# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

# Guideline scope

# Renal replacement therapy and conservative care for people with chronic kidney disease

## *Topic*

NHS England has asked NICE to develop a guideline on renal replacement therapy (RRT), including conservative care and transplant.

This guideline will also be used to update the NICE quality standard for RRT.

The guideline will be developed using the methods and processes outlined in Developing NICE guidelines: the manual.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the context section.

## *Who the guideline is for*

- People using services, families and carers and the public.
- All healthcare professionals.
- Providers of RRT and conservative care.

It may also be relevant for:

- Private sector or voluntary organisations commissioned to provide services for the NHS or local authorities.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

### *Equality considerations*

NICE has carried out an equality impact assessment [add hyperlink in final version] during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to access to RRT and conservative care in rural areas, age, minority groups and social class.

# 1 What the guideline is about

## *1.1 Who is the focus?*

**Groups that will be covered**

- Adults (18 and over) with chronic kidney disease (CKD) stages 4 and 5.
- Children (under 18) with CKD stages 4 and 5.
- The following groups have been identified as needing special consideration:
  - Older people
  - Children under 2 years
  - People from black, Asian and minority ethnic groups
  - People with type 1 and type 2 diabetes
  - People who have RRT without previous planning.

**Groups that will not be covered**

- People with CKD stages 1–3 (except in the context of preparing for RRT).

## *1.2 Settings*

**Settings that will be covered**

- All settings where NHS commissioned care is provided to people who might need RRT (including care at home).

**Settings that will not be covered**

- RRT in intensive care (level 3) and high dependency units (level 2).

## *1.3 Activities, services or aspects of care*

We will look at evidence on the areas listed below when developing the guideline, but it may not be possible to make recommendations on all the areas.

**Key areas that will be covered**

1 Assessment for people with deteriorating renal function for whom RRT might be appropriate.
2 Information, education and support for people for whom RRT might be appropriate and their families or carers.
3 Decision-making with people for whom RRT might be appropriate and their families or carers, including the option of conservative care.
4 RRT and conservative care: which option for which person, when and how frequently.
5 Recognition of symptoms.
6 Fluid restriction and dietary management of, for example, sodium, protein and potassium.
7 Transferring between forms of RRT (for example, switching between in-centre and home dialysis).
8 Discontinuing RRT.
9 Coordination of care for people undergoing RRT or conservative care (for example, between different specialities involved in their care).

**Areas that will not be covered**

1 Management of CKD.
2 Management of acute kidney injury.
3 Anaemia in CKD.
4 Bone mineral disorder and hyperphoshataemia.
5 Symptom management (except recognition of symptoms).

6 Technical aspects of delivery of RRT – for example, dialysis prescription (except for frequency of sessions), creation and management of dialysis access, transplant surgery, transplant immunosuppression.
7 Management of growth in children with CKD.

## *1.4 Economic aspects*

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses primarily using an NHS and Personal Social Services (PSS) perspective.

## *1.5 Key issues and questions*

While writing this scope, we have identified the following key issues, and draft questions related to them:

1 When should people with progression to later stages of CKD be assessed for RRT?
2 What assessment is needed for people with deteriorating CKD for whom RRT may be appropriate?
3 What information, education and support is useful for people and their families or carers when considering or undergoing RRT or conservative care and when transitioning from one form of RRT to another or to conservative care?
4 How should decision-making be supported for people for whom RRT may be appropriate?
5 How should people be prepared for RRT or conservative care?
6 What is the most clinical and cost effective way of planning dialysis access formation, transplant listing and/or conservative care?
7 What is the clinical and cost effectiveness of each form of RRT?
8 Are there factors which suggest that certain forms of RRT may be more appropriate for certain groups of people?

9 What are the indicators (e.g. symptoms or symptom scores, biochemical or functional measures) for initiating RRT?
10 Are there groups of people in which conservative care is more appropriate than RRT?
11 What are the most important symptoms to recognise for people undergoing RRT or receiving conservative care?
12 What is the clinical and cost effectiveness of diet (for example, sodium, potassium and protein) and fluid management in people being prepared for RRT, undergoing RRT or receiving conservative care?
13 How frequently should people on the different forms of RRT be reviewed?
14 What is the most clinical and cost effective way of coordinating care during RRT or conservative care (for example, between different specialties involved in their care)?
15 What is the clinical and cost effectiveness of different sequences of RRT?
16 What are the indicators for transferring between the different forms of RRT?
17 What are the indicators for discontinuing RRT?

## *1.6 Main outcomes*

The main outcomes that may be considered when searching for and assessing the evidence are:

1 Health-related quality of life (for example, EQ-5D, SF-36)
2 Symptom scores and functional measures
3 Psychological distress and mental wellbeing
4 Patient, family and carer experience of care
5 Survival (mortality)
6 Growth
7 Malignancy
8 Adverse events
- infections
- vascular access issues

- dialysis access issues (for example, peritoneal dialysis catheter)
- hospitalisation
- family and carer outcomes
- time to failure of different forms of RRT
- acute transplant rejection episodes.

# 2 Links with other NICE guidance, NICE quality standards, and NICE Pathways

## *2.1 NICE guidance*

**NICE guidance that will be updated by this guideline**

- Chronic kidney disease (stage 5): peritoneal dialysis (2011) NICE guideline CG125
- Guidance on home compared with hospital haemodialysis for patients with end-stage renal failure (2002) NICE technology appraisal guidance TA48

**NICE guidance about the experience of people using NHS services**

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to RRT:

- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76
- Medicines optimisation (2015) NICE guideline NG5
- Transition from children's to adults' services for young people using health or social care services (2016) NICE guideline NG43

**NICE guidance that is closely related to this guideline**

***Published***

NICE has published the following guidance that is closely related to this guideline:

- Chronic kidney disease in adults: assessment and management (2014) NICE guideline CG182
- Chronic kidney disease: managing anaemia (2015) NICE guideline NG8
- Acute kidney injury (2013) NICE guideline CG169
- Chronic kidney disease (stage 4 or 5): management of hyperphosphataemia (2013) NICE guideline CG157
- Intravenous fluid therapy in adults in hospital (2013) NICE clinical guideline CG174
- Intravenous fluid therapy in children and young people in hospital (2015) NICE guideline NG29
- Tolvaptan for treating autosomal dominant polycystic kidney disease (2015) NICE technology appraisal guidance 358
- Machine perfusion systems and cold static storage of kidneys from deceased donors (2009) NICE technology appraisal guidance 165
- Cinacalcet for the treatment of secondary hyperparathyroidism in patients with end-stage renal disease on maintenance dialysis therapy (2007) NICE technology appraisal guidance 117
- Immunosuppressive therapy for renal transplantation in adults (2004) NICE technology appraisal guidance 85
- Guidance on the use of ultrasound locating devices for placing central venous catheters (2002) NICE technology appraisal guidance 49
- Acute kidney injury (AKI): use of medicines in people with or at increased risk of AKI (2016) NICE advice KTT17

***In development***

NICE is currently developing the following guidance that is closely related to this guideline:

- Faltering growth - recognition and management of faltering growth in children NICE clinical guideline. Publication expected October 2017.
- End of life care for infants, children and young people NICE clinical guideline. Publication expected December 2016.
- End of life care for adults in the last year of life: service delivery NICE clinical guideline. Publication expected January 2018.

- Kidney transplantation (children, adolescents) - immunosuppressive regimens (review of TA99) NICE technology appraisal. Publication date to be confirmed.
- Kidney transplantation (rejection) - everolimus NICE technology appraisal. Publication date to be confirmed.
- Multiple frequency bioimpedance devices (BCM - Body Composition Monitor, BioScan 920-II, BioScan touch i8, InBody S10 and MultiScan 5000) for fluid management in people with chronic kidney disease having dialysis Diagnostics guidance. Publication expected June 2017.

## *2.2 NICE quality standards*

**NICE quality standards that may need to be revised or updated when this guideline is published**

- Acute kidney injury (2014) NICE quality standard 76
- Renal replacement therapy services for adults (2014) NICE quality standard 72
- Chronic kidney disease in adults (2011) NICE quality standard 5

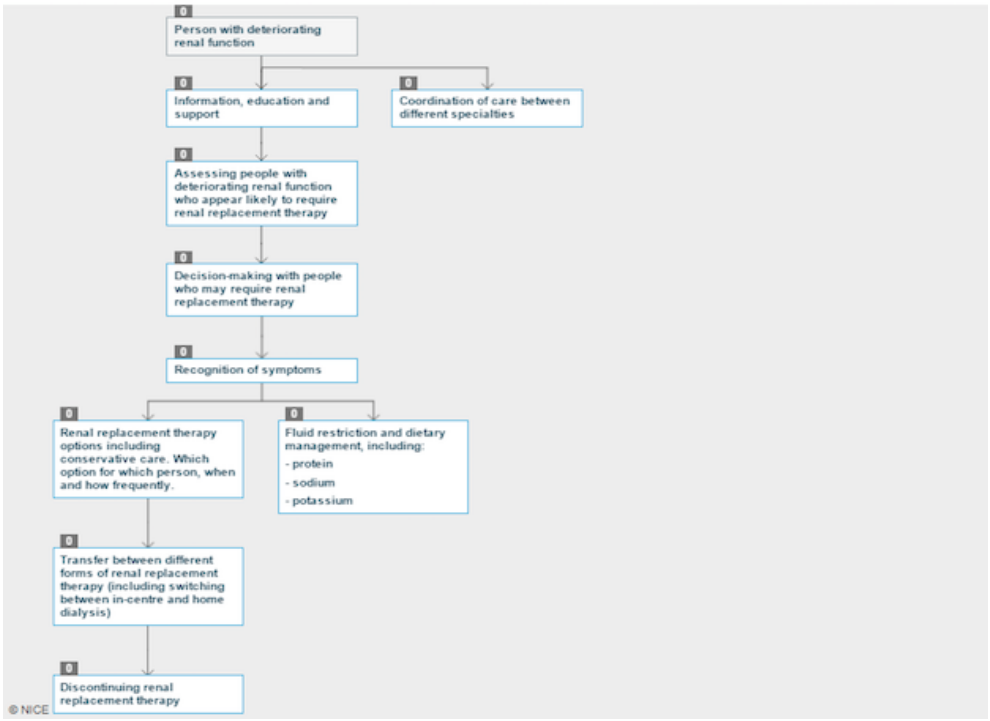
## *2.3 NICE Pathways*

When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive topic-based flowchart.

A draft pathway outline (overview) on RRT, based on the 'key areas that will be covered' section of this scope, is included below. The pathway outline highlights the levels of care provided for a person needing RRT. Each box will contain recommendations from the guideline related to that level of care. It will be adapted and more detail added as the recommendations are written during guideline development. Pathways provide topic guideline recommendations in an interactive flowchart and do not follow a care pathway structure.

This pathway will be integrated into the NICE pathway on kidney conditions and is relevant to the NICE pathway on chronic kidney disease.

Renal replacement therapy and conservative care for people with chronic kidney disease overview




# 3 Context

## *3.1 Key facts and figures*

The kidneys excrete certain waste products, excess water, acid and salts from the body. People with CKD have an irreversible and progressive decrease in kidney function. CKD (stages 3–5) may affect up to 4–5% of the adult UK population.

In 2% of people with CKD, the condition progresses to kidney failure, and RRT is needed for survival. RRT essentially comprises either transplantation or dialysis (artificially removing waste products and excess water from the blood). Transplantation can be from living or deceased donors, and for some people it may involve the transplantation of more than one organ simultaneously (for example, combined pancreatic and renal transplantation for people with type I diabetes mellitus). In some cases transplantation may be pre-emptive, occurring before the point at which dialysis would be needed. There are 2 main types of dialysis: haemodialysis (where the blood is filtered outside of the body using a dialysis machine) and peritoneal dialysis (where

the person's abdominal lining is used to filter the blood). A dialysis prescription details how to deliver dialysis optimally for each patient, given by a specialist for an individual depending on their preferences, fluid balance and other needs.

According to the 18th annual report by the UK Renal Registry (2015), on 31 December 2014 there were 27,804 adults in the UK receiving dialysis (and over 30,000 in receipt of a kidney transplant). Of these, 86.9% were on haemodialysis (44.0% in satellite units, 38.6% in hospitals, 4.3% at home), 5.8% were on continuous ambulatory peritoneal dialysis and 7.0% were on automated peritoneal dialysis. In addition, 190 children and young people under the age of 18 years were on dialysis (103 on haemodialysis and 87 on peritoneal dialysis). Reported 1- and 2- year survival rates for adult patients on dialysis were 85.0% and 72.1%, respectively, however survival rates for patients with diabetes on maintenance haemodialysis is significantly less than people who do not have diabetes. The median age of all people newly requiring RRT was 64.8 years, although this varied by ethnicity: 66.4 years for white people and 58.7 years for black people, Asian people and people from minority ethnic groups.

Approximately 5,500 adults and children are currently on the renal transplant waiting list (NHS Blood and Transplant), with about 3,000 renal transplants performed each year. The median time to transplantation for those on the national transplant list is around 1,000 days for adults and 300 days for children. The two Clinical Reference Groups for the specialised commissioned aspects of renal disease – renal dialysis and renal transplant - have produced service specifications on behalf of NHS England.

Some people choose not to receive RRT such as dialysis or transplant but continue to receive other supportive and symptomatic treatment for their end-stage kidney disease – for example, treatment for their anaemia or dietary modification. This is most commonly called conservative care. People may also receive end-of-life care, and this may include both supportive and palliative care.

RRT is an expensive treatment. The total cost of CKD in England in 2009–10 was estimated at £1.45 billion. Even though only 2% of people with CKD receive RRT, more than half of this sum was spent on RRT.

This guideline aims to improve the care of people with CKD who need RRT or conservative care of CKD. The guideline will cover the choice preparation for and switching between different forms of RRT for children and adults, as well as aspects of management and coordination of care.

### *3.2 Current practice*

Most people who have RRT are treated with haemodialysis. Within 90 days of starting RRT 66.3% of people are on haemodialysis, 19.1% are on peritoneal dialysis, 9.7% have a functioning transplant and 4.8% have died or stopped treatment.

Access to transplantation demonstrates considerable inequality across racial groups. There are relatively fewer numbers of black, Asian and minority ethnic groups on the organ donor list. These populations, however, have a higher incidence and prevalence of CKD needing RRT and they tend to reach this stage at a younger age.

The number of people receiving conservative treatment varies between renal units and has been difficult to establish, but up to 40% of patients aged over 70 choose this treatment option. Most of these people still receive their care and treatment through renal services.

## 4 Further information

This is the final scope, incorporating comments from registered stakeholders during consultation.

The guideline is expected to be published in October 2018.

You can follow progress of the guideline.

Our website has information about how NICE guidelines are developed.