Supplementary Material 1. Question Guide

Hi everyone. Thank you for coming along today and we appreciate that you have agreed to be part of this discussion group. My name is <AT/TG> and I am a researcher at The University of Sydney. The reason we are here today is because we are interested in your thoughts about some of the words (terms) used in chronic kidney disease. We were asked by KDIGO to conduct this project. KDIGO is a global kidney organization that develops guidelines and wants to make sure that the words and terms used to describe kidney function and disease, and treatment, are 'patient-centred" – that they make sense, are meaningful, and easily understood. This is because the terms used in research may be understood or interpreted differently between patients and health professionals, and the terms used may be confusing. They want to improve the terms used to create a patient-centred glossary of terms related to kidney function, kidney disease, and treatment, to support better communication. We want to understand patient perspectives on the definitions, interpretation and impact of the terms used in chronic kidney disease.

1. **Introduction**
   Think about the times you have talked with doctors or things may have read or heard about kidney function/kidney disease.
   - What do you think are the most difficult or challenging terms/words used – why?
   - How do you define these, did anyone explain or define them? (include written/online sources)
   - What do these terms mean to you personally?
   - What impact do these terms have (e.g. emotional, identity, social, self-management and control)?
   - What words/terms would you use instead?
   - Are there any words/terms that you think should never be used or would change – why?

2. **Terms to describe kidney function and disease (based on KDIGO Nomenclature Scope of Work)**
   - What are your thoughts about the following terms – how would you define it, what do these terms mean to you, and what impact does it have? Would you change the term, what would you change it to, why? If the term was changed, what impact do you think it would have (e.g. perceived severity, perception of diagnosis/treatment, decision-making)?
     a) Kidney versus renal
     b) Kidney function and measures *e.g. glomerular filtration rate, CKD stages*
     c) Chronic kidney disease
     d) End-stage kidney disease
     e) Kidney failure
   - What term would you use to describe a patient with chronic kidney disease but does not yet need dialysis or kidney transplant - why? (non-dialysis-dependent CKD, pre-dialysis, CKD/kidney failure without kidney replacement therapy)

3. **Symptoms to characterize kidney failure**
   - Did the symptoms (and severity) shape your decisions about treatment – how/why? Did you consider these in the context of other things that influence your decisions?
   - Should we use terms relating to symptoms to try and describe the severity of kidney failure, and to classify kidney failure in a consistent and meaningful way – why/how?

Table S1. Focus groups contributing to each theme

Theme	Focus group ID
Provoking and exacerbating undue trauma	
Fear of the unknown	1, 5, 6, 9, 10
Denoting impending death	1, 2, 3, 4, 5, 6, 7, 8, 9, 10
Despair in having incurable or untreatable disease	1, 2, 4, 5, 6, 7, 8, 9, 10
Premature labelling an assumptions	1, 2, 3, 4, 5, 7, 9, 10
Judgment, stigma, and failure of self	1, 2, 3, 4, 5, 6, 7, 8, 9
Frustrated by ambiguity	
Confused by medicalized language	1, 2, 3, 4, 5, 6, 7, 8, 9, 10
Lacking personal relevance	1, 2, 3, 7, 8, 9
Baffled by imprecision in meaning	1, 2, 4, 5, 6, 7, 9, 10
Opposed to obsolete terms	7
Making sense of the prognostic enigma	
Conceptualizing level of kidney function	1, 2, 3, 4, 5, 6, 7, 8, 9, 10
Correlating with symptoms and life impact	1, 3, 4, 5, 6, 7, 8, 10
Predicting progression and need for intervention	1, 2, 3, 4, 5, 6, 7, 8, 9, 10
Mobilizing self-management	
Confronting reality	1, 2, 3, 4, 5, 6, 8, 9
Enabling planning and preparation	1, 2, 4, 5, 9
Taking ownership for change	1, 2, 3, 4, 5, 8, 9
Learning medical terms for self-advocacy	2, 5, 8, 10
Educating others	5, 6, 7, 9