renal peer support volunteers J Adv Nurs. 2002 Apr;38(1):40-9
08	Baxter Healthcare Ltd	Effective management of patients starting dialysis	It is well recognised that a planned start to dialysis is preferable for both clinical and psychological reasons. However, for varying reasons, many patients still start dialysis in an unplanned manner. These patients are not solely those who present late to the nephrologist, but are also those who have had input from the renal unit but have a sudden deterioration in renal function and therefore often do not receive their	The CKD Quality standards state that "*People with established kidney failure start dialysis with a functioning arteriovenous fistula (AVF) or peritoneal dialysis catheter in situ*". Despite this the Renal Registry's recent publication reported that "*Of those referred at least 90 days prior to commencing dialysis, 50.1% started on an AVF compared to only 4.3% of those starting more acutely*." This same	UK Renal Registry 16th Annual Report: Chapter 14, 2012. Multisite Dialysis Access Audit in England, Northern Ireland and Wales and 2011 PD One Year Follow-up: National and Centre-specific Analyses

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			treatment of choice and usually start dialysis with temporary access.	report found that centres that had high usage of AVFs as starting access were also more likely to start patients on a PD catheter. This suggests that there is a real need to ensure all renal units have the availability and resource to place appropriate permanent dialysis access in a timely manner for all patients	
09	Baxter Healthcare Ltd	Effective management of patients switching between modalities, temporary transfers and the management of failing transplant patients transition to dialysis	In line with the suggested are for quality improvement above, patients changing modality should also be as planned as possible to avoid the requirement to start dialysis without adequate preparation. This should also be extended to those patients whose transplant is failing and an expected requirement for an alternative RRT is anticipated within 12 months.	Regular review of all patients RRT requirements is not currently routine practice in English renal units	Renal Association Guideline Post-operative Care of the Kidney Transplant Recipient. February 2011
10	Baxter Healthcare Ltd	Multidisciplinary Team (MDT) approach to patient management to include dietician, psychologist, pharmacist, doctor nurse social worker and patient	It is accepted in the renal community (British Renal Society (BRS) and Renal Association) that the MDT approach in renal care is essential.	The BRS is currently assisting in the development of the content of the renal section of the Skills for Health workforce planning website. There is a joint project between the Department of Health and Skills for Health to look at the workforce planning issues within renal services and should be considered as part of these quality standards.	http://www.britishrenal.org/Workforce-Planning.aspx
11	Baxter Healthcare Ltd	Regular and frequent data capture for all dialysis patients	The UK Renal Registry (UKRR) continues to provide a national source of NHS healthcare data on patients dependent on renal	This data collection should continue to expand and there is a huge opportunity for its accuracy and quality to improve as dialysis	

ID	Stakeholder	Key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
		including those that are outside of the acute setting (telehealth)	replacement therapy (RRT).	devices are linked to on-line data collection and patient management mechanisms.	
12	British Kidney Patient Association	Preparation and Choice All people approaching end-stage renal disease, or moving from one type of treatment for end-stage renal disease to another, understand and are given sufficient time and support to prepare for a treatment that is suitable for them, chosen from the full range of options.	People with end-stage renal disease (ESRD) do not currently have access to the full range of treatments on a consistent basis. Where possible, all suitable patients must be pre-emptively listed or transplanted. Instead, access to pre-emptive transplantation, either from a living or cadaveric donor, is influenced by location. There is also variation between units in their approach to home haemodialysis, self-care dialysis, acute peritoneal dialysis (PD) and assisted PD. Late referral for RRT to renal units is a major and avoidable cause of poor outcome. The rate of late referral has reduced since 2006, but has however changed little since 2009. It remains highly variable across the UK, with more than 30% referred late, within 90 days of commencing renal replacement, in a number of centres.	Data from the UK Renal Registry indicate that, in 2011, 20% of new renal replacement therapy patients were treated with PD. However, the proportion treated with PD in individual renal centres ranged from 0% to 47%, and was less than 10% in several units. The institutional factors that underlie much of this inequity and restrict patient choice need to be highlighted and tackled. All appropriate treatments must be available to all patients irrespective of where they live, so that they can select the option that best meets their clinical and lifestyle needs. Sufficient time is required to prepare for renal replacement therapy (RRT). Whilst some late referrals will be unavoidable, closer working and better communication between primary and secondary care will help minimise these and reduce unwarranted geographic variation. Preparation for RRT is an exemplar for shared decision making and requires the involvement of an appropriately skilled multi-professional team, including doctors, nurses, dieticians, pharmacists and social workers.	Kidney Health: Delivering Excellence http://www.britishrenal.org/getattachment/Kidney-Health/Kidney-Health-Delivering-Excellence.pdf.aspx Renal Association 2012. The UK Renal Registry 15th Annual Report (http://www.renalreg.com/Reports/2012.html) National Institute for Health and Care Excellence 2011. Peritoneal Dialysis in the treatment of stage 5 chronic kidney disease (http://www.nice.org.uk/nicemedia/live/13524/55517/55517.pdf) Fluck, R., Pilcher, D. and Steenkamp, R. 2012. Vascular Access Report. UK Renal Registry and NHS Kidney Care (http://www.renalreg.com/Reports/2012.html)

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				The multi-professional team also have an important role in ensuring that any transitions of care experienced by kidney patients are smooth. Patients are at their most vulnerable when moving from one treatment type to another. This can be compounded by a loss in continuity and communication, as the clinical team providing the care within the kidney unit may change simultaneously. Renal units must ensure that effective systems of handover are in place so that patients are clear who their key points of contact and support are. People with existing kidney disease, particularly those who have experienced transplantation or dialysis, can all be part of the multi-professional team - peer support for newer patients is very important and helpful. Access to other kidney patients, especially when considering choices of treatment, should be supported and made possible by all renal units. Many people with ESRD will experience more than one treatment type during their lifetime. It is important that decisions to choose a particular treatment are not seen in all-or-nothing terms. Discussions with patients should emphasise, where relevant, a longer term approach, where	

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				treatment types are seen as complementary rather than competitive. The advantages or disadvantages of the various sequences and combinations should be considered in the shared decision-making process, and consideration given to the preferential use of pre-emptive transplantation over any dialysis where this is possible, and of peritoneal dialysis over haemodialysis in those with significant residual kidney function and without significant co-morbidities. The needs of patients and their options for treatment should be regularly reviewed with the multi-professional team. Proven aids to decision making can enhance (not replace) time spent with the healthcare team. Kidney services have been at the forefront of developments in shared decision making and the use of patient decision aids. A programme of multidisciplinary research, co-designed by patients, will provide us with the best information on how healthcare professionals should support patients when they are making decisions about their treatment for ESRD. Whilst early referral is a pre-requisite, good practice within renal units is vital to ensure a good	

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				transition onto renal replacement. There is evidence that shows outcomes are less good in patients starting haemodialysis via a central venous catheter. However in 2011 only 43% of patients commenced haemodialysis with definitive vascular access, and significant variation between centres was apparent. This is not explainable solely on the basis of referral practices: the need to provide a flexible, dynamic access service for both haemodialysis and peritoneal dialysis should be regarded as a key target for improvement within renal units. Patients with ESRD who are referred late to renal services must not be disadvantaged compared with those referred early; they must be offered the same information, education and choices, and have access to an expedited service for definitive vascular access or PD catheter insertion.	
13	British Kidney Patient Association	Lifestyle on dialysis - People should receive all of the information and education they require to engage fully in the planning and delivery of their dialysis, and are supported to	Many patients have raised concerns that dialysis treatment was being provided with too little involvement of the patient in their care. Treatment has a major impact on patients' lifestyles and personal ambitions. It is essential that these lifestyle needs are considered when managing dialysis. Adherence to treatment is closely linked to the way it is	Whilst the level of involvement desired by patients will vary, support for the engagement of patients in their own care is frequently inadequate and not offered proactively. Encouraging patients to be involved in their treatment should also promote greater uptake of self-care dialysis, which includes peritoneal dialysis,	Kidney Health: Delivering Excellence http://www.britishrenal.org/getattachment/Kidney-Health/Kidney-Health-Delivering-Excellence.pdf.aspx NHS Kidney Care 2012. Patient Transport Audit (http://www.kidneycarematters.nhs.uk/i/assets/Kidney%20Patient%20Transport%20Audit%202012%20-%20Web%20Version.pdf)

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		minimise the detrimental impact of treatment on their lifestyle and to self-care if they wish.	provided.	home haemodialysis and self-care haemodialysis within dialysis units. There are clear benefits of self-care dialysis for those that choose it related to freedom, lifestyle and control. There is evidence that older people may find peritoneal dialysis less intrusive than haemodialysis despite longer treatment times. There are barriers to self-care including a lack of understanding and fear of social isolation but these can be overcome by educational interventions. Dialysis for end-stage renal disease (ESRD) is life-saving but also intrusive, demanding and, unless the patient receives a successful kidney transplant, continues until the end of life. Home dialysis should be an available option for any patient who is clinically suitable. Patients may wish to exercise this choice after some time on a different type of treatment. Minimising the impact of dialysis on lives, enabling patients to continue to work, care for children or other family members, and travel is fundamental. For some patients, psychological support is needed and may help patients to continue dialysis if they wish to do so. The lifelong nature of treatment means transport to dialysis sessions in hospital is much more than a	McLaughlin, K., Jones, H., VanderStraeten, C., Mills, C., Visser, M., Taub, K., & Manns, B. 2008. Why do patients choose self-care dialysis? *Nephrol.Dial.Transplant.*, 23, (12) 3972-3976 Brown, E.A., Johansson, L., Farrington, K., Gallagher, H., Sensky, T., Gordon, F., Da Silva-Gane, M., Beckett, N., & Hickson, M. 2010. 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.*, 25, (11) 3755-3763 McLaughlin, K., Manns, B., Mortis, G., Hons, R., & Taub, K. 2003. Why patients with ESRD do not select self-care dialysis as a treatment option. *Am.J.Kidney Dis.*, 41, (2) 380-385 Manns, B.J., Taub, K., VanderStraeten, C., Jones, H., Mills, C., Visser, M., & McLaughlin, K. 2005. The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney Int.*, 68, (4) 1777-1783

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				convenience. Patient transport is an essential part of the patient experience. Poor transport can undermine good dialysis care and have a major impact on patients' quality of life. The 2012 Kidney Patient Transport Audit showed that two-thirds of patients who travelled for haemodialysis did so using hospital transport. While it indicated improvements in transport arrangements since the previous audit in 2010, around one-third of users reported delays of more than 30 minutes in pick-up times on outward and return journeys and journey times of over 30 minutes each way, caused by multiple pick-ups or drop-offs. In some cases, 45 minute journeys could take up to two hours. Transport must be an integral part of dialysis care and must be organised in a patient-focused way. Funding for patient transport should be clearly identified and detailed specifications, to which patients have had the chance to contribute, should be included within any transport contract.	
14	British Kidney Patient Association	Access to Allied Services	All people with kidney disease should know about, and have access to, a specialist multi-professional team. Specialist allied healthcare professionals play a vital role in advising, treating and supporting	People with advanced kidney disease need individualised care plans that include guidance on many lifestyle and medical factors, which can include fluid intake, diet, anaemia management, treatment of	Kidney Health: Delivering Excellence http://www.britishrenal.org/getattachment/Kidney-Health/Kidney-Health-Delivering-Excellence.pdf.aspx Evidence gathered at Kidney Health evidence gathering meeting held in

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			people with kidney disease to achieve better medical outcomes and quality of life. However, many people are not informed about the help that these practitioners offer and are frequently unaware of the psychological and social support services that should be available to them. Access to allied services is inadequate, inconsistent, and is not always coordinated with other aspects of kidney care.	chronic kidney disease (CKD) mineral bone disorder, and assessment for suitability for transplantation. Expertise in the medical, surgical, nursing, dietetic, pharmacological, psychological and social issues unique to these patients is essential. This care can only be provided through a multi-professional team of specialists, rapidly able to shift and coordinate care as the patient's needs change. For some of these areas, a proportion of this need is still met by voluntary organisations; this is not sustainable.	London on 18th June 2013 The British Kidney Patients Association (BKPA) Commitments 2013. (http://www.britishkidney-pa.co.uk/images/stories/downloads/BKPA_Commitments.pdf)

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15	British Kidney Patient Association	Person-centred care, taking into account individual needs and preferences, quality of life, symptom burden and the presence of co-existing medical conditions	Many factors other than clinical performance are important to patients. Person-centred care is the delivery of a system of care that takes into account the individual needs and preferences of the patient and their family/carers. Patient needs include clinical needs, but often are more holistic in nature, and must be seen in the context of an individual's ethnicity, religion and culture, as well as their lifestyle.	Quality of Life (QOL) is increasingly seen as an important marker of the quality of care in the management of long term conditions. The extent to which patients' perceived physical and mental functioning are affected on a day to day basis by a chronic disease is an especially important marker of care in the management of kidney disease, where even with the best treatment options available, there can be a significant reduction in patients' sense of well-being. QOL is significantly reduced in advanced CKD across all treatment types and strongly associated with both hospitalisation and mortality. People with advanced kidney disease (both pre-dialysis and dialysis) experience a wide range of disease and treatment-related physical and emotional symptoms which will contribute to this marked impairment in QOL. Where beneficial treatments for quality of life are available, care is not applied consistently.	Kidney Health: Delivering Excellence http://www.britishrenal.org/getattachment/Kidney-Health/Kidney-Health-Delivering-Excellence.pdf.aspx Wyld, M., Morton, R.L., Hayen, A., Howard, K., & Webster, A.C. 2012. A systematic review and meta-analysis of utility-based quality of life in chronic kidney disease treatments. *PLoS.Med.*, 9, (9) e1001307 Mapes, D.L., Lopes, A.A., Satayathum, S., McCullough, K.P., Goodkin, D.A., Locatelli, F., Fukuhara, S., Young, E.W., Kurokawa, K., Saito, A., Bommer, J., Wolfe, R.A., Held, P.J., & Port, F.K. 2003. Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int.*, 64, (1) 339-349 Abdel-Kader, K., Unruh, M.L., & Weisbord, S.D. 2009. Symptom burden, depression, and quality of life in chronic and end-stage kidney disease. *Clin.J.Am.Soc.Nephrol.*, 4, (6) 1057-1064
16	Royal College of Nursing	Nurses caring for people with renal condition were invited to comment on the proposals. There are no comments to submit on behalf of the Royal College of Nursing at this stage.			
17	National Kidney Federation (NKF)	Patient Transport to Haemodialysis	For those patients that require it, transport is an essential component of a 'dialysis day' – patients have six journeys per week. Good patient transport enables a good experience	Variation across the country exists and we would like to see continuity in a service which provides a valuable element to the treatment, especially for the more vulnerable	NICE Quality Statement: Patient Transport (2011) NHS KC Transport Audit 2012

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			of haemodialysis and leads to a good quality of life, this is where patients are picked up from home and delivered to the dialysis unit on time and picked up and delivered home on time. Bad patient transport includes lateness, non-arrival and unsuitable transport.	patients.	UK Renal Registry Renal Association Clinical Practice Guideline: Haemodialysis (audit measure 2)
18	National Kidney Federation (NKF)	Access to Home Therapy	Home Therapy presents a valuable option for those patients seeking a dialysis option that allows more flexibility than Hospital or Satellite Unit based haemodialysis – allowing greater quality of life, and enabling patients to continue with working. Home Therapy includes all types of Peritoneal Dialysis (PD) and Home Haemodialysis (HHD). HHD provides the opportunity for some patients to undertake nocturnal HD and with its' increased hours can lead to significant clinical benefits. Home Therapy presents an opportunity for cost savings for both Trusts and CCG's, and has the potential to increase capacity.	Variation currently exists across the country and does not appear to reflect geography and is perhaps based upon the population mix or a perceived 'bias' to one dialysis modality over another. It is important that all patients have equal access to the opportunity of having Home Therapy. While many patients enjoy the benefits of being cared for together with the social atmosphere often reported patient requirements change over time influenced by personal circumstances and a viable home option should always be available when the patient wishes. The NKF held a Home Dialysis Summit in 2013 and finding from the summit are available to read provided in the link attached. Within this area there are also concerns about the variation in Home Dialysis reimbursement in terms of electricity, heating and	The Atlas of Variation for Kidney Disease 2012 NKF Home Dialysis Manifesto http://www.kidney.org.uk/documentlibrary/Home_Dialysis_Report.pdf

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				water.	
19	National Kidney Federation (NKF)	Improving the Live Donor Pathway	While the Living Donor programme in England is to be praised problems reported to us as an organisation singularly relate to the length of time for the 'work-up' for transplant. Patients will often know in advance they have a failing kidney and within twelve to eighteen months will be requiring a transplant however the process for testing, cross-matching, and communicating results can often be frustratingly slow.	Living Donation is a key source for kidney transplants in the UK, providing increased opportunity for pre-emptive transplantation which is largely recognised as the gold standard treatment for End Stage Renal Failure. If patients can be kept off dialysis then their long-term health outcomes are improved and the need for dialysis is avoided.	A07 Renal Transplant Specification
20	National Kidney Federation (NKF)	Access to Dialysis Away From Base (DAFB)	DAFB provides essential opportunity for patients to have a holiday, visit friends/family, participate in work/college commitments all things that aid quality of life, but it also provides essential respite for the carer/family.	While many patients do enjoy the benefits that DAFB allows there are continuing problems largely associated with capacity issues particularly at 'popular' UK holiday destinations; elsewhere patients are often left frustrated by the lack of opportunity available and there is a commonly held belief that some units are not always transparent about what capacity exists.	NHS England are currently preparing policy guidance due for adoption Summer 2014.
21	National Kidney Federation (NKF)	Psychological/Social Support	For CKD patients requiring RRT adjustment to treatment, managing existing comorbidities, managing finances and perhaps losing employment then applying for benefits can be extremely difficult – living with a long term health condition is very hard both mentally and financially for many patients, the two issues are very much interrelated.	Again variation exists across the country in terms of access to psychological or social support; where it does exist there is sometimes limited access or the service is in a state of flux due to financial pressures. However the benefits to patient/carers from this service should not be underestimated in terms of quality of life, concordance with treatment,	The Joseph Rowntree Foundation 2007: Long Term Ill Health, Poverty and Ethnicity.

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				reduced burden of treatment for instance.	
22	NHS ENGLAND	Equity of access to options for renal replacement therapy	Transplantation is (for those who are fit enough) felt to be the gold standard therapy for ESRF. Home based therapies also 1) improve medical outcomes - high dose HD 2) enhance patient experience 3) are more cost effective	Home based dialysis therapies are endorsed with existing NICE guidance, yet overall use across England with marked variation between centres cannot be explained by variation in population. Rates vary from <5-35% by renal centre. This needs to be integrated with equitable transplant provision and organisation to reduce unwarranted variation in transplantation rates (see Transplant CRG submission)	UK Renal Registry reports at www.renalreg.org Kidney Health: Delivering Excellence report available at www.britishrenal.org
23	NHS ENGLAND	Patient participation	Participation in planning and providing care is essential for individuals with long term conditions.	Shared decision making - a new area that needs development. Existing tools are untested and there is a need to educate the workforce in the methodology whilst also measuring benefit Shared care for in centre haemodialysis - a number of centres around the UK have tested this model, based on international work. This may allow individuals to access high dose HD in centre (see above) Data and information sharing - Renal Patient View is an exemplar in this field but could be enhanced by providing two way interaction and using as vehicle to deliver PREM and PROM collection - see below.	Renal Patient View - renalpatientview.org - currently 33000 patients are signed up and 48/52 centres in England are offering it to patients, but with variable take up

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24	NHS ENGLAND	Safety	Renal replacement therapies are potentially complicated procedures with risk to the individual.	Infection is an important complication of RRT - transplant and dialysis - there are data on MRSA, MSSA, EColi and CDT for dialysis, but no data for equivalent risks in Transplant. NHSBT do collect data on cancer and ?CMV in transplant population. There is a need to develop a wider suite of safety measures within renal centres.	Trigger Tool for HD - Maarten Taal at Royal Derby Hospital Bacteraemia in dialysis population - UK Renal Registry reports NHS BT data
25	NHS ENGLAND	Quality measures	Underpins any quality improvement strategy	Renal Registry collect survival data and laboratory data for patients in renal centres in UK. No agreed data set for patient related outcomes - need to develop PROMS and PREMS and test them.	UK Renal Registry
26	NHS ENGLAND	Conservative care	The option of not having dialysis when someone reaches end stage renal failure is an important choice for many individuals who have high levels of comorbidity and little evidence of benefit from dialysis therapy.	There is no agreed definition of conservative care and hence no systematic data collection to support a knowledge base around this option. There is a need to consider a better definition, and to separate the debate about conservative care from end of life care.	
27	NHS ENGLAND	When to commence RRT?	Risk and benefit are poorly defined when considering when to start RRT - preemptive transplant or dialysis	There is a need to provide consistent guidance to support patients and clinicians in the timing of renal replacement therapy. Current systems tend to be based around estimated GFR, but these fail to take into account symptomatology, trajectory, planning of options etc	UK Renal Association standards UK Renal Registry data on eGFR at start of dialysis

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28	NHS ENGLAND	Unplanned RRT starts	Individuals who commence dialysis in an unplanned way have higher morbidity and mortality and reduced access to home therapies and transplantation	There is a need for consistent terminology to allow appropriate measures to be designed.	UK Renal Registry Report data on late presentation - note this is not the same as 'unplanned start'.
29	NHS ENGLAND	Appropriate access to the kidney transplant list	Kidney transplantation is the best form of renal replacement therapy for medically suitable patients	Renal Registry data shows that there is a variation in the percentage of dialysis patients who are on the transplant list	The latest Renal Registry Report is available at http://www.renalreg.com/Reports/2012.html
30	NHS ENGLAND	Timely access to the kidney transplant list	Pre-emptive kidney transplantation is recommended with NICE quality standards	Renal Registry data shows that there is centre variation and patients in referring renal units taking longer to be listed than those in transplant centres	The latest Renal Registry Report is available at http://www.renalreg.com/Reports/2012.html
31	NHS ENGLAND	Consistent evidence based acceptance criteria for deceased donor organs	Earlier transplantation reduces time on dialysis which impacts upon patient quantity and quality of life	NHSBT data shows centre variation in acceptance criteria and this impacts upon patient waiting time for a transplant	Centre waiting times are available at http://www.organdonation.nhs.uk/statistics/centre-specific_reports/kidney_centre-specific_reports.asp
32	NHS ENGLAND	Long term graft and patient survival	Good long term graft and patient survival improves patient quality and quantity of life	There is a shortage of organs for transplant and it is important to maximise patient and graft health	Centre 1 and 5 year graft and patient survivals are available at: http://www.organdonation.nhs.uk/statistics/centre-specific_reports/kidney_centre-specific_reports.asp
33	Clinical Reference Group for Renal Dialysis	Rate of renal transplantation per million population	Renal transplantation offers the best quality of life for patients with CKD 5. It offers a survival advantage compared to patients who are on the transplant waiting list but remain on dialysis. It is substantially cheaper to care for patients with successful transplants compared to dialysis treatment.	There is evidence of different rates of renal transplantation per million populations in England. The rate is greatly influenced by the rate of retrieval of cadaveric organs. But prompt work up for placement on transplant waiting lists and the processes for identification of live donors is principally performed in renal units, rather than transplant	NHS Atlas of Variation NHS-BT website statistics UK Renal Registry, Nephron Clinical Practice 2013 Vol 125 Issue 1-4. See Service Specifications: A06/S/e Assessment and Preparation for Renal Replacement Therapy (including establishing dialysis access) A06/S/C

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				units.	Peritoneal Dialysis to treat established renal failure A06/S/a In centre haemodialysis (ICHD): main and satellite units Renal Association Clinical Practice Guidelines http://www.renal.org/Clinical/GuidelinesSection/Guidelines.aspx
34	Clinical Reference Group for Renal Dialysis	For patients with severe and progressive chronic renal failure to be involved in shared decision making regarding conservative care versus the various options for renal replacement therapy (RRT). To increase the number of patients starting RRT electively with permanent access. To increase the number of patients starting RRT by transplantation.	To ensure informed patient choice. Starting dialysis treatment either as an emergency without prior preparation or with temporary haemo-dialysis access is associated with poorer outcomes. If patients have chosen peritoneal dialysis then they should start dialysis with this modality. For transplantation advantages see above.	There is evidence of different rates of renal transplantation prior to the need to start dialysis per million populations in England. The proportion of patients who start dialysis with peritoneal rather than haemodialysis vary from approximately 3 to 53% in England it is not likely that this is all explained by case mix or patient choice. Renal shared decision making aids are used inconsistently in England.	NHS Atlas of Variation NHS-BT website statistics UK Renal Registry, Nephron Clinical Practice 2013 Vol 125 Issue 1-4. See Service Specifications: A06/S/e Assessment and Preparation for Renal Replacement Therapy (including establishing dialysis access) A06/S/C Peritoneal Dialysis to treat established renal failure Renal Association Clinical Practice Guidelines http://www.renal.org/Clinical/GuidelinesSection/Guidelines.aspx http://sdm.rightcare.nhs.uk/pda/established-kidney-failure/ http://sdm.rightcare.nhs.uk/pda/established-kidney-failure-dialysis/ http://sdm.rightcare.nhs.uk/pda/established-kidney-failure-transplant/
35	Clinical Reference Group for Renal Dialysis	To ensure patients are informed and involved in their care.	There is substantial evidence that clinical outcomes are improved in many areas of medical care the more patients are involved in	Proxy indicators of “patient engagement” vary in England. Such proxy indicators include the proportion of patients who are able	See Service Specification A06/S/a In centre haemodialysis (ICHD): main and satellite units

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		Wider adoption of patient reported outcome measures.	managing their chronic illness. There is circumstantial evidence that this is the case in the setting of chronic haemodialysis.	to undertake a minimum of 5 tasks related to their haemodialysis treatment independently as well as the proportion of patients with access and instruction in the use of Renal Patient View. Renal Patient View is an on line system that gives patients access their blood results and in some units other relevant information. The use of patient reported outcomes is inconsistent in England	Clin J Am Soc Nephrol 5: 2024 –2033, 2010. doi: 10.2215/CJN.01620210 Renal Association Clinical Practice Guidelines http://www.renal.org/Clinical/GuidelinesSection/Guidelines.aspx
36	Clinical Reference Group for Renal Dialysis	For all clinically suitable patients to have option of having home based treatments, either peritoneal or home haemo-dialysis	To ensure informed patient choice. There is good evidence that home dialysis therapies (both peritoneal and haemodialysis) offer advantages for suitable patients.	The proportion of prevalent patients who have peritoneal rather than haemodialysis vary from approximately 0 to 24% in England it is not likely that this is all explained by case mix or patient choice. The proportion of prevalent patients who have home haemodialysis rather than in-centre haemodialysis ore peritoneal dialysis vary from approximately 0 to 11% in England it is not likely that this is all explained by case mix or patient choice.	See Service Specifications: A06/S/b Haemodialysis to treat established renal failure performed in a patients home A06/S/C Peritoneal Dialysis to treat established renal failure Renal Association Clinical Practice Guidelines http://www.renal.org/Clinical/GuidelinesSection/Guidelines.aspx
37	Clinical Reference Group for Renal Dialysis	To reduce delays in transfer to a renal unit from for treatment of AKI.	The incidence of AKI requiring intermittent HD is not known in England as most published data comes from single centres. As a consequence of this lack of data, the cost to the health service is not exactly known, but it has been estimated that treating all AKI costs	Despite the severity and frequency of AKI, treatment is often less than good. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) AKI enquiry, which was confined to patients who had died with AKI, highlighted that 20% of cases of AKI developing in	A06/S/d Renal dialysis – Intermittent Haemodialysis and Plasma Exchange to treat Acute Kidney Injury Health Service Journal Supplement, 23/06/2011. Renal Association Clinical Practice Guidelines

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			the NHS between £434 and £620 (millions) per annum The cost for dialysis will be a significant fraction of this estimated cost. These patients have a high mortality rate.	hospital were predictable and avoidable, and that 50% of patients received care that was considered to be less than good.	http://www.renal.org/Clinical/GuidelinesSection/Guidelines.aspx
38	NHS England Patient Safety Division	Safety of water supply in Haemodialysis units	After a fatality in 2008 we produced a Rapid Response Report related to safety of water supply in haemodialysis units	Whilst the Rapid Response Report was developed before NPSA processes were NICE accredited, we suggest it is used in QS development discussions as a reminder of the importance of safety as well as effectiveness in the delivery of high quality care	The Rapid Response Report can be found at http://www.nrls.npsa.nhs.uk/resources/?EntryId45=59893
39	NHS England Patient Safety Division	Safety of Continuous Renal Replacement Therapy.	After a recent fatality, we produced an Alert relevant to risk of hypothermia in Continuous Renal Replacement Therapy.	Whilst the Alert has been developed under new NHS England processes which are not yet NICE accredited, we suggest it is used in QS development discussions as a reminder of the importance of safety as well as effectiveness in the delivery of high quality care	The Alert can be found at http://www.england.nhs.uk/wp-content/uploads/2014/02/hypothermia.pdf
40	SCM1	Vascular Access for Haemodialysis (HD)	"The safety of dialysis patients while hospitalised with vascular complications of their disease requires special consideration in the commissioning of dialysis services".	The UK Renal Registry Report 2012 found wide variation in the care and survival rates of vascular access in haemodialysis patients, i.e interventions, timeliness of interventions and timely identification of complications. Standardisation of care and appropriate placement of patients	Please see the UK Renal Registry 2013 Report at www.renalreg.com

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				(on Renal wards as opposed to General wards) is crucial to ensure high quality care	
41	SCM1	Renal Transplantation	Survival rates of Kidney Transplantation is recommended within NICE guidance, Renal Association Standards and the Renal NSF. The criteria for referral would normally be a rise in Creatinine, based on the Renal Association standards	Renal Transplant patients developing AKI (Acute Kidney Injury) and ATN (Acute Tubular Necrosis) on Renal Wards and General Wards is increasing with a number of late referrals resulting in loss of allograft. There needs to be specific criteria for the care of the post operative Transplant patient to ensure early identification.	Please see Renal NSF at www.dh.gov.uk Please see the UK Renal Registry 2013 Report at www.renalreg.com Please see Post-operative care of the kidney transplant recipient. The Renal Association (2011).
42	SCM1	Renal Transport	Renal NSF recommends access to Haemodialysis treatment within 30 minutes	Delays in access to Haemodialysis Treatment is mainly due to a lack of special contracting for transport for Haemodialysis patients. In most centres, providers contract renal transport within the central hospital contracting without due consideration for the specialist needs of Renal patients. This needs to be within specialist commissioning with direct reporting arrangements to be held within Renal Directorates of hospitals/centres providing Haemodialysis	Please see the Merseyside Report-2007 Please see Renal NSF at www.dh.gov.uk
43	SCM1	Haemodialysis and Vascular Access	Renal NSF recommends maintaining vascular access in order to ensure timely and optimum Haemodialysis treatment	The UK Renal Registry Report (2010, 2011, 2012, 2013)shows a wide variation of access survival in different centres. One of key reasons noted has been a variation in needling practicesd with no	Please see Renal NSF at www.dh.gov.uk Please see the UK Renal Registry 2013 Report at www.renalreg.com

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				specific competencies in most centres. As part of the current revalidation agenda all haemodialysis nurses should be competency assessed to ensure standardisation of practice and better access survival rates.	
44	SCM2	Patients requiring RRT are managed as close to home as possible	Many patients are managed in HD units a long distance from their homes, requiring long journeys via patient transport. Ideally they should have RRT services as close to home as possible which would reduce travelling time, costs and stress on the patients.	Problems relating to transport to and from dialysis units is a constant theme in the trusts I work for non-clinical incident reports. Delayed pick up from home/unit leads to delayed treatments and extra costs in staff time.	CKD QS
45	SCM2	Patients requiring RRT have their medications reviewed and updated on a regular basis and are given support to ensure that their medicines are optimised to suit their individual needs.	Satellite dialysis patients are often neglected in terms of medication review. Reasons given for this are that the patients do not wish to visit the GPs (they are already in a "hospital environment enough (3xweek)". The GPs do not wish to alter the patient's medicines due to fear of it affecting dialysis or vice versa.	There is potential for other healthcare professions working in renal medicine to act as a liaison between the GPs, community pharmacists and consultants to optimise the medication treatment regimens in this "outpatient setting". This would improve adherence, and communication as well as ensuring cost effective use of medicines.	NICE medicines adherence CG76 Kidney Health: Delivering excellence.10/2013
46	SCM2	Patients requiring RRT are reviewed regularly by an MDT to help optimise their treatments and proactively manage	Maintaining health of patients needing a RRT requires a MDT approach. Preventing raised phosphate, managing anaemia, ensuring appropriate protein intake will all help reduce complications associated with RRT and improve	Across the UK there is a variation in what is deemed an MDT approach. Not all RRT patients have access to specialist pharmacist's, dieticians, physiotherapists, social workers, and counsellors. Using specialist members of the team will improve	NICE Anaemia CG114 NICE Hyperphosphataemia CG157 Kidney Health: Delivering excellence 10/2013

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		conditions associated with RRT.	patient's quality of life.	the holistic care of the patient and quality of life.	
47	SCM2	Patients requiring RRT will have an agreed care plan and are supported to receive a kidney transplant if they are medically suitable	Patients on RRT do not always have an agreed plan and there are variations in practice across the country in regards to work up for transplantation leading to long unnecessary waits. Patients on PD are not always informed of the risks of ESP and therefore need to be informed of plans around reducing this from occurring and a realistic plan made.	Ideally a smooth pathway needs to be available in all units that guide the physician through each step of the transplant work up. Other specialities involved in the work up process, must also have pathways in place to expedite process to ensure RRT patients are not delayed form being activated on the transplant waiting list unnecessarily.	CKD Quality Standard
48	SCM2	Patients who require RRT are offered and supported to manage their treatment at home	Patients who dialyse at home do not require as many medications for RRT induced symptoms. Therefore HHD should be promoted. PD is a good treatment choice for those patients who wish to remain independent and do not want HD.	There is variation across the country on how treatments are offered to the local population leading to large variations in HD and PD numbers.	Kidney Health: Delivering excellence 10/2013 RA CPG Haemodialysis RA CPG Peritoneal dialysis.
49	SCM3	Patient transport for Haemodialysis patients to and from dialysis sessions	Quality of life.	Patients leave home 1.5 to 2.5 hours before they are put on the machines for dialysis and do not arrive home up to 2.5 hours after treatment ends. This results in patients being away from home for 8 to 9 hours per session. They have to endure this 3 times every week 52 weeks per year. Standards of transport differ from region to region	National renal patient transport surveys. Local performance figures available to Hospital Trusts from transport providers and supplied to commissioners. This data proves that patient transport is not meeting the need of patients.
50	SCM3	Patients holiday away from base unit.	Renal patients benefit from holidays and long weekend breaks. This would improve the quality of life for	Quality of life. Giving patients the chance to have a break from the routine would improve their health	We all benefit from holidays and weekend breaks.

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			patients.	and would help in reducing very many patients feeling depressed about their life.	
51	SCM4	Restricted transplant	Transplant restricted because of high levels of antibodies lowering probability of transplant from list.	Quality of life for dialysis patients much improved after transplantation. Dialysis does not remove all toxins with most premature ageing and declining health. Historic blood transfusions, pregnancies, transplants all help increase antibody level and lower probability of transplants without plasmapheresis.	Not much available as transplant surgeons do not tell patients a transplant from the pool is highly unlikely. The only probable transplant is from a live donor following plasmapherisis. Patients deliberately misled. http://www.bakpa.org.uk/livingkidneydonation.html
52	SCM4	Loss of kidneys	Loss of kidneys as liver transplants are prioritised over kidney transplants. Many Kidneys lost because families not approached.	If a change of management or increase in trained surgeons is widespread less viable kidneys will be lost.	The only evidence is surgeons talking over the decades as liver dies quicker and the operation is longer so is usually done first making the kidney un-viable.
53	SCM4	Vascular Access and buttonholes	Wide variations of good practice.	In some centres with challenging access patients have died who could have been saved in other areas. Infections of fistulas controlled badly as a new fistula in different area not an option or a fistula's life extended by using the buttonhole technique not available in some centres.	The lumps scare children and others creating patient isolation. Education of all fistula options between centres is variable, some hospitals more advanced than others and offer more solutions.
54	SCM4	Home dialysis cost reimbursement	(Better practice abroad) inter alia bedding washing) Blood leaks elec, water, carer allowance etc.	There is wide variation through the country and abroad and new evidence is showing that patients are nervous at home haemo dialysis as non reimbursed costs are a barrier.	This subject has widespread patient discussion regarding un-reimbursed costs and no standardised formulae for calculating reimbursement costs at different hospitals. Big patient issue in home HD.
55	SCM4	Dialysis education	Diabetes, better education for patients and carers, cause and	Dialysis education is insufficient. Some patients do not understand	Lack of patient education and understanding.

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			control.	protocol and “cheat” without immediate consequence building up worse future problems.	http://www.kidney.org.au/ForPatients/Management/DiabetesandCKD/tabid/704/Default.aspx