

## CKD treatment burden and capacity

## Appendix 1 – Interview guide for patient interviews

<p><b>Experience of CKD and treatment burden</b></p> <p>(how patients make sense of CKD and its treatment in the context of their other conditions)</p>	<p><i>Can you tell me a bit about your health with regard to your kidneys and what you understand?</i></p> <p>have you been told you have a problem with your kidneys? Were you told this is called chronic kidney disease (CKD)?</p> <p>How did you find out about your chronic kidney disease?</p> <p>What medical tests did you have and why?</p> <p>What have you been told about CKD?</p> <p><i>Do you have other medical conditions? If so can you tell me about it?</i></p> <p><i>Have you been given treatment and do you know what they are for?</i></p> <p>How many treatment/medication do you have?</p> <p><i>What are your thoughts/ideas/worries about your treatments and management?</i></p> <p>For example, your experience of side effects, your ability to keep appointments.</p> <p><i>How difficult do you find it is to remember how or when to take medication?</i></p> <p><i>What things do you think influences whether you do what you are meant to with regard to treatment?</i></p> <p><b>How else have you found out about your treatments?</b> (Have you asked friends and family, read leaflets or books, watched television, looked on the internet?)</p> <p><b>Have you received lifestyle or other advice? From whom? And what do you understand from this advice?/What do you need to do to manage your health, from what you understand?</b></p> <p><i>What are the most challenging things you or people in your situation experience in regards to CKD and your other conditions?</i></p>
<p><b>Engagement with medical/care services and others</b></p> <p>(how CKD patients engage with others in terms of communicating about their illness and involving others in their care – cognitive participation)</p>	<p><i>How, if at all, are friends and family involved in your medical conditions and their treatments?</i></p> <p><i>Have you asked for help with finding out about your treatments or deciding on altering treatment plans?</i></p> <p><i>Do you ask friends and family to help you with treatments and lifestyle changes or do you do everything yourself?</i></p> <p><i>How do you organize getting prescriptions? (<b>organizational skills</b>)</i></p> <p><i>How do you organize getting to appointments?</i></p> <p><i>Thank you. Can you tell me a bit more about your typical month living with CKD and your other conditions?</i></p> <p>How many different types of clinics or therapists do you have to attend? For example, how often do you go to the GP or hospital each week or month? How many different specialists/hospital clinics do you see/go to?</p> <p><i>Do you experience difficulty with communication with health services? What is the nature of that difficulty?</i></p> <p><i>How confident are you in your GP? and other health professionals? (<b>separate the two</b>)</i></p>

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	<p><i>What are your thoughts about how well care is coordinated? How well do health professionals communicate with each other and with you?</i></p> <p><i>What sort of things do you discuss with your GP or specialist about your treatment?</i></p> <p><i>When would you ask the doctor for help, for example, make an emergency appointment?</i></p> <p><i>How difficult or easy is it to get appointments, or access advice?</i></p> <p><i>Do you experience any problems related to the location of the health services being?</i></p> <p><i>What is your perception of the ability of people to access health services? Do you think this is fair?</i></p> <p><i>What would you change about the health services of care that you use if you could?</i></p>
<p><b>Capacity components and strategies</b></p> <p><b>(this section should be guided by the responses to the previous sections)</b></p>	<p><i>Have you adapted or modified treatments in any way in order to help you manage? If so, what sort of things have you done?</i></p> <p><i>What strategies have you used to overcome barriers? e.g. physical, psychological, practical</i></p> <p><i>For example have you altered priorities, set routine to cope with symptoms, exacerbations?</i></p> <p><i>How have you controlled risks associated with recovery and how have you ensured you achieve goals?</i></p> <p><i>How have you integrated your condition into social circumstances? Adjust to new social roles?</i></p> <p><i>What do you feel are the helpful things in your life that enable you to cope with your conditions?</i></p> <p><i>Do you do particular things to keep up to date with new treatments or the latest information on your condition? (<b>routine self-monitoring</b>)</i></p> <p><i>What have you done in order to overcome/deal with the communication issues in health services we discussed earlier?</i></p> <p><i>Have there been changes in health services that have positively or negatively influenced your ability to manage your conditions?</i></p>

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## Appendix 2- Topic guide for kidney care team

<b>The burden of CKD</b>	<ol style="list-style-type: none"> <li>1. <u>What things do you perceive that patients with CKD have to do to manage the condition well?</u></li> <li>2. <u>Which aspects of having and managing CKD do you think place a burden on people with CKD?</u></li> <li>3. <u>What role do you think other co-existing long term conditions play in the burden people with CKD experience?</u></li> <li>4. <u>How do you think the burden of CKD changes if it gets more severe from CKD stage 3b to 4, and from 4 to 5?</u></li> <li>5. <u>What factors would you look for that indicate a patient is struggling to manage their CKD?</u>  Prompts: <ol style="list-style-type: none"> <li>a. DNA, non-compliance with medication</li> </ol> </li> <li>6. <u>What are your thoughts on current guidelines for CKD and the burdens they place on patients?</u>  Prompts: <ol style="list-style-type: none"> <li>a. What are your thoughts on the current NICE guidelines?</li> <li>b. How easy are the guidelines to follow?</li> <li>c. What questions do the guidelines leave you with?</li> </ol> </li> </ol>
Capacity among people with CKD	<ol style="list-style-type: none"> <li>1. <u>What things do you perceive help patients with CKD manage the condition?</u> Prompt – which things influence patient capacity?</li> <li>2. <u>Which things do you think might alleviate the burden on people with CKD we discussed earlier?</u></li> <li>3. <u>What role do you think other co-existing long term conditions play in influencing people’s capacity?</u></li> <li>4. <u>How do you think people’s capacity changes if CKD gets more severe?</u></li> <li>5. <u>How do you think imbalances between workload and capacity might affect self-care/outcomes?</u> For example if workload is high and capacity is low.</li> </ol>
<b>Services for people with CKD</b>	<ol style="list-style-type: none"> <li>1. <u>How do you think the care you give influences patient burden?</u></li> </ol>

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	<ol style="list-style-type: none"><li>2. <u>Which aspects of the care and the way it is delivered might increase burden?</u> Prompt: Are there ways in which you organise your service that help or hinder people with CKD?</li><li>3. <u>Are there any problems experienced related to location of services for people with CKD?</u></li><li>4. <u>What is your perception of the ability of people across this region to access services for their CKD?</u></li><li>5. <u>What might you do differently in your service if your focus was treatment burden?</u></li><li>6. <u>In what ways do you think clinicians can enhance patient capacity?</u></li></ol>
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