RRT: scope workshop discussions Date: 08/07/16		
Scope details	**Questions for discussion**	**Stakeholder responses**
1.1 Who is the focus		
Groups that will be covered: • Adults (18 and over) with CKD	• Is the age cut off aligned with how clinical services are organised?	Stakeholders agreed with the age cut off being proposed for adults; however, they felt the stage of CKD should be made explicit so not to contradict the groups not covered. Stakeholders offered suggestions for rephrasing such as 'CKD stages 4 & 5'.
• Children (under 18) with CKD	• Is the age cut off aligned with how clinical services are organised? • Is it reasonable to include children and adults in one guideline	Most stakeholders agreed that children should be covered in the development of this guideline, although they recognised this would be challenging. There was consensus that one of the most important reasons for keeping both groups would be to find a mechanism to close the gap between children and adult services so that those moving between the two are prepared for the transition. Stakeholders felt the age cut was appropriate to how clinical services are organised, although some centres currently use a cut-off of 16 years of age. A number of stakeholders mentioned that the under 2's should be given special consideration for the way they are managed with the exception of the technical aspects of dialysis which will not be covered by the guideline. In addition some research exists for this population.
Special consideration will be given to: • Older people	• Is there a specific age threshold? • What are the specific considerations for this group?	Stakeholders noted the difficulty of defining a specific age threshold and felt that frailty/multimorbidity might be a more relevant issue than age. However, they concluded that it probably is helpful to have this as a group to focus people on conservative management. In the context of reviewing the evidence they felt that a minimum reasonable age would be around 70 years.
• People from Black, Asian and minority communities	• What are the specific considerations for this group?	Stakeholders highlighted communication, education in communities and access to transplantation as areas that required specific consideration for this group. It was considered a useful group to have.

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• People with diabetes	• What are the specific considerations for this group?	Some stakeholders pointed out there are other conditions whose outcomes are more divergent than diabetes (e.g., people on immunosuppression, with hypertension or with cardiovascular disease). However, most stakeholders agreed that there is a difference for people with diabetes in outcomes for transplantation and in transplant modality (pancreas and kidneys). These differences would justify transplanting earlier in people with diabetes and therefore they could be considered separately. Stakeholders also pointed out that Type 1 and 2 may have to be considered separately - there are more issues around lifestyle management for Type 2. Moreover, many people with Type 2 diabetes do not have diabetes as the cause of their renal failure; the diabetes usually is the cause with Type 1.
• Are there any other groups that have not been mentioned (in lists above)?		The majority of stakeholders reported unplanned starters (crash landers) were an important group for inclusion (both those who know and do not know they have kidney failure). This population is of particular importance as they often miss the information and support given to people who have a planned introduction of RRT .
Groups that will not be covered: • People with Stages 1- 4 CKD except when planning/preparing people for RRT • People with Acute Kidney Injury (AKI)	• Are the exclusions appropriate for the guideline?	Stakeholders felt that CKD stage 4 should not be excluded as searches may miss important evidence on early planning of RRT. It would be appropriate to exclude stages 1-3. Stakeholders felt the wording around AKI needed improving as it might currently imply that those with AKI provoking a long term need for RRT would be excluded. The exclusion stakeholders feel is appropriate is those with AKI requiring short term RRT whose need for RRT is expected to resolve in the near term.
1.2. Settings		
• All settings where NHS commissioned	• Are the listed settings appropriate?	Settings were considered appropriate by stakeholders.

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care is provided to people who might require renal replacement (including home care)	• Are there other settings that should be considered?	
1.3 Activities, services or aspects of care		
Key areas that will be covered: 1 Assessment and monitoring of people with deteriorating renal function who appear likely to require RRT - when should they be seen by the nephrologist and multidisciplinary team to discuss and prepare people/families for RRT - what assessment is required (identifying needs, history and examination, special investigations) - what monitoring is required following initial assessment	SEE LIST OF KEY QUESTIONS • Is this area clear/understandable? • Are there any specific issues relating to assessment and monitoring to consider? • Have any areas not been mentioned? **NOTE:** specific questions about assessment and monitoring are discussed below. This relates to the broad issues.	Stakeholders felt this section had an overlap with the CKD guideline (except for children) and so the area could focus more specifically on preparation for RRT. With regards to monitoring, stakeholders were not in favour of specifying a time-point for monitoring as it depends on the individual's disease/comorbidities. They also felt that monitoring should be accompanied by follow-up to ensure an on-going review process. Stakeholders also noted that a wider group of specialists may be involved in the MDT. For example, a surgical/transplant team is also involved at this early stage. A number of stakeholders felt that it should be made clear that an individual may be on two pathways at the same time, for example, those on the transplant pathway alongside the RRT pathway and that planning, monitoring and follow-up should take this into account.
2 Information and support for people who may require RRT and their families or carers	• Is this area clear/understandable? • Are there any specific issues relating to information and support to consider? **NOTE:** specific questions about information and support are discussed below.	Stakeholders felt this was an important area. One issue that was highlighted was how information is provided (written, face-to-face, telephone, electronic). All options should be considered, discussed and documented. It was pointed out that one particular format should not be relied upon alone. The importance of face-to-face discussions was highlighted, and it was suggested that a single standardised national information booklet would be very helpful. Moreover, many stakeholders felt that education which includes information would be more comprehensive rather than information on its own. The

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			stakeholders discussed the variation across the country with regards to the provision and uptake of education programmes although highlighted that there is some evidence on these from Australia and New Zealand.
3	Decision-making for people who may require RRT and their families or carers, including choice of conservative management	• Is this area clear/understandable? • Are there any specific issues relating to decision making and patient choice to consider? • Are the issues the same for adults and for children **NOTE:** specific questions about decision-making are discussed below.	Stakeholders suggested that decisions should not be seen as once-only decisions and that the emotional and psychosocial needs of the person and their family /carers should be factored in, together with modality and other issues that may affect decision-making (e.g. access issues).
4	Renal replacement therapy - which modality for which person and when	• Is this area clear/understandable? • Are there any specific issues relating to the delivery and timing of different models of RRT? • Any considerations for specific groups? • Are the issues the same for adults and for children? **NOTE:** specific questions about the delivery and timing of RRT are discussed below.	Stakeholders were in agreement for the inclusion of this key area and suggested that there is some evidence pointing towards the pattern of offering/receiving certain treatments before others, although differences in outcomes between modalities are not pronounced. The importance of patient and family /carers choice was reiterated: individuals should know they can change their mind and choose a different form of RRT if they wish. Moreover, stakeholders pointed out local issues related to access to the different modalities. Stakeholders noted that conservative therapy is currently less well characterised than other modalities and therefore it should be explicitly added as an alternative option to the other modalities.

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5	Symptomatic and metabolic management and self-management (treatment and interventions, side effects and complications) for people being prepared for or receiving RRT or conservative management of end stage kidney disease (e.g. diet and fluids, blood pressure)	• Is this area clear/understandable? • Does it make sense to include these different groups i.e. people being prepared for/receiving RRT/conservative care • Are there any specific issues relating to the management and self-management? • Have any areas not been mentioned? • What symptomatic and metabolic areas should we include? **NOTE:** specific questions about management and self-management are discussed below.	The group felt that this area of the scope was too broad and highlighted that some key issues are addressed in other guidelines (e.g. anaemia management in CKD). Given the range of symptoms and management strategies it was felt that symptom control may be more applicable and that this should be separated from metabolic management. Moreover, stakeholders noted that management is a blend of clinical advice and patient participation, so there is no need to distinguish between management and self-management. From a paediatric perspective it was noted that growth is a fundamental issue.
6	Ongoing care including transitioning between forms of RRT and conservative management (follow-up and review, health maintenance)	• Is this area clear/understandable? • Are there any specific issues relating to the ongoing care? • Have any areas not been mentioned? **NOTE:** specific questions about ongoing care are discussed below.	Stakeholders felt there were a number of additional areas to include, for example, the transition from children to adults services, as well as the transitioning from home to hospital and vice versa. It was noted that NICE already have a guideline on transition from children to adult services. The stakeholders discussed the transfer to conservative management and different terminological options were suggested to convey the idea that the person is still receiving care. The stakeholders noted that the transfer from transplant back onto dialysis or conservative care is perhaps the most difficult transfer.
7	Coordination of care between different specialties involved in the care of patients (e.g. diabetes/cardiology/liver specialists/primary care/mental health	• Is this area clear/understandable? • Are there any specific issues relating to the coordination of care? • Have any areas not been mentioned? • Is there evidence in this area?	Stakeholders agreed that coordination is poor at present and service availability is not uniform across the country. For this reason, it is useful to keep in this area of the scope to encourage improvement. Stakeholder suggested that it would be useful to have a section of models of care within the guideline.

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teams)	NOTE: specific questions about coordination of care are discussed below.	It was noted that models of care have been established for young people in Manchester, Oxford, London (Royal Free). There is also the Ready. Steady, Go model in Southampton. Moreover, there are published MDT models around the diabetic foot that may be relevant to consider here/ use as a good example for a model which works well for coordinated care. Some stakeholders suggested that a hub and spoke model may work quite well – it could be relevant to consider geographical coordination as well as coordination between specialties.
Areas that will not be covered: 1 Assessment and management of chronic kidney disease 2 Acute kidney injury 3 Anaemia in CKD 4 Bone mineral disorder 5 Technical aspects of delivery of RRT	• Are the excluded areas appropriate?	Stakeholders agreed with the proposed exclusions; however, they noted that AKI should be covered when it provokes a need for long-term RTT; the management of AKI should be excluded. It was also highlighted that guidance on BCM (body composition monitoring) is being developed at the moment. Other areas of potential overlap with other guidance are preparation for RRT (CKD guideline) and conservative management (Palliative care guideline).
1.4 Economic Aspects		
An economic plan will be developed that states for each review question/key area in the scope, the relevance of economic considerations, and if so, whether this area should be prioritised for economic modelling and analysis.	• Which practices will have the most marked or **biggest health or cost** implications for the NHS? • Are there any **new practices** that might **save the NHS money** compared to existing practice?	Conservative management was highlighted as a key economic issue: • Currently there is no tariff for conservative management. Stakeholders agreed it needs to be legitimised as an option. They also pointed out that conservative management is currently funded separately from RRT. • The value of conservative management was also considered to be important as it is the most cost effective option.

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	• Do you have any further comments on economics?	Transport, support and access costs were identified by stakeholders as issues that need to be considered – it was noted that it is important to include these when costing different modalities of RRT.
1.5 Key issues and questions		
This section expands upon the areas mentioned in section 1.3. This section should therefore give more of the detail of what the key issues are within that area and what questions will be asked to address those issues.	SEE LIST OF KEY QUESTIONS • Are there any critical clinical issues that have been missed from the Scope that will make a difference to patient care? • Would you like to add any additional questions to this list? • Are there any areas currently in the Scope that are **irrelevant** and should be deleted?	Questions were discussed alongside the scope and as such discussion of questions is incorporated above.

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1.6 Main Outcomes		
1. Health related quality of life (e.g. EQ-5D, SF-36) 2. Symptom scores and functional measures (e.g. Karnofsky, Barthel, WHO 1-5, IPOS-Renal)? 3. Rehabilitation/return to work 4. Psychological distress/mental wellbeing 5. Patient experience of care 6. Survival (mortality) 7. Adverse events – infections – vascular access issues – dialysis access issues (e.g. PD catheter) – cardiac events? – hospitalisation – family and carer outcomes – transplant rejection and failure	**General** • Is the list of outcomes appropriate? Are any key outcomes missing? • How would you prioritise the outcomes?	Stakeholders suggested that failure as an outcome refers not only to transplants but to any RRT. On the other hand, transplant rejection may be an episode. The addition of live donors outcomes was suggested by some stakeholders. The 'return to work / usual activities' outcome was considered problematic to pin down. Some stakeholder felt that cardiac events were not helpful as an outcome.

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GDG Membership

Full committee members

Chair	1	
Clinical Lead	1	
Nephrologist	1	
Paediatric Nephrologist	1	
Transplant physician/surgeon	1	
GP	1	
Renal specialist nurse	2-3	Including community, adult and paediatric
Lay members	2-3	
Care of the elderly physician	1	
Social worker	1	Adult or paediatric with experience of working in RRT
Psychologist	1	
Palliative care physician/nurse	1	

Co-opted expert witnesses

Area of expertise	No.	Notes
Renal pharmacist	1	
Dietitian	1	

- Are any full members missing?
- Could some of the listed members be expert advisors instead?

A number of additions were suggested by stakeholders

<u>Full members</u>

- Transplant and dialysis renal specialist nurses
- Renal psychologist or counsellor

<u>Co-opted members</u>

- Young person (could be a lay member) who would be key when looking at the transition between children and adult services
- Youth advocate/worker
- Social worker. Stakeholders felt it could be a topic-specific expert rather than a full member.

Further questions:	**Stakeholder responses**

Further questions:	**Stakeholder responses**
1. Are there areas of **diverse or unsafe practice** or uncertainty that require addressing?	
2. Is there anything in draft scope that we do not need to look at	
3. Are there any areas that you think should be included for the purposes of the **quality standard**? Are there any **service delivery** or service configuration issues that you think are important?	
4. Are there any specific equality considerations that the guideline needs to take into account?	
5. Any other issues raised during subgroup discussion for noting:	