Renal replacement therapy

Consultation on draft scope
Stakeholder comments table

03/08/2016 to 07/09/2016

ID	Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
1.	Baxter Healthcare	3	72	We are pleased to see the inclusion of "Ongoing care including transferring between forms of RRT (for example, follow-up and review, switching between in-centre and home dialysis)". Please could this section include guidelines for appropriate staffing levels? The NICE RRT Quality Standard recommended the importance of clinical champions for each modality and appropriate staffing levels, particularly for home based therapies. This is to ensure that staffing levels are adequate for patient training, on-going clinical management and support and timely transfer between modalities. Would the team also consider including consideration of Remote Patient Management (such as cloud-based, dialysis device-linked, on demand data systems) to assist clinical decision making for patients who are treated at home? Although these innovations are relatively new to the area of renal dialysis there is growing clinical opinion to suggest the use of that such technology might support clinical decision making and provide additional confidence for patients and clinicians in the initiation of home dialysis and transfer between treatment modalities. This could be particularly helpful in supporting patients to have a smooth transition and maintain them on a home treatment. *Kim et al. DOI: 10.1089/tmj.2015.0170*	Thank you for your comment. NICE clinical guidelines are unable to make recommendations on appropriate staffing level but may describe the competencies that are required. Service delivery aspects will not be specifically addressed in this guideline and it will up to local services to determine how their services are best configured to adopt this recommendations. Your comment will be considered by the guideline committee when they refine the review questions.
2.	Baxter Healthcare	4	104	In section 1.5 "Key issues and questions" point 4 covers "How should decision-making for people who may need RRT be supported?" Please could this section include the wider issues associated with choice of treatment such as staffing and dialysis capacity. For example a thorough assessment of the patient pathway is vital to ensure that the mechanisms are in place to allow patients to receive their preferred dialysis treatment of choice. For example, free capacity of in-centre haemodialysis stations may have a negative impact on patients likelihood of being offered home dialysis. Pre-planning access for dialysis may also impact choice of treatment. If there is no or limited capacity to insert PD catheters in a	Thank you for your comment. The guideline will address what should be offered to patients in the NHS based on evidence of clinical and cost effectiveness. Service delivery aspects will not be specifically addressed in this guideline and it will up to local services to determine how their services are best configured to adopt this recommendations.

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				timely manner, central venous catheters are frequently used to start dialysis in patients who have no permanent access, despite the risks associated with this method. *Mazonakis et al Hemodialysis International 2009; 13:6–10* *And* *Oliver et al. J Am Soc Nephrol 15: 1936–1942, 2004*	
3.	Baxter Healthcare	4	83	Point number 5 "Areas that will not be covered" includes "Technical aspects" of dialysis. Please could you confirm that this does include the frequency of dialysis? There is growing body of evidence, to demonstrate the adverse clinical impact of providing HD three times a week, due to the two day intradialytic gap. The impact of the two day gap covers patient's quality of life, symptom control, morbidity and mortality, all of which are important considerations for patients who are choosing a dialysis modality. *Fotheringham et al. Kidney International May 2015; doi:10.1038/ki.2015.141* In addition, we would also suggest that assisted dialysis services (PD and HHD) should also be included. Assisted PD is now a recognised dialysis modality which has an associated tariff and has been shown to benefit patients on both a long term and temporary basis. *Iyasere et al, Clin J Am Soc Nephrol 11: ccc–ccc, 2015. doi: 10.2215/CJN.01050115* *And* *Béchade et al. Perit Dial Int 2015; 35(6):663–666* *And*	Thank you for your comment. We have made it clearer what we are and are not including covering under this scope topic. Frequency of dialysis is included in the scope of this guideline. The scope topic does include mode of renal replacement therapy but the specific review question will be refined by the guideline committee.

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				Pierratos et al. Hemodialysis International 2016; DOI:10.1111/hdi.12476	
4.	Baxter Healthcare	4	85	In the section on Economic Aspects, we think it would be helpful to include wider service considerations such as patient transport to and from In-Centre Haemodialysis sessions. This not only has a huge impact on the patients' experience of the therapy, but it is also a significant cost to the NHS. Currently, transport costs are not paid directly by the hospital Trust/renal unit and so rarely considered in their business planning. However, with the prospect of co-commissioning dialysis services, this may become a factor in future decision making. We also feel that it is important to include the impact of supporting people to remain on a home therapy through the temporary use of assisted PD programmes in the health economic assessments. There have been studies to support this option on cost effective grounds. *Brown et al. Nephrol Dial Transplant (2007) doi:10.1093/ndt/gfm399* *And* *Oliver et al. Kidney International 2007; doi:10.1038/sj.ki.5002107*	Thank you for your comment and the references provided. All costs incurred by the NHS will be taken into account. A review of the published literature will be undertaken for all areas of the guideline and new analyses will be undertaken in selected areas that are prioritised by the GC during guideline development. Thank you for your reference. Any evidence from the reference provided that meets the review question protocol criteria will be presented to the guideline committee.
5.	British Association for Paediatric Nephrology	1	4 - 5	The title of the guideline could better reflect the scope detailed in the document. "Renal replacement therapy including conservative care" suggests a very wide ranging scope that could cover all aspects of RRT care. This is clearly not the case. The focus is on informed choice and the necessary preparations by the clinical teams and patient/family group to make those choices. It is commendable that children are included in the guideline and perhaps it could be	Thank you for your comment. The title of the guideline reflects the topics included in the scope. The scope topics reflect the discussions at the stakeholder workshop. They identify areas where there is variation in practice and/or areas of clinical uncertainty.

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				explicit in the title that this is for adults and children.	NICE does not include populations in the title where all populations are covered by the guideline in this case adults, young people and children are covered.
6.	British Association for Paediatric Nephrology	2	37	Patients with failed transplants returning to dialysis may be a special sub-group that need consideration, especially as many will be highly sensitized and are likely to remain on dialysis for a long time before a second transplant is possible.	Thank you for your comment. The transition of patients from failed transplant to another form of renal replacement therapy will be covered in the questions on transitions. This section of the scope is intended to identify groups for whom there will be special considerations throughout. For each review, the guideline committee will consider whether additional subgroups may be appropriate in order to make recommendations specific to those identified.
7.	British Association for Paediatric Nephrology	2	37	There is no prospective observational study in children <2 years age (leave alone an RCT) to guide decision making. We suggest that this subgroup is excluded from a guideline and that it may be better to consider this as a separate topic once the IKID (Nidus) study on infant haemodialysis has concluded.	Thank you for your comment. The guideline committee will look for evidence in this population and if none is identified, will, where appropriate, consider consensus or research recommendations.
8.	British Association for Paediatric Nephrology	2	39	Within the paediatric population, discussion about renal replacement therapy (RRT) often commences during CKD stage 3b, particularly if that relates to creation of an AV fistula for haemodialysis.	Thank you for your comment. We have edited the scope to make it clearer that people with CKD 1-3 may be included under the scope topic related to preparation for renal replacement therapy.

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9.	British Association for Paediatric Nephrology	2	39 43	It is encouraging that differences are recognised even within the paediatric population. While the guideline will not include additional recommendations on transition from paediatric to adult services where NICE guidelines (NG43) are already in place, young people in transition through renal services will have needs that may merit a Young Person focus on this overlapping age group.	Thank you for your comment. Where appropriate in the evidence reviews and if possible adult and child data will be evaluated separately. How these groups are defined will be discussed with the guideline committee. We have advertised for a paediatric nephrologist to be on the guideline committee.
10.	British Association for Paediatric Nephrology	3	60	Accepted practice in paediatric nephrology is to plan for pre-emptive transplantation where possible. We note that transplantation, unlike dialysis, is not mentioned as a specific form of RRT.	Thank you for your comment. We have edited the section 'context' to refer to a pre-emptive transplant. We have also made it clearer in this section that renal replacement therapy includes transplant.
11.	British Association for Paediatric Nephrology	3	60	Separate consideration for children with profound learning difficulties would be very useful.	Thank you for your comment. The 'special consideration' section identifies groups who may have needs specific to renal replacement therapy. Learning disabilities is a 'protected characteristic' under the Equality Act and will therefore be considered when making all of the recommendations.
12.	British Association for Paediatric Nephrology	3	66	The concept of choice in decision making about modality of RRT is different when the patient is a child too young to be Fraser-competent.	Thank you for your comment. The evidence will be reviewed separately for children and adults and different recommendations will be made where appropriate.

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13.	British Association for Paediatric Nephrology	3	70 - 71	Points 5 and 6 on symptom management and diet and fluid management are separate topics in themselves and hugely extend the remit of the guideline. Just as anaemia management or CKD-MBD management are (appropriately) excluded, we suggest that these are excluded too.	Thank you your comment. We agree that this topic is very large and we have made it clearer what we will be covering. The scope reflects the discussions at the stakeholder workshop and also where there is variation in practice or uncertainty regarding clinical practice.
14.	British Association for Paediatric Nephrology	3	75 - 77	The liaison with other specialties should include community/general paeds and school particularly for children with neurodevelopmental disability	Thank you for your comment. This is not an exhaustive list of specialties. We have provided a limited number of examples but community and general paediatrics will be considered by the guideline committee when reviewing this topic.
15.	British Association for Paediatric Nephrology	4	84	While management of growth in children with CKD will not be covered it is included as an outcome measure (page 5, line 137). Will this be dealt with by cross referencing to separate recommendations elsewhere on management of growth in children?	Thank you for your comment. We now refer to the NICE guideline currently in development on 'Faltering growth - recognition and management of faltering growth in children' under the section on 'related NICE Guidance' and will refer to this guidance where appropriate.
16.	British Association for Paediatric Nephrology	4	85	Economic plans should be made for specific scenarios: - Costs of assisted PD separately for children and adults - Costs of access formation (again, different in adults and children) - Costs of different dialysis modalities – HD, HDF, home HD, CAPD, CCPD, assisted PD - For all haemo modalities, cost of transport as well as dialysis needs	Thank you for your comment. Cost effectiveness will be considered for all areas of the guideline and will take into consideration all costs relevant to an NHS and PSS perspective including transport costs as appropriate. The impact of various modalities and their subtypes

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				considering - Consideration needs to be given to the need for increased frequency of dialysis for some children	will be taken into account in the clinical and cost effectiveness analysis. Where costs vary between adults and children this will also be taken into account. A review of the published literature will be undertaken and new analyses will be undertaken in selected areas that are prioritised by the GC during guideline development.
17.	British Association for Paediatric Nephrology	4	85	It should be noted that there is no national tariff for dialysis in children and that adult national tariffs are higher than many locally-negotiated tariffs for children.	Thank you for your comment and information.
18.	British Association for Paediatric Nephrology	4	93	It is suggested that the clinical and cost effectiveness of different RRT modalities in the failed transplant should be included amongst this section.	Thank you for your comment. Draft review questions will be refined by guideline committee. Your suggestion will also be addressed in the questions about optimal transfers from different forms/modalities of RRT.
19.	British Association for Paediatric Nephrology	4	93	Decision aids like the NKF, the modality of giving information (in person vs written vs DVD etc) as well as where the info is given (central vs local hospitals) needs discussion.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review question.

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20.	British Association for Paediatric Nephrology	5	118	It is suggested that point 11 should be excluded as discussed above (comment number 9).	Thank you for your comment. We have edited this scope topic to make it clearer that we are covering specific aspect of fluid restriction and dietary management
21.	British Association for Paediatric Nephrology	5	132	Different paediatric specific health related QoL outcomes will be required.	Thank you for this information. The guideline committee will refine the outcomes for each review question.
22.	British Association for Paediatric Nephrology	5	137	There is an apparent discrepancy in including growth amongst outcome measures. The BAPN would welcome including growth as an outcome measure but notes that management of growth in CKD is excluded in section 1.3.	Thank you for your comment. The section 'areas that will not be covered' states that management of growth in children with CKD is not within the scope. Growth is listed under the main outcomes as the guideline committee will still consider negative impacts on growth to be worth consideration in comparing interventions, even if strategies to manage this impact are beyond the scope of this guideline.
23.	British Association for Paediatric Nephrology	6	150	Please note that the CKD and peritoneal dialysis guideline CG125 excludes children. Separate considerations will need to be made for children when referencing this document.	Thank you for your comment. The NICE guideline Chronic kidney disease (stage 5): peritoneal dialysis (NG125) includes adults, children and infants. Where appropriate in the evidence reviews and if possible adult and child data will be evaluated separately. A paediatric

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					nephrologist will be a member of the guideline committee.
24.	British Association for Paediatric Nephrology	6	155 - 163	The guideline will not include additional recommendations on transition from paediatric to adult services where NICE guidelines (NG43) are already in place. The guideline should address specific issues where preparation for introduction of renal replacement therapy (RRT) is planned in the young person during transition. This would specifically include young people who present as emergencies.	Thank you for your comment. The scenario you describe is included under the scope topic on information, education and support. Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings. This is because it would require a different guideline committee composition to cover the aspects of management that are different to those outlined in this scope.
25.	British Dietetic Association Renal Nutrition Specialist Group	General	General	Dietetic input is integral to the management of people with Chronic Kidney Disease, as recognised by the inclusion of section 6 'Diet and Fluid Management' line 71, page 3. In addition there is a need for dietetic considerations throughout many of the other listed sections in the proposed scope of the guideline. Given the importance of diet and nutrition in the treatment of CKD it is our recommendation that a Registered Dietitian ought to be fully involved in the development of this guideline as a full member the guideline committee (and not only as a co-opted specialist).	Thank you for your comment. The guideline committee will consider fluid restriction and dietary management throughout the guideline where relevant. The co-optee will be involved in all discussions of the evidence and recommendations relevant to this area.
26.	British	1	7 - 8	We suggest that for clarity this description includes all the options 'NHS England	Thank you for your comment. We are unable to

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	Kidney Patient Association			has asked NICE to develop a guideline on *preparation for* renal replacement therapy (RRT), including *transplant, dialysis and* conservative care.'	change the remit of the guideline as this is provided by NHS England. The title of the guideline reflects the topics included in the scope. The scope topics reflect the discussions at the stakeholder workshop. They identify areas where there is variation in practice and/or areas of clinical uncertainty.
27.	British Kidney Patient Association	2	40 - 41	To the groups for special consideration please add the 'adolescent transition group' (18-25) as highlighted in the NHS England Renal Service Specification; the transition to adult care from paediatrics is difficult in terms of out-patient clinic setting, treatment environment, and management of transplant i.e. immunosuppressant regimen.	Thank you for your comment. We refer to NICE guideline 'Transition from children's to adults' services for young people using health or social care services' (NG43) in the scope document. At the stakeholder workshop no issues specific to renal replacement therapy were identified for children and adolescents who transition to adult services.
28.	British Kidney Patient Association	3	64	There is no mention of carers, or parents, in the focus statement. Could the wording be amended to reflect that they will also be included, particularly parents?	Thank you for your comment. The relevant scope topics and draft review questions refer to carers and this includes parents.
29.	British Kidney Patient Association	3	64	Late starters (people who start as an emergency, needing dialysis urgently) – please can you consider including these specifically, as they lose the opportunity to make a planned choice, usually go on to haemo, and this can make it harder for them to choose PD subsequently. Special care needs to be taken for these patients, representing 4 out of the 19 whose kidneys fail daily in the UK.	Thank you for your comment. People who receive care in the critical care setting are included if they then go on to require management in the longer term setting. Under the section 'settings that will not be covered' we

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					have added renal replacement therapy in intensive and high dependency care settings. This is because it would require a different guideline committee composition to cover the aspects of management that are different to those outlined in this scope.
30.	British Kidney Patient Association	3	74	'Discontinuing RRT' – we assume this means end of life care and would therefore ask that you make this clearer. The resulting guidance and linkage with other guidelines will be improved by this clarity.	Thank you for your comment. People may discontinue renal replacement therapy for a number of reasons and not just for end of life care. We now refer to palliative care and end of life care in the section 'context'.
31.	British Kidney Patient Association	3	75	Please consider adding another line or including allied health care professionals in this list; it is not just specialists in other disciplines who are essential to the care of the RRT patient. Counselling, psychological support, renal social workers or welfare support all make a vitally important support mechanism for kidney patients facing RRT in terms of how individuals will cope particularly with the choice of dialysis. Of course there is variation in availability or type across the scope area but clearly these services are necessary to ensure quality of life. The input of such services provides mental breathing space, structured psychological support, assistance in accessing statutory services and support in accessing financial benefit. Such support is highlighted in the Renal Service Specification.	Thank you for your comment. We have edited this scope topic so that we now refer to coordination of care for example between different specialities involved in a patient's care. We have removed the example of specific specialities. Your comment will be discussed with the guideline committee when refining the review questions.
32.	British Kidney Patient Association	4	102	Symptom management should include education – patients report that they do not disclose symptoms and do not know whether they are renal or otherwise. Others will say that for instance they are itching badly and had no idea that this is a symptom of kidney failure.	Thank you for your comment. We have made it clearer that we are only including the recognition of symptoms and not their management (see topics that will and will not be

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					covered). Where appropriate we will refer to these guidelines. However, education is not excluded under this scope topic. The review question(s) will be refined by the guideline committee.
33.	British Kidney Patient Association	4	107	If children are included in the scope, then 'transferring' should also include the move to adult from paediatric care, accepting that there are other, more detailed guidelines out there for this.	Thank you for your comment. We refer to the NICE guideline 'Transition from children's to adults' services for young people using health or social care services' (NG43) in the scope document. At the stakeholder workshop no issues specific to renal replacement therapy were identified for children and adolescents who transition to adult services.
34.	British Kidney Patient Association	4	107	People who transfer back to dialysis following a failed transplant should be added here. They will be moving from one set of professionals to another and sometimes drop off the radar.	Thank you for your comment.
35.	British Kidney Patient Association	4	135	Patient experience is rightly mentioned, we have developed with the Renal Registry and patients a PREMS survey which has collected over 6000 responses and will be repeated next year. Analysis and (planned) validation are ongoing. It would be very helpful to understand whether this sort of community product will be acceptable to the guideline group. The statement otherwise may be taken as simply referring back to the NICE patient experience guidelines and will then not reach the level of detail which is particular to the kidney patient and	Thank you for your comment. We will contact you if the work you refer to is relevant for any of the review questions and meets the review protocol criteria.

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				should inform this guideline.	
36.	British Kidney Patient Association	Title	Title	The draft scope describes preparation for kidney failure, changing therapies, and making choices about treatment. If it included management as well it would be impossible to get to an effective level of detail. Please can the title of the guideline be changed to reflect that this is '*Preparation* for RRT …….'	Thank you for your comment. The remit for this guideline includes conservative care and transplant and the title of the guideline reflects this. We have edited the section 'context' and we now refer to 'preparation for renal replacement therapy'.
37.	British Renal Society	1	4 - 5	"Renal replacement therapy including conservative care". This title implies an extremely broad scope, which may be difficult to achieve. In addition the title seems misleading as the rest of the document implies an emphasis on preparation for RRT and modality choice rather than all aspects of RRT.	Thank you for your comment. The title of the guideline reflects the topics included in the scope. The scope topics identify areas where there is variation in practice or broadly define aspects of care or service provision for which most advice is needed. These topics were identified at the stakeholder workshop.
38.	British Renal Society	3	60	Key areas that will be covered. The focus seems to be on preparation for renal replacement therapy and modality choice or change. However, point 7 adds "ongoing care" implying care of patients receiving dialysis. If this is what is intended it should be made more explicit. If the intention is to cover all aspects of preparation for RRT, care of the patient on RRT, transferring between different modalities and discontinuation of RRT it may be best to subdivide the guidance and consider an advisory group for each section.	Thank you for your comment. We have edited the scope topic by removing the term ongoing care. We have clarified in the section 'context' what we mean by the term renal replacement therapy i.e. that it include transplantation. The composition of the guideline committee reflects the scope topics under consideration. People can be co-opted for topics where additional expertise is required.

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39.	British Renal Society	3	75	Care of the elderly should be added here as a specialty	Thank you for your comment. We have removed the examples of specific specialities. Your comment will be discussed with the guideline committee when refining the review questions.
40.	British Renal Society	4	83	It is not clear what is meant by "technical aspects of dialysis delivery". Does this refer only to aspects such as water quality and choice of dialyzer or does it include aspects related to vascular access? The BRS would want to see vascular access included within the scope of the guideline as it is a vital aspect of preparation for and delivery of haemodialysis.	Thank you for your comment. We have made it clearer what we are and are not including covering under this scope topic. Dialysis prescription is now excluded except for frequency.
41.	British Renal Society	4	93	Key Issues and Questions. We suggest adding the following questions: What is the role of nurses and Allied Health Professionals in the preparation of people for Renal Replacement Therapy? What is the optimal model for the delivery of pre-RRT care (e.g. dedicated multidisciplinary clinics versus general nephrology clinics or multidisciplinary review meetings)? What are the most effective interventions for increasing the number of patients opting for a home therapy in RRT (peritoneal dialysis or home haemodialysis)? What is the role of nurses and Allied Health Professionals in the care of people receiving Renal Replacement Therapy? What is role of self-care in RRT? What is the optimal model for the delivery of RRT care?	Thank you for your comment. The scope sets out the key areas for review and draft review questions. A number of your suggested questions overlap with those outlined in the scope. The precise wording of the review questions will be discussed by the guideline committee during development.
42.	British Renal Society	5	115	What are the most important symptoms to manage for people being prepared for RRT…. If the guideline is to identify the most important symptoms, should it not also provide guidance on control of the symptoms?	Thank you for your comment. At the stakeholder workshop no symptoms were identified that require management

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					specific to people undergoing renal replacement therapy. The scope therefore focuses on the recognition of symptoms. We have made it clearer that we are not including symptom management under 'topics that will not be covered'. The guideline will cross refer to related NICE guidance on symptoms management where appropriate.
43.	British Renal Society	5	121	What is the most clinical and cost effective way of delivering care during renal replacement therapy? This is a very broad and poorly defined question. Does it refer to the staff required, model of care, location and funding of dialysis units, home versus unit based therapies or all of the above? We recommend rephrasing the question to make it more specific.	Thank you for your comment. The review question(s) for this scope topic will be refined by the guideline committee. We have clarified what we are and are not covering with respect to technical aspects.
44.	British Renal Society	5	124	"What is the clinical and cost effectiveness of different sequences of RRT in people with end stage CKD?" The precise meaning and therefore the scope of this question is not clear. Is the intention to investigate whether it is better to start with PD or HD or will this question also consider transplantation before dialysis?	Thank you for your comment. Transplantation is included in renal replacement therapy and we have edited the section 'context' to make this clearer. The review question(s) for this scope topic will be refined by the guideline committee.
45.	British Renal Society	5	130	The main outcomes that may be considered when searching for and assessing the evidence are: We suggest that frailty should be added to this list.	Thank you for your comment. This list of outcomes is not exhaustive but outlines the main categories of outcomes that will be considered for most questions. Other outcomes will be discussed with the committee during development and included in reviews where

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					relevant. Frailty is difficult to define but the outcomes of quality of life and functional measures will capture much of the impact of frailty.
46.	British Renal Society	9	217	Home haemodialysis should be added as an RRT option in the figure and all considerations in the guideline related to RRT modality.	Thank you for your comment. The diagram is intended to give an overview of the scope topics we will cover rather than provide a care pathway for patients. The diagram will be edited by the guideline committee.
47.	British Renal Society	9	222	Health Survey for England data reported a prevalence of 5.2% for CKD stage 3-5 and 7.1% for CKD stage 1-2. Suggest specify CKD stage 3-5 if this is what is intended.	Thank you for your comment. We have amended this sentence in accordance with your suggestion.
48.	Faculty of Intensive Care Medicine	General	General	It is clear that it focuses on patients with advanced chronic kidney disease who n replacement therapy. Acute kidney injury and acute renal replacement therapy is As such, the document is mainly relevant for nephrologists working in a renal unit issues which are outlined in the document may also be relevant to Intensive Care	Thank you for your comment.
49.	Faculty of Intensive Care Medicine	General	General	If the answer to any of the following points is 'yes', the Faculty would recommend including an intensivist in the guideline development: 1. Occasionally, patients with advanced CKD who are not on dialysis yet are admitted to the ICU with an acute illness. The stress of the acute illness often means that they need to start dialysis treatment during admission and then stay	Thank you for your comment. 1) Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings This is

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				on chronic dialysis. Since the guideline will address questions related to initiation of RRT, will it also cover this particular scenario? 2. Will the guideline address the question which type of RRT chronic dialysis patients should receive if they are admitted to ICU? 3. The guideline intends to address the question "What are the indicators for transferring between the different forms of RRT?" Occasionally, patients need to change modality of RRT whilst in ICU, for instance, patients on peritoneal dialysis are transferred to haemodialysis for clinical reasons. Will the guideline cover this particular aspect?	because it would require a different guideline committee composition to cover the aspects of management that are different to those outlined in this scope. However, this guideline does include people who require renal replacement following treatment received in a critical care setting. 2) See above. The guideline will not cover the type of dialysis someone should receive in ICU. 3) See comment (1) above. The scenario you describe is excluded.
50.	Faculty of Pain Medicine	General	General	Pain management should be given consideration in the symptom treatment section of the Guideline, as it is important and can be problematic in renal replacement.	Thank you for your comment. Your comment will be discussed with the guideline committee when they discuss the review questions for this topic.
51.	Guy's & St Thomas Hospital	General	General	1. Occasionally, patients with advanced CKD who are not on dialysis yet are admitted to the ICU with an acute illness. The stress of the acute illness often means that they need to start dialysis treatment during admission and then stay on chronic dialysis. Since the guideline will address questions related to initiation of RRT, will it also cover this particular scenario?	Thank you for your comment. Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings. This is because it would require a different guideline committee composition to cover the aspects of management that are different to those outlined in this scope.

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					However, this guideline does include people who require renal replacement following treatment received in a critical care setting. Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings
52.	Guy's & St Thomas Hospital	General	General	2. Will the guideline address the question which type of RRT chronic dialysis patients should receive if they are admitted to ICU?	Thank you for your comment. Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings. This is because it would require a different guideline committee composition to cover the aspects of management that are different to those outlined in this scope. However, this guideline does include people who require renal replacement following treatment received in a critical care setting. Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings
53.	Guy's & St Thomas Hospital	General	General	3. The guideline intends to address the question "What are the indicators for transferring between the different forms of RRT?" Occasionally, patients need to change modality of RRT whilst in ICU, for instance, patients on peritoneal dialysis are transferred to haemodialysis for clinical reasons. Will the guideline	Thank you for your comment. The focus of the guideline is on long term renal replacement therapy and the question about transferring between different forms is intended

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				cover this particular aspect?	primarily to address long term changes in modality. Under the section 'settings that will not be covered' we have added renal replacement therapy in intensive and high dependency care settings. This is because it would require a different guideline committee composition to cover the aspects of management that are different to those outlined in this scope.
54.	Guy's & St Thomas' Kidney Patients Association	General	General	Although 'transplant' is included in the first paragraph of the document, it is not included in the title and draft seems to largely focus on dialysis. The title of this Guideline scope should be revised to read: Renal replacement therapy including transplant and conservative care It is essential that transplantation, including pre-emptive transplantation, is acknowledged and positioned throughout the scope as a form of renal replacement therapy (RRT), and as the first-choice treatment for any appropriate patient regardless of their sex, geographical location, age, ethnicity or social class.	Thank you for your comment. In the section 'context' we explain that renal replacement therapy includes transplantation. We feel that the title (which has been amended) accurately reflects the scope topics. A draft review question included in the scope is 'What is the clinical and cost effectiveness of each form of RRT?'
55.	Guy's & St Thomas' Kidney	General	General	Who is the focus? Teenagers who are transferring from paediatric to adult renal services also	Thank you for your comment. We refer to NICE guideline 'Transition from children's to adults' services for young people using health or social

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	Patients Association			require special consideration. They are a vulnerable group who need individualised care to reduce the risk of non-adherence to their renal treatment. See Watson AR. Kidney Int 2011;80:704-707. http://www.sciencedirect.com/science/article/pii/S0085253815551193	care services' (NG43) in the scope document. At the stakeholder workshop no issues specific to renal replacement therapy were identified for children and adolescents who transition to adult services.
56.	Guy's & St Thomas' Kidney Patients Association	General	General	Activities, services or aspects of care (7) It is essential to also consider the needs of patients switching from a failing transplant to dialysis, whose needs differ from those of patients switching between different dialysis modalities.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review question.
57.	Guy's & St Thomas' Kidney Patients Association	General	General	**Question 1** 1. This is highly dependent on the causation of CKD. Patients with CKD diagnoses where the likely progression to RRT will be relatively quick – e.g. within 2-3 years - need to have access to RRT information materials. This is not only important for the patient but also for their family, carers and friends. 1.1. Notwithstanding the above, the economic costs of preparing patients should be balanced against benefit, as many patients at stages I-III may never within the course of their lifespan progress to IV or V. Therefore, it seems reasonable to assess patients based on the stage of CKD rather than any other marker such as disease pathway.	Thank you for your comment. We have clarified that we are including people with CKD stages 1-3 for the scope topic and review question on preparation for renal replacement therapy. Your comment will be considered by the guideline committee when refining the review questions.
58.	Guy's & St Thomas'	General	General	Question 2 2. Assessment should focus on home dialysis (whether peritoneal and	Thank you for your comment. Your comment will be considered by the guideline committee

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	Kidney Patients Association			haemodialysis) as being the primary source of deliverable RRT modality. This shifts towards the original clinical response in the 1970s prior to the growing industry of hospital and unit-based dialysis provision. Patients should be assessed for their health beliefs, levels of motivation and capacity to manage the rigours of dialysis self-management. 2.1. Patients need information on both the realities of the benefits and harms of each RRT modality. Anecdotally, some patients report they were not fully advised about the consequences of RRT interventions; for example, citing the lack of information on the likelihood of complications due to infection in peritoneal dialysis. This experience is also reflected in the haemodialysis population and for transplant patients coping with the ill effects of the medication regimen. 2.2. As well as advising patients about the realities of each RRT modality, it is of equal importance to actively advise patients of the coping strategies they may need to learn or adopt to manage adversity, either during a RRT intervention or when in transition between RRTs.	when refining the review questions.
59.	Guy's & St Thomas' Kidney Patients Association	General	General	Question 3 3. Anecdotal experience is indicative of some renal staff having a poor understanding of the models of adult learning. At education and support sessions there has been little evidence of adult learning styles or data to support the efficacy of these educational and support sessions.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review questions.

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				3.1. Training patients with a chronic and life threatening disease in a poorly lit room; with a succession of clinicians, practitioners and workers each with a power-point presentation effectively lecturing patients for 3 hours could hardly be a more effective way to demotivate patients! 3.3. There needs to be better collaboration between clinicians and 'patients as partners' to improve communication to enable patients and staff to learn. The endeavour to educate patients must also be linked to the Think Kidneys Project, which is focussed on activating patients using psychometric measures to adjust input to where the patient is in terms of health beliefs and motivation. Why spend and increase costs for patients who are already highly motivated? 3.4. PAM a psychometric measure is being rolled out to be used as an evidence-based measure to help patients and clinicians to better understand the health beliefs and activation or motivation of patients. See Link: https://www.england.nhs.uk/2015/11/ollie-hart/	
60.	Guy's & St Thomas' Kidney Patients Association	General	General	Question 7 7.1. In terms of conservative management (CM), there are anecdotal reports that some patients may be prematurely offered CM because of insufficient access to dialysis compromised by poor local planning. CM should never be a 'post code lottery' outcome. NICE Guidance should set an unequivocal standard for CM in renal care to avoid any similarities with concerns around the implementation of the Liverpool Care Pathway.	Thank you for your comment. Service delivery aspects will not be specifically addressed in this guideline and it will be up to local services to determine how their services are best configured to adopt this recommendations. However, this guideline will inform the quality standard on renal replacement therapy.

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61.	Guy's & St Thomas' Kidney Patients Association	General	General	Question 8 8.1. The prospect of dialysis is frightening and life changing. So some patients, particularly if they feel relatively well even though their renal function may be 12% or less, will resist RRT and this can be seen as an adaptive response. Being dependent on a machine or mechanism to support life is shattering to the body-self, and even the prospect of a transplant means exposure to carcinogenic medication and taking immune-suppressants for the life of the transplanted kidney, or longer. 8.2. The opportunity to start RRT is a fine balance between planning, patient acceptance and avoiding the catastophic consequences of life-threatening renal failure. 8.3. There should be guidance on the appropriate time point to commence RRT irrespective of how well a patient feels. Failure to have a clear clinical response to patients reluctant to start dialysis is effectively surrendering the patient to conservative management, where their renal function could collapse and there is the possibility the patient might not survive. 8.4. Patients should never be allowed to avoid RRT where such action could threaten their lives unless they understand and have previously agreed to the CM or a palliative care pathway.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review questions.
62.	Guy's & St Thomas'	General	General	Question 9 9.1. CM may be an option for those patients for whom RRT is not a viable	Thank you for your comment and references. Your comment will be considered by the

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	Kidney Patients Association			intervention to sustain life or where RRT in conjunction with other morbidities is medically ill advised. 9.2. The default for CM should never be based on age. 9.3. CM should not be considered in any patient who has a mental health problem or any condition that could adversely affect their judgement. 9.4. Clinicians should follow standard guidance for treating patients who lack 'capacity' prior to making any decision regarding CM in renal patients. 9.5. Gloucester has developed a Course for Concern Register and Patient Assessment. See link* http://www.gloshospitals.nhs.uk/SharePoint75/Palliative%20Care%20Web%20Documents/SUPPORTIVE%20CARE%20FOR%20RENAL%20PATIENTS.pdf 9.6. See a conservative management leaflet produced by Queen Elizabeth Hospital Birmingham** http://www.uhb.nhs.uk/Downloads/pdf/PiConservativeKidneyManagement.pdf 9.7. The absence of a Clinical Reference Group (CRG) service specification for conservative management may allow for regional variations:	guideline committee when refining the review questions.

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				https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a06/ 9.8. It is helpful to differentiate between conservative management and supportive care. The former might be a response to RRT and the latter a response to the prognosis of end of life care irrespective of the RTT modality. Consequently, NICE needs to clearly define conservative management and demarcate it from supportive/end of life/palliative care.	
63.	Guy's & St Thomas' Kidney Patients Association	General	General	Question 11 11.1. Patients appear to respond very positively to other renal patients advising them about diet and fluid management. Unfortunately, leaflets provide generic advice, for example, restricting fluid input may not be useful information if you are still able to pass copious amounts of urine. Dietary review must be specific to the patient based on the impact of the disease and the patient's coping skills.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review questions.
64.	Guy's & St Thomas' Kidney Patients Association	General	General	Question 12 12.1. It is important to assess patients' compliance to the RRT modality; their overall fitness and coping ability. 12.2. Medical practitioners in primary care continue to be the gatekeepers to specialist services and could ideally act to co-ordinate patient care. However, GPs must be competent to recognise and effectively treat CKD, which includes	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review questions.

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				knowing when to refer to specialist services. 12.3. Primary care practitioners should not treat renal patients using a CM RRT pathway, unless this has been agreed with specialist services and, of course, the patient.	
65.	Guy's & St Thomas' Kidney Patients Association	General	General	1.6 Main outcomes The inclusion of Psychological distress and emotional wellbeing as main outcomes is welcome, as they are a particular concern for renal patients, especially as management of these areas is under-resourced in some renal units. The multiple comorbidities experienced by RRT patients are not reflected in the current list. As well as malignancy, other comorbidities that adversely affect renal patients include cardiovascular disease, bone and mineral disorders, sexual dysfunction, depression and anxiety.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review questions.
66.	Heart of England NHS Foundation Trust	3	75	We suggest the inclusion of Vascular Surgery as a further speciality involved in the care of patients. Vascular surgical colleagues are a critical component of Vascular Access creation and monitoring; close co-operation and multi-disciplinary working underpin the effective management of Dialysis Access in both the pre-dialysis and dialysis environments. There is also frequently shared care between diabetes, vascular surgery and nephrology in the care of CKD patients with diabetic foot disease.	Thank you for your comment. We have edited this scope topic so that we now refer to coordination of care for example between different specialities involved in a patient's care. We have removed the specific example of specialities. Your comment will be discussed with the guideline committee when refining the review questions.

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67.	Heart of England NHS Foundation Trust	4	83 109	We are concerned regarding the committee's ability to effectively evaluate the clinical and cost effectiveness of different forms of RRT without due consideration of the 'Technical aspects of delivery of RRT'. Dialysis in particular is a technically demanding undertaking; differences in the technical delivery of dialysis (e.g. haemodialysis vs haemodiafiltration) have the potential to alter both treatment costs as well as treatment efficacy. We suggest that an appropriate evaluation of these technical aspects is advantageous for this guideline.	Thank you for your comment. We have made it clearer what we are and are not including covering under this scope topic. Dialysis prescription is now excluded except for frequency.
68.	Heart of England NHS Foundation Trust	4	83 109	In addition to our comment 3 above, we would also welcome guidance regarding haemodialysis session length. This is also an area that will significantly affect both cost and efficacy.	Thank you for your comment. We have made it clearer what we are and are not including covering under this scope topic.
69.	Heart of England NHS Foundation Trust	4	83 109	In addition to our comments 3 and 4 above, we would also welcome guidance regarding the cost and clinical utility of gradual RRT start, both in terms of haemodialysis (by reduction of session length and/or frequency) and peritoneal dialysis. This would include consideration of the impact of residual renal function on dialysis requirements.	Thank you for your comment. We have made it clearer what we are and are not including covering under this scope topic. Dialysis prescription is now excluded except for frequency.
70.	Heart of England NHS Foundation	5	115	We welcome the focus on patient reported symptoms but would welcome further extension of the 'key questions' to include an evaluation of the optimal methodology to assess Patient Reported Outcomes in RRT patients. The scoping document does refer to Health-related Quality of Life as well as a	Thank you for your comment. The guideline committee will refine the outcomes for each review questions. Identifying the optimal methods to assess

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	Trust			range of other outcomes in section 1.6, however the tools referred to (SF-36/EQ-5D) are not specific for those undergoing dialysis. More specialised, or more frequent, assessment is very likely to be more informative.	Patient Reported Outcomes is not within the remit of this guideline.
71.	Heart of England NHS Foundation Trust	5	118	We would be keen to ensure that the committee's evaluation of dietetic management included muscle mass / lean body mass preservation, alongside other areas such as mineral bone disease.	Thank you for your comment. The precise interventions and strategies assessed within the review of dietary management, potentially including muscle mass/lean body mass preservation will be discussed within the guideline committee.
72.	Heart of England NHS Foundation Trust	5	133	We would be keen to ensure that the committee's evaluation of patient symptoms is sufficiently wide to include uraemic itch and post-dialysis recovery time.	Thank you for your comment. The guideline committee will identify which symptoms are most important to people receiving renal replacement therapy or conservative care of chronic renal disease. The precise structure of reviews and questions will be refined during the development process. We have made it clearer that we are covering the recognition of symptoms. Where it is available this guideline will refer to existing NICE guidance, on the management of symptoms.
73.	Heart of England NHS	General	General	We welcome the publication of this scoping document and support the development of NICE guidance for Renal Replacement Therapy.	Thank you for your comment.

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	Foundation Trust				
74.	Institute for health research, university of bedfordshire	5	128	There are 3 pertinent questions that the scope does not currently include: 1. Are there groups of people in which Living donation should be more actively offered than deceased organ donation? 2. Are rates of living donation equitable across the UK? 3. Are living donation and deceased donation promoted across all groups of people?	Thank you for your comment. The scope topic and related review question(s) address the clinical and cost effectiveness on each form of renal replacement therapy. We have also highlighted inequalities related to access of renal replacement therapy in rural areas, age, minority groups and class in the scope.
75.	Institute for health research, university of bedfordshire	General	General	1. Which interventions or forms of practice might result in cost saving recommendations if included in the guideline? Wilkinson E, Randhawa G, Brown E, Da Silva Gane M, Stoves G, Warwick G, Akhtar T, Magee R, Sharman S, Farrington, K. (2016) Exploring access to end of life care for South Asian people with end stage renal disease through recruitment in action research. BMC Palliative Care. **DOI:** 10.1186/s12904-016-0128-1 Wilkinson E, Randhawa G, Farrington K, Feehally J, Choi P, Lightstone L.(2012) A multi-centre qualitative study exploring the experiences of UK South Asian and White Diabetic Renal Patients. BMC Nephrology. doi:10.1186/1471-2369-13-157. Wilkinson E & Randhawa G (2012) Concordance Facilitates Access in	Thank you for your comment and for highlighting these studies. We will ensure that any of these studies meeting the review protocol criteria are considered by the guideline committee.

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				diabetes care – service provider perspectives of service improvement and cultural competency. Diabetic Medicine. 29, 1440-1446. Randhawa G & Neuberger J (2016) The role of religion in organ donation - Development of the UK Faith and Organ Donation Action. Transplantation Proceedings. 48: 3, 689–694. doi:10.1016/j.transproceed.2015.10.074 Sharp C & Randhawa G (2016) Death practices, attitudes toward the body after death and life after death in deceased organ donation: A UK Polish migrant perspective. Journal of Palliative Care and Medicine 6: 262. doi:10.4172/2165-7386.1000262 Morgan M, Sims J, Jain N, Randhawa G, Sharma S & Modi K (2015) Inequalities in waiting times for kidney transplantation among Black and minority ethnic groups: causes and strategies. British Journal of Renal Medicine. 20(1):4-7.	
76.	Kidney Research UK	11	258 - 262	Patient feedback: when is start of RRT calculated? Is it at stage 4/5 of CKD or the day that dialysis starts or from confirmation that dialysis is needed? Some indication of this would help.	Thank you for your comment. The purpose of this section is to provide a general overview and context.
77.	Kidney Research UK	4	101	There is a clear role here for expert patients to engage with other patients, using their experience	Thank you for your comment. Your comment will be considered when the guideline committee refine the review questions. Lay representatives are to be members of the

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					guideline committee
78.	Kidney Research UK	4	104	The phrasing 'decision-making for people who may need RRT' implies that the decisions are made by someone other than the person requiring RRT. Suggest 'decision-making with people who may need RRT' – this phrasing would better support shared decision-making	Thank you for your comment. We agree and the wording of the scope has been amended.
79.	Kidney Research UK	4	106	'Clinical' cost-effectiveness requires careful definition. A large body of research (summarised well in Lee MB, Bargman JM. Clin J Am Soc Nephrol 2016;11;1083: Survival by dialysis modality – who cares?) indicates that for many patients, quality of life outweighs duration of survival; so yet another analysis of survival on peritoneal dialysis vs haemodialysis to support a statement on 'clinical cost-effectiveness' would be a wasted opportunity. It is therefore important to ensure that quality of life is explicitly included in the analysis of 'clinical' cost-effectiveness	Thank you for your comment. As per NICE methodology, quality of life measures such as EQ-5D, SF-36 and any renal specific scales will be included in the review of clinical evidence and construction of any economic models as relevant. Duration of survival will also be included.
80.	Kidney Research UK	4	93	Living kidney donor transplantation is, for many people with kidney failure, the option that confers the best quality of life and life expectancy. However, there are marked variations in use of living kidney donor transplantation between centres; and marked variations by socioeconomic status (SES) – people of low SES are less likely to undergo living kidney donor transplantation. The 'availability' of potential living kidney donors is, in our view, a key issue, and includes questions about how best to support potential transplant recipients in identifying and approaching potential donors.	Thank you for your comment. The scope includes living kidney donor transplantation as well as inequalities in access.
81.	Kidney Research UK	5	112	It is likely that one of the major 'indicators' (most people use the word 'indications') for initiation of RRT will turn out to be hyperkalaemia that is refractory to adjustment of drug treatment and dietary intake. However, there are	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review question.

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				drugs likely to be on the market by the time that this guideline comes into force that promise to improve the management of hyperkalaemia. Some thought needs to be given to how best to anticipate this development so as to ensure that the guideline is not out of date before it's printed.	
82.	Kidney Research UK	5	137	P4 line 84 states that growth in children is not within the scope; adults seldom grow; so why is growth listed as one of the main outcomes of interest?	Thank you for your comment. The section 'areas that will not be covered' states that management of growth in children with CKD is not within the scope. Growth is listed under the main outcomes as the guideline committee. We now refer to the NICE guideline currently in development on 'Faltering growth - recognition and management of faltering growth in children' under the section on 'related NICE Guidance'.
83.	Kidney Research UK	General	General	The scope clearly includes both 'active' Renal Replacement Therapy (dialysis, transplant) and Conservative management. At times the document appears to use the abbreviation 'RRT' to cover both of these options; in other places, 'RRT' is used as an alternative to Conservative management, suggesting that 'RRT' is a term for active treatment with dialysis or transplant (as in conventional usage). For instance in page 3 lines 62-63, the scope covers 'Assessment and review of people with deteriorating renal function who appear likely to need RRT'. On line 68, Renal Replacement Therapy and Conservative Management are set out as alternatives to each other. Given that 'need' is often defined as 'capacity to benefit from', it is possible to imagine a situation in which some people, whose benefit from active dialysis treatment might be considered marginal in terms of quality of life or life extension (e.g. the elderly, those with major co-morbidity	Thank you for your comment. We have edited the title so that it is clear that renal replacement therapy and conservative care are distinct. We have also defined what we mean by the term conservative care in the section 'context. We have edited the scope topic you refer to say 'in whom it might be appropriate'.

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				including frailty) would be considered out of scope because they would not 'appear likely to need RRT'. In our view, inclusion of such patients, and other 'marginal' groups, is imperative, and this requires more careful use of terminology.	
84.	Kidney Research UK	General	General	No specific mention is made of patients with so-called cardiorenal syndrome type 2) in whom heart failure leads to a progressive deterioration in kidney function and refractory fluid overload. These patients often present late, via heart failure services, and may not meet conventional criteria for referral based on eGFR (estimated Glomerular Filtration Rate). Provision of dialysis therapy for this group of patients is complex (for instance, construction of an arteriovenous fistula for dialysis in a patient with a marked reduction in cardiac output may not be beneficial), and survival is poor. The scope should specifically include this group of patients	Thank you for your comment. People with cardiorenal syndrome are not excluded from the scope. It is not possible to list all of the possible reasons why a person may require renal replacement therapy but we do specify those groups and topics that are specifically excluded.
85.	Kidney Research UK	General	General	Patient feedback: the term 'conservative management' is not well understood. This is also the charity's experience. Some definition of this term would help.	Thank you for your comment. The term conservative care has been more clearly defined in the section 'context'.
86.	NHS Blood and Transplant	1	7 8	This should more accurately read: "NHS England has asked NICE to develop a guideline on renal replacement therapy (RRT) which incorporates transplant and dialysis, along with conservative care". At the moment it reads as though transplant is a last option after conservative care, whereas half of the patients alive today on RRT are there by virtue of a functioning transplant. It would be helpful to define RRT up front, including transplantation, peritoneal dialysis and haemodialysis. Furthermore you may consider patients with a GFR<15, the point at which pre-emptive transplantation is considered.	Thank you for your comment. We are unable to change the remit of the guideline as it is provided by NHS England. We have made it clearer in the section 'context' to disrobe the role of transplantation.

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87.	NHS Blood and Transplant	10	244 - 8	Long term outcomes for transplantation should be mentioned, and the annual centre specific report should be referenced. Reference should also be made to the NHSBT TOT2020 strategy and the 2020 Living Donor Strategy. There should also be a statement about which RRT patients are likely to be medically suitable for transplantation and that this encompasses 20-30% of dialysis patients, and ages approx. 2yrs to mid/late 70s. There should also be a statement to say that pre-emptive transplantation is the best form of RRT.	Thank you for your comment. The purpose of this section is to provide a general introduction and context. The scope and review questions include the clinical and cost effectiveness of each form of renal replacement therapy.
88.	NHS Blood and Transplant	10	245	The NHSBT link should take you to the ODT website (http://www.odt.nhs.uk) and not the NHSBT homepage	Thank you for your comment. This has been updated in the context section.
89.	NHS Blood and Transplant	10	247	905 days for adults, 266 for children. Waiting times are only relevant for deceased donor transplants, and not those from living donors.	Thank you for your comment. The figures quoted were obtained from the Annual Report on Kidney Transplantation 2013/2014 and these do refer to 'median time to transplantation'.
90.	NHS Blood and Transplant	10	252	It states that RRT is an expensive therapy but it should acknowledge that renal transplantation is cheaper than any form of dialysis.	Thank you for your comment. The clinical and cost effectiveness of renal replacement therapy and conservative care will be addressed in the guideline.
91.	NHS Blood and Transplant	11	258	It is not clear what this section is trying to cover.	Thank you for your comment. The purpose of this section is to provide a general overview and context.

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92.	NHS Blood and Transplant	11	258 - 271	If this section is looking at variation in practice, then there is more than just ethnicity that needs to be addressed. For example, variation in living donor transplant rates, use of standard and extended criteria donors, age range of patients on waiting list, referral patterns in dialysis vs transplant centres, and so on.	Thank you for your comment. This list is not meant to be exhaustive and we use this example because it is also identified in the section 'equality considerations'.
93.	NHS Blood and Transplant	11	259	Prevalent RRT patients – the majority are probably served by transplantation and not haemodialysis. Most people who have dialysis, not RRT, are treated with haemodialysis. Or is this statement referring to incident patients, in which case this needs to be clear.	Thank you for your comment. We have amended this paragraph and now refer to the number of people who have had a transplant.
94.	NHS Blood and Transplant	2	32	"access issues". Access, in RRT, usually refers to dialysis access (e.g. an arteriovenous fistula or PD catheter). This phrase may be better rephrased as : "This guideline will look at inequalities relating to access to RRT in rural areas…."	Thank you for your comment. We agree and have made the change you have suggested.
95.	NHS Blood and Transplant	2	42	Define older.	Thank you for your comment. We do not want to define older adults in terms of an age category. Instead it is used to refer to loss of kidney function due to age or the varying effectiveness of interventions due to age.
96.	NHS Blood and Transplant	2	43	Infants (under 2). Suggest write more fully, under 2 years of age.	Thank you for your comment. We agree and have made the change you suggested.
97.	NHS Blood and Transplant	2	45	Some patients may be in renal failure as a consequence of the more unusual forms of diabetes, such as type 5 or following pancreatectomy for nesidioblastosis. Suggest state "People with diabetes mellitus".	Thank you for your comment. We refer specifically to type 1 and type 2 diabetes as these are much more prevalent than type 5 and

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				Diabetes is mentioned here in the scope, but there is no mention of combined pancreas and kidney transplantation for diabetics in renal failure in the scope.	we will not be seeking to make recommendations in the latter group. We have added combined transplant to the context section. It is not excluded by the scope but we are unable to list every type of transplant we are including.
98.	NHS Blood and Transplant	3	60	Could the transplant pathway be included as a separate subheading rather than being lumped the rest of RRT. That pathway would include transplant assessment, maintenance on the list, transplant episode, transplant follow-up . The pathway ends with re-transplantation, return to dialysis or death.	Thank you for your comment. The diagram is intended to give an overview of the scope topics we will cover rather than provide a care pathway for patients. Currently RRT includes transplant and dialysis however the diagram will be edited by the guideline committee and as recommendations are developed are likely to be separated out.
99.	NHS Blood and Transplant	4	93	This section would fit transplantation if the scope of RRT is more clearly defined and transplant was identified as a separate pathway	Thank you for your comment. The diagram is intended to give an overview of the scope topics we will cover rather than provide a care pathway for patients. Currently RRT includes transplant and dialysis however the diagram will be edited by the guideline committee and as recommendations are developed are likely to be separated out.
100	NHS Blood and	5	129	Suggest including removal from the transplant list for medical unsuitability or death	Thank you for your comment. This list of outcomes is not exhaustive but outlines the

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	Transplant				main categories of outcomes that will be considered for most questions. Other outcomes will be discussed with the committee during development and included in reviews where relevant. This may include the outcome of removal from the transplant list, although removal due to death will already be covered in mortality.
101	NHS Blood and Transplant	5	139	Adverse events are all dialysis related. For transplant you might consider rejection	Thank you for your comment. Transplant rejection will be considered under the heading of "time to modality failure".
102	NHS Blood and Transplant	6	145	Is this meant to include kidney transplant failure (graft failure)? This could be made explicit by including transplant outcomes	Thank you for your comment. Transplant rejection will be considered under the heading of "time to modality failure". This list of outcomes is not exhaustive but outlines the main categories of outcomes that will be considered for most questions. Other outcomes will be discussed with the committee during development and included in reviews where relevant.
103	NHS Blood and Transplant	9	217	The flow diagram is simplistic. Coordinating care between different specialties – no mention of transplant surgery/surgeons The flow diagram would be better if it included separate pathways for transplantation and dialysis	Thank you for your comment. The diagram is intended to give an overview of the scope topics we will cover rather than provide a care pathway for patients. Currently RRT includes transplant and dialysis however the diagram will

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					be edited by the guideline committee and as recommendations are developed are likely to be separated out.
104	NHS Blood and Transplant	9	219	Nowhere in the document, and specifically this section, does it mention what proportion of the RRT population are served by a functioning transplant. The figure is around 50% (25000 people). It would seem that given the size of this constituency it should be clearly stated here.	Thank you for your comment. We have amended this section and now include the number of people with a transplant.
105	NHS Blood and Transplant	9	244	The figure at 31st March 2016 was 5275 active patients, but a total of 8605 including those suspended for some reason	Thank you for your comment. The purpose of this section is to provide a general introduction and context and is not possible to quote all of the data.
106	Polycystic Kidney Disease Charity	3	60	We would like the guideline to take account of any special needs of patients needing RRT who have inherited kidney diseases.	Thank you for your comment. The guideline will be covering the renal replacement therapy for people with chronic kidney disease irrespective of aetiology.
107	Polycystic Kidney Disease Charity	4	98	We would like the assessment to take account of the impact of massive cystic kidneys. For example indications for nephrectomies prior and post start of RRT, sarcopenia/anorexia.	Thank you for your comment. Assessment related to specific aetiologies will not be covered by this guideline.
108	Polycystic Kidney Disease Charity	general	general	We welcome the new guideline.	Thank you for your comment.
109	Renal	1	4 - 8	**Scope:** The title of this Scope for Guideline suggests a guideline covering all	Thank you for your comment.

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	Association			clinical aspects of preparation, care, treatment modality switching & withdrawal of treatment for stage 4-5 CKD, Home and Hospital/satellite HD, all forms of peritoneal dialysis, all forms of renal transplantation and conservative care for adults and children. This is misleading. In practice the scope largely focuses on choice and access to these forms of treatment of ESRD. It does not aim to cover any of the technical/medical aspects of these treatments. As such it is not a Guideline covering the full care of these patients. A guideline covering all aspects of CKD 4-5, RRT & conservative care in children and adults would be massive & likely to be unachievable or ineffective in aims. As such we recommend that the title of the scope guideline should be changed as at present it is misleading. Perhaps 'Choice, preparation for and switching of treatment modalities for children and adults approaching or receiving treatment for End Stage Renal Disease' We strongly welcome the emphasis on preparation and choice for patients & we suggest that the wording of the scope reflects this focus. .	The remit from NHS England is to develop a guideline on renal replacement therapy, including conservative care and transplant. We feel that the title reflects the remit and the scope topics define what areas the guideline will cover as it is not possible to cover all aspects of assessment and management. The topics included identify areas where there is variation in practice or broadly define aspects of care or service provision for which most advice is needed. We have added your suggested wording to the section 'context'.
110	Renal Association	2	37 - 46	**Children and adults;** Although there is overlap in the preparation for and care of children and adults requiring renal replacement therapy (RRT) and conservative care, there are also substantial differences. These differences must be clearly identified in the scope and guidance lest the document lose credibility or utility.	Thank you for your comment. We agree and where appropriate in the evidence reviews and if possible adult and child data will be evaluated separately.

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111	Renal Association	3	60	It is very important that the transfer of treatment modality in a patient with a failing transplant is included in this guidance. This return to dialysis is poorly managed in some settings. Ie patients with a failing transplant should have the same access & choice as patients presenting with CKD.	Thank you for your comment. Your comment will be considered by the guideline committee when defining and refining the review questions and when they discuss the available evidence.
112	Renal Association	3	78 - 84	Noted-these wide exclusions should be clarified by changing the title of the scope.	Thank you for your comment. We have clarified the scope to make it clear what we are and are not covering.
113	Renal Association	5	128	Recognise that indicators may not be best term. As all cases differ it may be more appropriate to call 'factors associated with poor experience on RRT '. We are not clear that experience is adequately covered in the scope, a key measure for most people with ESRD	Thank you for your comment. The guideline committee will refine the outcomes for each review question. Indicators would include 'factors'. The experience of people on renal replacement therapy will be captured by outcomes such as quality of life, symptom scores, functional measures and experience of care.
114	Renal Association	5	129 - 145	It may be very difficult to tease out the factors associated with bad experience/outcomes on different forms of RRT in light of the broad case mix of patients receiving any particular modality of treatment.	Thank you for your comment. For each review, the guideline committee will consider whether additional subgroups may be appropriate.
115	Renal Association	6	1490 153	This guideline will update the 2 guidelines below: Chronic kidney disease (stage 5): peritoneal dialysis (2011) NICE guideline 150 CG125 151 & Guidance on home compared with hospital haemodialysis for patients with 152 end-stage renal failure (2002) NICE technology appraisal guidance TA48	Thank you for your comment. The guidelines you refer to are being replaced by this guideline. The scope topics and review questions cover those of the guideline you refer to. However, the guideline committee may

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				This makes it imperative that the guideline is sufficiently detailed to adequately update these. This goes back to the issue of definition of the scope. Where the guideline overlaps previous guidelines it is appropriate to update but it would be important to recognise areas where there is no overlap. Loss of past guidance without full replacement would be a loss to the system.	refine the review questions.
116	Renal Association	8	199 - 207	The same applies here as for point 8. The guideline will not include additional recommendations on transition from paediatric to adult services where NICE guidelines (NG43) are already in place. The guideline should address specific issues where preparation for introduction of renal replacement therapy (RRT) is planned in the young person during transition. This would specifically include young people who present as emergencies.	Thank you for your comment. We refer to the NICE guideline 'Transition from children's to adults' services for young people using health or social care services' (NG43) in the scope document. At the stakeholder workshop no issues specific to renal replacement therapy were identified for children and adolescents who transition to adult services.
117	Royal College of General Practitioners	2	32	Access should particularly consider transport challenges and variation in access to peritoneal dialysis. (SF)	Thank you for your comment. We agree and we have included access issues to renal replacement therapy in rural areas, age, minority groups and social class in the equalities impact assessment for the guideline and will be given consideration throughout the development process. Where appropriate, the guideline committee may decide to include this population as a subgroup when developing protocols for review questions.
118	Royal College of	2	47	The RCGP suggests that people with learning disability should be added to the list of people needing special consideration.	Thank you for your comment. The 'special consideration' section identifies

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	General Practitioners			(SF)	groups who may have needs specific to renal replacement therapy. Learning disabilities is a 'protected characteristic' under the Equality Act and will therefore be considered when making all of the recommendations
119	Royal College of General Practitioners	3	69	The RCGP feels that included in consideration of modality needs to be discussion of pre-emptive transplant. (SF)	Thank you for your comment. Your comment will be considered by the guideline committee when they refine the review questions and discuss the available evidence.
120	Royal College of General Practitioners	3	70	It may be worth it if the list specifically mention discussion about the timing of vascular access. (SF)	Thank you for your comment. We have edited the scope to make it clearer what technical aspects we are and are not covering. Timing of vascular access is outside of the scope of this guideline.
121	Royal College of General Practitioners	3	76 - 77	An overview defining the roles of each professional group would be desirable, with essential and optional (to be agreed locally) responsibilities discussed. This is particularly relevant for GPs in 2 areas: 1. Educating, supporting patients to make informed choices, 2. Prescribing- whose responsibility? If GPs have a role, than please see comment 1. Possibly, a chart could provide this. Also, some emphasis should be placed on how to inform patients about these roles. (LL)	Thank you for your comment. The guideline committee will consider your comment when they discuss the review questions for each scope topic.

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122	Royal College of General Practitioners	5	121 - 123	Recommendations are desirable here for optimal communication and referral pathways. (LL)	Thank you for your comment. Your comment will be passed to the guideline committee when they refine the review questions for this topic area
123	Royal College of General Practitioners	General	General	As other specialities (non-renal), including general practices, may have variable or limited expertise in the end-stage CKD and RRT, it may be useful to: 1. Recommend, where feasible, that non-specialist teams have a designated lead in this area; 2. That such leads' educational needs are identified and appropriate support provided to enable them to acquire the needed skill sets to optimise patient care. (LL)	Thank you for your comment. The guideline committee may specify the competencies required to deliver a recommendation but it will not provide guidance on who this should be.
124	Royal College of Nursing	2	42	What is meant by 'older people'? Perhaps define.	Thank you for your comment. We do not want to define older adults in terms of an age category. Instead it is used to refer to loss of kidney function due to age or the varying effectiveness of interventions due to age.
125	Royal College of Nursing	2	46	Commonly known as 'crash landers'. Perhaps add in brackets?	Thank you for your comment**.** The scope and guideline is relevant to this group and will be read by non-specialists and people undergoing renal replacement therapy. We feel that the terminology we have used is therefore

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					appropriate.
126	Royal College of Nursing	3	60	What about vascular access, will this be covered? (I.e. preparation for renal replacement therapy (RRT))	Thank you for your comment. We have made it clearer what will not be covering under 'technical aspects' and this includes creation and management of dialysis access.
127	Royal College of Nursing	4	101	Consider adding 'withdrawing from dialysis' as follows *What information, education and support is useful for people and their families/ carers when considering RRT, when transitioning from one form of RRT to another, when considering conservative management or withdrawing from dialysis?*	Thank you for your comment. Information, education and support for people considering conservative care includes those withdrawing from dialysis. The review questions will be refined by the guideline committee.
128	Royal College of Nursing	4	106	There are two questions here – consider splitting into two as the issues cannot be easily assessed together *What is the most clinical and cost effective way…*	Thank you for your comment. As per NICE methodology, all relevant evidence will be gathered and analysed to inform the assessment of clinical effectiveness. The assessment of cost effectiveness will be informed by the assessment of clinical effectiveness.
129	Royal College of Nursing	4	109	This sentence is not clear… *What is the clinical (what?) and cost effectiveness of each form of RRT?*	Thank you for your comment. This is standard NICE phraseology for a question assessing both the clinical effectiveness and cost effectiveness of a (or multiple) intervention(s).
130	Royal	5	132	What Quality of Life (QoL) tools will be used? There are dialysis-related tools.	Thank you for your comment and this

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	College of Nursing				information. The guideline committee considers the most appropriate outcomes to measure effectiveness of the treatments when reviewing the evidence. The list of main outcomes in section 1.6 of the scope is not an exhaustive list but the main outcomes that are expected to be used within the guideline.
131	Royal College of Nursing	5	132	Will the developers compare QoL in differing modalities? (I.e. haemodialysis versus conservative management. Haemodialysis versus peritoneal dialysis etc). It would be helpful to have evidence based	Thank you for your comment. Evidence assessing quality of life will be included in the comparisons between different modalities of renal replacement therapy, where identified.
132	Royal College of Nursing	6	145	*'Time to modality failure'* is not clear. This term needs changing or elaborating.	Thank you for your comment. This outcome will be further refined by the guideline committee.
133	Royal College of Nursing	General	General	The Royal College of Nursing welcomes proposals to develop these guidelines. The RCN invited members who care for people with renal condition to review and comment on the draft document on its behalf. The comments below include the views of members.	Thank you for your comments which we have responded to below.
134	Royal College of Physicians of	11	268	Are there groups of people in which conservative management is more appropriate than RRT? This is a subjective issue, however for those with significant frailty and multiple co-morbidities – the evidence suggest this group gain little from RRT.	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.

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	Edinburgh	5	113	If a patient suffered from severe dementia this would mean RRT would be potentially inappropriate due to the challenges in delivering the treatment.	
135	Royal College of Physicians of Edinburgh	**3** 4	62 96	When should people be assessed for RRT? There is variation in this, but in the majority of cases when the eGFR is persistently below 15ml/min. People with diabetes should be assessed earlier in view of the fact that they are not infrequently symptomatic at a higher eGFR and because of the potential for a combined kidney-pancreas transplant and need for intensive work up: this could be later if the infrastructure for obtaining the necessary investigations is in place.	Thank you for your comment. Where evidence for specific groups is available the guideline committee will consider making separate recommendations.
136	Royal College of Physicians of Edinburgh	**3** 4	62 98	What assessment (for example history, examination, investigations) is needed for those people with deteriorating CKD being considered for RRT The most important aspect is to establish patient co-morbidities. It is assumed that measures of reversibility are in place so the main focus is an assessment of suitability for RRT which includes pre-emptive kidney or kidney-pancreas transplantation. Basic history, investigation of cardiac risk (Newcastle score) and investigations to prepare for transplantation are necessary. Tests to assess suitability for vascular access or peritoneal dialysis tube insertion are also required, and Hepatitis and HIV serology is essential.	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.

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				Social, mental health and carers input should also be taken into account.	
137	Royal College of Physicians of Edinburgh	**3** 4	66 104	What information, education and support is useful for people and their families/ carers when considering RRT, when transitioning from one form of RRT to another or considering conservative management? Impartial information is key to making a decision. Information should be delivered by the multi-disciplinary team comprising doctor, specialist nurses, dietician and social care. Input may also be helpful from a pharmacist and clinical psychologist, as well as referral to vascular surgery. 1. types of RRT 2. details of each modality 3. impact on patient and their job/responsibilities 4. impact on family – e.g. transport 5. impact on activities of daily living (ADLs) and dietary intake 6. risks associated with each 7. what conservative care actually means and involves 8. there is a series of excellent leaflets from the National Kidney Foundation and British Kidney Patients' Association – for example - **Kidney Failure: What choices do I have?** which are very readable for patients	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.
138	Royal College of Physicians	3	66	How should decision-making for people who need RRT be supported? Currently specialist low clearance nurses are an excellent resource and a focal	Thank you for your comment. Your comments will be considered by the guideline committee when they refine the review questions and

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	of Edinburgh	4	104	point for patients to refer to in order to obtain unbiased information to make an informed decision. In addition, there are currently decision aids and a wealth of digital information available for patients as outlined above. It is essential also to assess the home circumstances as there should be a drive towards home dialysis therapies and this needs the patient to be able to understand how to self-dialyse and, in the case of haemodialysis, a carer or partner having the knowledge and desire to help.	discuss the available evidence.
139	Royal College of Physicians of Edinburgh	3 5	70 115	What are the most important symptoms to manage for people being prepared for RRT, undergoing RRT or receiving conservative management of end-stage CKD? Preparing for RRT: - fluid balance - dietary measures - manage anaemia with IV iron and erythropoietin - acid-base management - avoiding nephrotoxins Receiving RRT: - restless legs - phosphate and calcium metabolism	Thank you for your comment. These symptoms, alongside those identified by systematic qualitative reviews, will be considered by the guideline committee when refining the review questions for this scope topic.

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				- itching Conservative management: - nausea - itching - pain if present – this is the most important - anaemia	
140	Royal College of Physicians of Edinburgh	3 5	72 126	What are the indicators for transferring between the different forms of RRT? The usual reason for transfer is first and foremost receipt of a kidney transplant – this gives the best outcomes. Otherwise, transfer could be due to failure of the initial mode of RRT or development of complications. This may be temporary eg for PD peritonitis, or permanent eg for sclerosing peritonitis. On occasion it is due to change in patient preference.	Thank you for your comment. The guideline committee will fully discuss the evidence for this scope topic and related review question(s) when making their recommendations.
141	Royal College of Physicians of Edinburgh	3 5	75 121	What is the most clinical and cost effective way of delivering care during renal replacement therapy (for example co-ordination between specialties, follow-up, review)? Co-ordinating care between specialities remains a challenge and those patients needing RRT are usually under the care of several specialities.	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.

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				Realistically, once a patient receives RRT most other specialities will take a lesser role in their care. In addition, patients usually attend for dialysis three times a week – considerable planning and co-ordination is needed to ensure that patients do not attend specialist clinics on those non-dialysis days; otherwise they will spend a huge amount of time in hospital.	
142	Royal College of Physicians of Edinburgh	4	106	What is the most clinical and cost effective way of preparing patients for RRT - planning, timeliness of access formation and transplant listing)? The dedicated "low clearance clinic" which serves as a multi-disciplinary meeting is the ideal and most cost effective single stop visit for patients. This also involves an access nurse to timely access planning and also transplant assessment and work up. More recently, central transplanting centres appear to want to see potential patients for transplant assessment and consent on a number of occasions – this is **not** cost effective or patient focused and would seem to be a poor use of resources: we would suggest that revision of this approach be considered.	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.
143	Royal College of Physicians of Edinburgh	4	109	What is the clinical & cost effectiveness of each form of RRT? Transplantation - when feasible - is the most effective and clinically beneficial option (live donor transplantation being the ideal option). Pre-emptive action should be encouraged as it can restore quality and quantity of life and also	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.

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		10	252	enable patients to return to work without disruption. Peritoneal dialysis is more cost effective than haemodialysis in a dialysis centre; satellite or home dialysis, however the choice of mode, should be based on patient preference and clinical suitability.	
144	Royal College of Physicians of Edinburgh	4 10 11	110 249 268	Are there factors which suggest that certain forms of RRT may be more appropriate for certain groups of people? Peritoneal dialysis is usually not suitable in very obese individuals; those with previous multiple abdominal surgery; hernias; or with known intra-abdominal adhesions. Transplantation is not suitable in those patients who have high cardiovascular risk or are, for any other reason, deemed unsuitable to undergo the surgical procedure. Clinicians should be more confident in offering conservative care to patients with advanced co-morbidity approaching end of life. Dialysis units tend to have some patients for whom the benefits of dialysis do not outweigh the costs – units need to be more realistic about the benefits of dialysis in this group and promote the concept of excellent supportive and palliative care. Also, patients without suitable family/carer support will not manage the home based therapies.	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.
145	Royal College of	5	112	What are the indicators for initiating RRT? This is variable and can either be driven by the patient or clinician:	Thank you for your comment. Your comment will be considered by the guideline committee

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	Physicians of Edinburgh			1. patient symptoms 2. level of kidney function, e.g. eGFR <8 ml/min – arbitrary cut off 3. persistent fluid overload not responding to medical therapy 4. persistent hyperkalaemia 5. clinical uraemia	when refining the review question
146	Royal College of Physicians of Edinburgh	5 10 3	118 250 71	What is the clinical and cost effectiveness of diet, and fluid management in people being prepared for RRT, undergoing RRT or receiving conservative management of end-stage CKD? These two simple measures are essential and extremely cost effective but a dedicated dietetic team is needed to ensure this is delivered effectively. This will help reduce hospital admissions and improve patients' quality of life but will not affect quantity of life.	Thank you for your comment. The guideline committee will refine the review question for this topic and fully discuss the available evidence when making their recommendations.
147	Royal College of Physicians of Edinburgh	5	124	What is the clinical and cost effectiveness of different sequences of RRT in people with end stage CKD? Ideally a patient should start RRT on their preferred option – changing between therapies adds cost and staff hours, in addition to disruption. A percentage of patients will change from dialysis to transplantation and vice versa. Movement to transplant is cost effective if the life expectancy of the	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review question.

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				transplant is at least 3 years – this is a potential future problem with the increasing use of marginal donors.	
148	Royal College of Physicians of Edinburgh	5 3	128 74	What are the indicators for discontinuing RRT? This remains a challenge when continuation of therapy becomes futile and not in the patient's best interests – the structure around this remains unclear and it often difficult to withdraw care with the patient's and family's consent. When the patient wants to stop, the process is much easier. There may be many reasons for this. Some feel that the treatment is too hard and the journey to the hospital 3 times a week is too much for them. Advancing heart disease or other chronic conditions can make the dialysis particularly difficult. Development of dementia may require consideration of stopping if it makes delivery challenging. However, old age itself is not a barrier to continuing dialysis.	Thank you for your comment. Your comment will be considered by the guideline committee when refining the review question.
149	University of Birmingham	4	101	We would like to highlight the need for and value of emotional and psychological support for people with CKD (and their carers). Dialysis and transplantation are demanding treatments that impact appreciably on the everyday lives of people with CKD often negatively affecting emotional and psychological wellbeing. Many people find the transition to dialysis frightening and traumatic. They can continue to experience periods of distress throughout their time on dialysis, due to the stress of treatment, loss of sexual function, altered body image, and	Thank you for your comment. Your comments will be considered by the guideline committee when discussing the review questions. Any evidence from the references provided that meet the review question protocol criteria will be presented to the guideline committee. Any evidence from the references provided that

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				decreased physical and cognitive functioning, as well as knock-on effects for employment, relationships and lifestyle. People with transplants experience many of the same stresses, along with fear of transplant failure and significant distress if a transplant does fail. [1] The prevalence of depression or anxiety in the RRT population is around four times higher than in the general adult population [2], while a recent study found that more than a third of patients on dialysis experienced emotional difficulties, particularly during the transition to dialysis and early months on dialysis. [3] Furthermore, untreated psychosocial problems are associated with withdrawal from dialysis, poor medication and diet compliance and reduced ability to engage in pre-RRT education and treatment choice. [1] Yet management of people's emotional and psychological difficulties, particularly at the lower level, remains suboptimal. Access to support is often restricted to patients with higher-level needs requiring psychiatric or psychological intervention. People want improved lower-level support, yet their needs tend to be ignored and frequently remain untreated. Significantly, people want flexible provision of support interventions around key points of need which can arise across the RRT pathway, not only at the key transition points. [4,5] Additionally, the implementation of low-cost support interventions[6] has the potential to save costs by helping prevent the increased hospitalisation associated with depression in people with RRT. [7] 1. Taylor F, Taylor C, Baharani J, Nicholas J, Combes G. Integrating emotional and psychological support into the end-stage renal disease pathway: A protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed. BMC Neph 2016; 17:111	meet the review question protocol criteria will be presented to the guideline committee.

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				2. Palmer S, Vecchio M, Craig JC et al. Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. Kidney Int 2013; 84: 179-191 3. Combes G, Allen K, Sein K, Girling A and Lilford R. Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates. Implement Sci 2015; 10:148 4. Early findings not yet published from: Taylor F, Taylor C, Baharani J, Nicholas J, Combes G. Integrating emotional and psychological support into the end-stage renal disease pathway: A protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed. BMC Neph 2016;17:111 5. Taylor F, Hare J, Combes G. Exploring patients' attitudes to different intervention approaches for supporting psychosocial needs. J Ren Care 2016 (In Press) 6. Taylor F, Combes G, Hare J. Improving clinical skills to support the emotional and psychological well-being of patients with end-stage renal disease: a qualitative evaluation of two interventions. Clin Kidney J 2016; 9(3): 516-524 7. Hedayati SS, Bosworth HB, Briley LP. Death or hospitalization of patients on chronic hemodialysis is associated with a physician-based diagnosis of depression. Kidney Int 2008; **74**:930-936	
150	University of Birmingha	4	101	The draft scope does not specifically include psychological support and treatment. Maybe this is intended to be covered under the heading of support. However, given that many renal units do not have adequate psychological	Thank you for your comment. Psychological support is included under the scope topic 'information, education and

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	m			services for renal patients, it would be useful to consider this aspect of support separately and in its own right.	support'. The proposed guideline committee membership includes a psychologist/counsellor.
151	University of Birmingham	4	102	The draft scope limits information, education and support to times of transition. This should not be restricted to transitions, as there is considerable evidence that RRT patients require and benefit from information, education and support being provided for patients on RRT on an on-going basis, as well as during the pre-dialysis period when patients are choosing their treatment. Example of evidence for the need for on-going support: Combes, G, Allen, K, Sein, K, Girling, A & Lilford, R 2015, 'Taking hospital treatments home: a mixed methods case study looking at the barriers and success factors for home dialysis treatment and the influence of a target on uptake rates' Implementation Science, vol. 10, no. 148, 148., 10.1186/s13012-015-0344-8	Thank you for your comment. The scope topic 'information, education and support' is not restricted to transitions. The guideline committee will consider your comment when refining the review questions.
152	University of Birmingham	9	217	The diagram is inconsistent with the text in section 1.5. The diagram shows information, education and support only in the pre-dialysis period, rather than at transition points (page 4 line 102).	Thank you for your comment. The diagram is intended to give an overview of the scope topics we will cover rather than provide a care pathway for patients. The diagram will be edited by the guideline committee.

Registered stakeholders

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