

# Design of a Patient-Informed Chronic Kidney Disease (CKD) Experience Interview Guide: Learnings From DISCOVER CKD

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## Background and objectives

- Patients with CKD have a high symptom burden and reduced health-related quality of life (HRQoL), even in the early stages of disease<sup>1,2</sup>
- Real-world data from patients with CKD, particularly regarding clinical management, treatment patterns and HRQoL in the context of new therapies and updated standard of care guidelines, are limited<sup>3</sup>
- DISCOVER CKD (ClinicalTrials.gov identifier: NCT04034992) is a multinational, observational study to characterise the epidemiology of CKD and describe clinical outcomes, including disease progression, pharmacological interventions and important clinical events across the patient journey
- From the prospective cohort of DISCOVER CKD, ~100 telephone-based interviews were conducted with patients from Japan, the US, the UK and Spain to understand more about the patient CKD experience, including symptoms, disease impact and care. A Discussion Guide was developed by a multidisciplinary team of patient-centred science experts, and medical and life sciences professionals to guide patient interviews
- The aim of this analysis was to obtain patient feedback about the Discussion Guide to evaluate whether the language and questions asked during the interviews are appropriate and presented in a manner that will help generate important insight about patient experiences of CKD


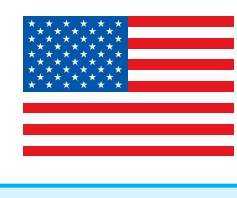



## Methods

- The Discussion Guide was reviewed by patient advocates who commented on clarity, order and relevance of individual sections/questions, and made recommended modifications
  - Patient advocates were identified from a patient council pool available via the AstraZeneca Patient Partnership Program

## Results

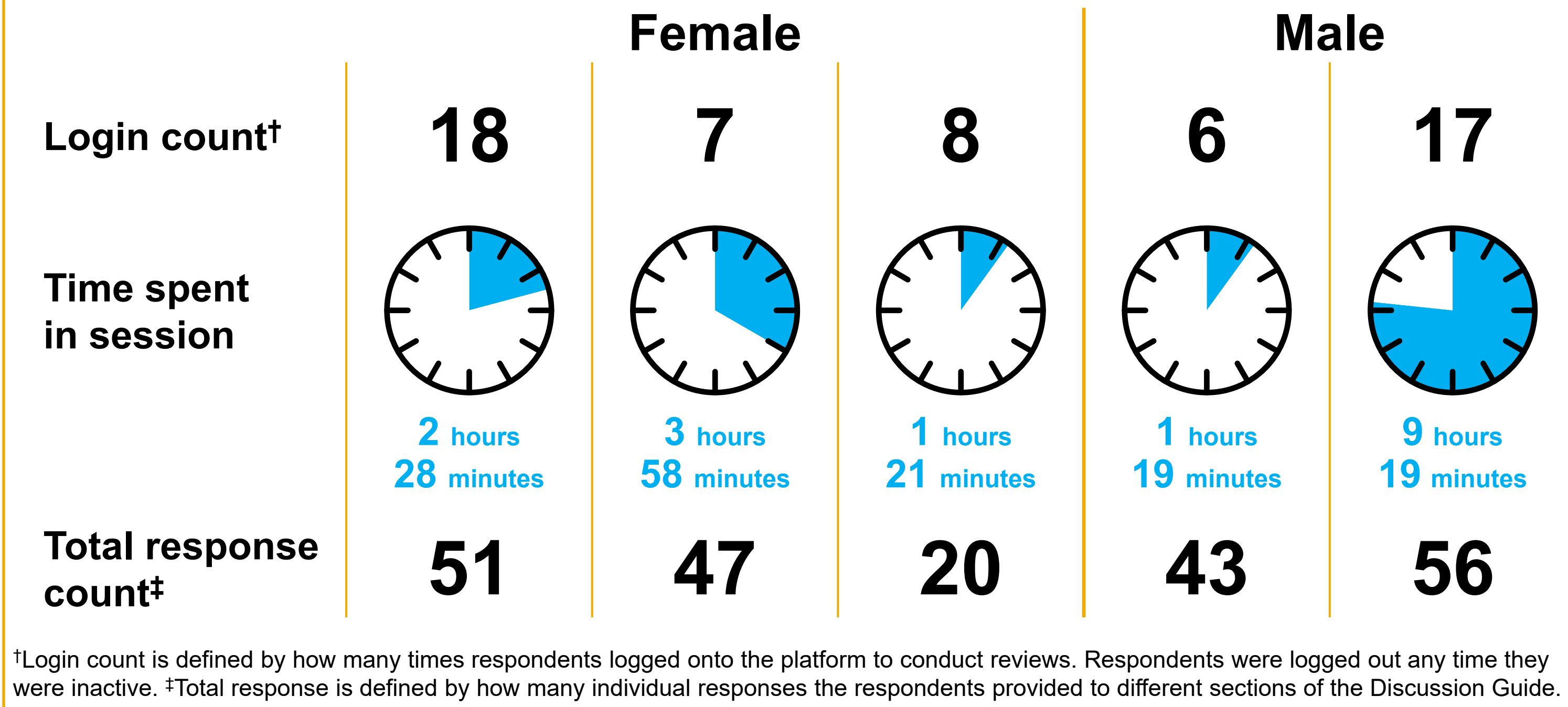
- Five patient advocates with a primary diagnosis of CKD reviewed the Discussion Guide (**Table 1**); the median time reviewing the Discussion Guide was ~2.5 hours (**Figure 1**)

Table 1. Patient advocate profiles

Sex	Country	Age range, years	Ethnicity	CKD stage	Years since CKD diagnosis
F	 UK	55–60	Black	3B	20
F	 US	65–70	White	5	13
M	 Australia	20–25	Asian	4	9
M	 UK	51–60	Black	5	7
F	 UK	55–60	African	3A	18

CKD, chronic kidney disease; F, female; M, male.

Figure 1. Participation metrics by patient advocates



## Discussion Guide overall feedback

- Most respondents (n=3) were unsure if there are too many questions to cover within 60–90 minutes
- According to all respondents, the most important sections of the Discussion Guide are:
  - Section B: “Diagnosis and Disease Progression”; Section C: “Disease Journey and Treatments”; Section D: “Current Experience with CKD”, including symptoms/impact
- Of the respondents who replied (n=4), none felt that there are any missing topics that should be considered for the interviews
- Respondents generally found the Discussion Guide to be well designed (**Table 2**)
  - There were recommendations for reordering, removing, adding and rewording questions for clarity/ simplicity, as well as ensuring provision for comfort breaks during interviews, and avoiding question repetition

Table 2. Patient advocate feedback on each section of the Discussion Guide

Questions asked to patient advocates	Section A: Introduction Questions to Patients	Section B: Diagnosis and Disease Progression	Section C: Disease Journey and Treatments	Section D: Current Experience with CKD
Did you find the questions easy to understand?	Yes (n=3); Unsure (n=1)	Yes (n=3)	Yes (n=3)	Yes (n=3)
Would you change the order of any questions?	No (n=2); Yes (n=1); Unsure (n=1)	No (n=3)	No (n=2); Yes (n=1)	No (n=3)
Would you remove any questions?	No (n=4)	No (n=3)	No (n=2); Unsure (n=1)	No (n=2); Unsure (n=1)
Would you add any other questions?	Unsure (n=1); No (n=1); Yes (n=1)	Unsure (n=1); No (n=1); Yes (n=1)	Unsure (n=1); No (n=1); Yes (n=1)	No (n=3)

CKD, chronic kidney disease.

## Key interview conduct recommendations

- Include provision for comfort breaks, as needed, during the interview
- Do not ask a question to which a patient already provided the answer as part of an earlier response

### Actionable recommendations

- Develop a CKD information leaflet or website for patients
  - Include information on different stages of disease
- Run educational sessions for patients to increase disease awareness
  - Include the importance of timely diagnosis and treatment
- Discuss with physicians the importance of explaining different stages of CKD to the patient
- Conduct sessions with general practitioners to support timely referral to a nephrologist of patients showing CKD symptoms
- Comfort breaks should be provided as needed during the interview
- Instruct interviewer to avoid repeating questions if the interviewee has already responded on that topic



“I think this (interview guide) is pretty comprehensive and I think the answers will be very frightening when people tell their tales of the CKD journey. I like the opportunity to have a real discussion on the shortcomings of diagnosis and treatment”

## Conclusions

- Patient involvement improved the Discussion Guide by streamlining the type and nature of questions included
- This could contribute to a better patient interview experience and lead to generation of more patient-relevant CKD insights

## References

- Brown SA et al. *Clin Kidney J.* 2017;10:788–796.
  - Cruz MC et al. *Clinics.* 2011;66:991–995.
  - Pecoits-Filho R et al. *Clin Kidney J.* 2021;14:1570–1578.
- Cartoon image by Studiostock on Freepik.

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