

**Supplementary Item 1.** Participating sites and institutional review boards.

Monash Medical Centre, Monash Health, Melbourne, Victoria, Australia

Princess Alexandra Hospital, Woolloongabba, Brisbane, Australia

Westmead Hospital, Westmead, Sydney, New South Wales, Australia

Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center, Torrance,  
United States

York Hospital, Clifton, York, United Kingdom

Imperial College London, South Kensington, London, United Kingdom

Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, United Kingdom

Queen Mary Hospital, The University of Hong Kong, Hong Kong

Tuen Mun Hospital, Tuen Mun, Hong Kong

Princess Margaret Hospital, Kwai Chung, Hong Kong

Pok Oi Hospital, Yuen Long, Northwest New Territories, Hong Kong

## **Supplementary Item 2.** Question guide

1. What are the major features that affect you day-to-day?
2. To what extent do you feel like you have control/ownership over your kidney health  
- why?
3. Is there anything that you do to “manage” your health – why?
4. Do you feel the need to have access to research figures and numbers in making  
decisions about your health?
5. What are your preferences about accessing this information? (i.e. online, healthcare  
provider or some other way)
6. What are the biggest challenges to deal with in managing your health and how do  
you cope?
7. What are your health goals in the short term (up to 3 years) and in the longer term;  
and is there anything you are thinking of/or doing in view of these goals?

**Supplementary Table 1.** Distribution of the identified themes by country, age group, stage of kidney disease and type of glomerular disease.

	<b>Themes*</b>			
	<b>Necessity of health-sustaining relationships</b>	<b>Empowered in autonomy</b>	<b>Striving for stability and normalcy</b>	<b>Overwhelmed by compounding treatment burdens</b>
Country				
Australia	100	169	175	129
United States	66	56	56	49
United Kingdom	48	51	54	41
Hong Kong	11	21	13	9
Age group (years)				
18-39	69	88	89	74
40-59	50	81	86	67
60-79	76	99	101	70
Treatment stage of kidney disease				
Chronic kidney disease	139	210	204	156
Hemodialysis	22	23	38	25
Peritoneal dialysis	13	15	15	4
Kidney transplant	29	29	26	29
Type of glomerular disease				
Lupus nephritis	36	38	57	44
ANCA-associated vasculitis	31	30	40	37
IgA nephropathy	30	75	45	27
Focal segmental glomerulosclerosis	29	33	35	22
Membranous nephropathy	6	17	15	11
Minimal change disease	8	15	12	13
Membranoproliferative glomerulonephritis	9	13	8	18
C3 glomerulopathy	15	12	9	6
Anti-glomerular basement membrane disease	-	2	11	4
IgG4-related disease	5	4	2	6

\*Number of coding instances for themes also varied by different numbers of participants per country, age group, stage of kidney disease and type of glomerular disease.