Appendix 1. Overview of key steps in the James Lind Alliance (JLA) chronic kidney disease priority-setting project
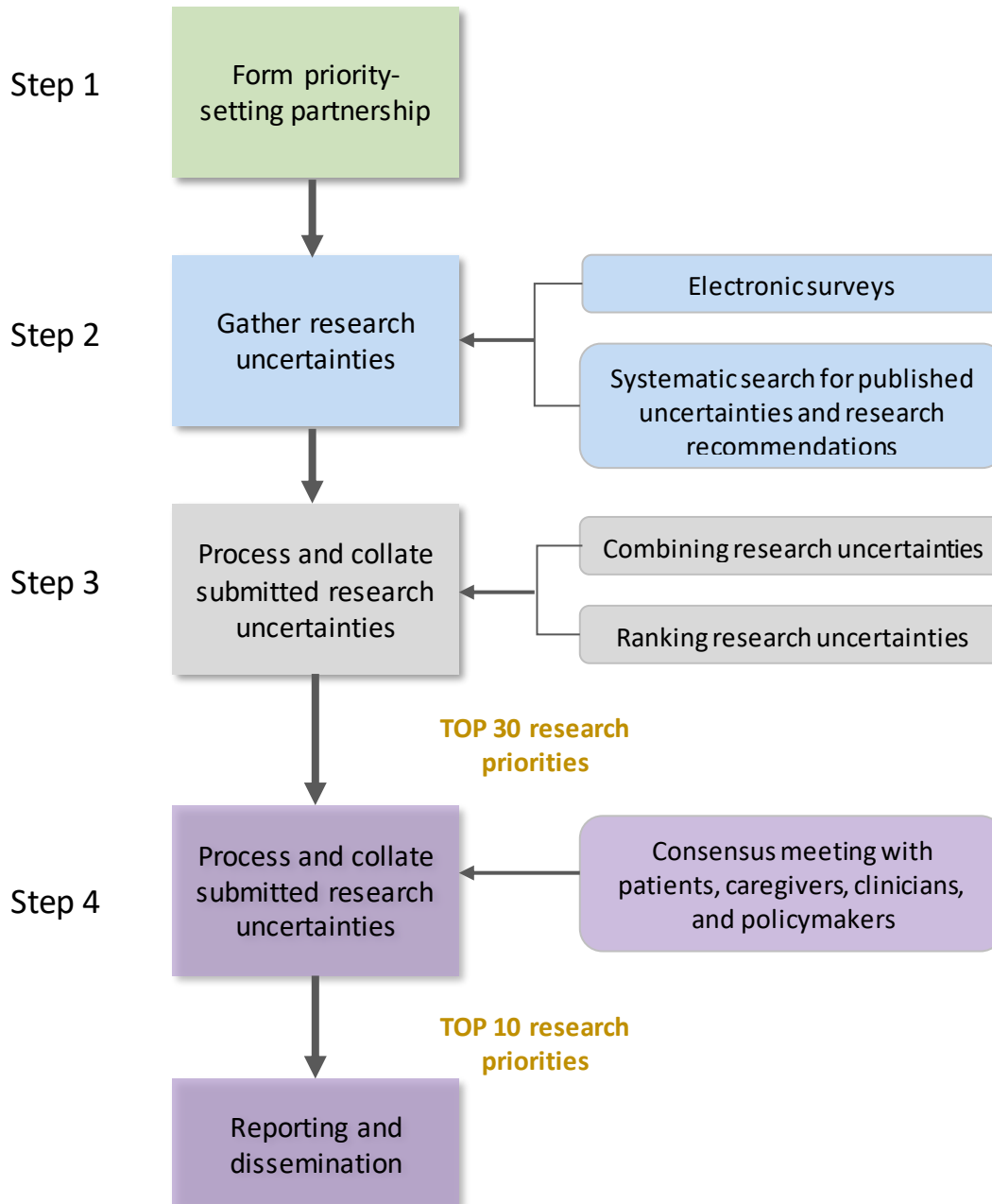
Step 1 — Form priority-setting partnership

Step 2 — Gather research uncertainties
- Electronic surveys
- Systematic search for published uncertainties and research recommendations

Step 3 — Process and collate submitted research uncertainties
- Combining research uncertainties
- Ranking research uncertainties

TOP 30 research priorities

Step 4 — Process and collate submitted research uncertainties
- Consensus meeting with patients, caregivers, clinicians, and policymakers

TOP 10 research priorities

Reporting and dissemination

Appendix 2. COREQ 32-item checklist

Item	Description
Domain 1: Research Team and Reflexivity	
1. Interviewer/facilitator	Meghan J. Elliott
2. Credentials	MD (MSc – this study formed part of her thesis project)
3. Occupation	Nephrologist
4. Gender	Female
5. Experience and training	Dr. Elliott is a nephrologist who undertook this project as part of her MSc thesis. She has several years' experience as a clinical nephrologist, including engagement of patients and other healthcare professionals in the clinical setting. She has experience in clinical epidemiological research and received formal training in advanced qualitative research methodology during her graduate degree.
6. Relationship established	Dr. Elliott had worked with participants on the prior CKD research priority-setting partnership as a steering committee member and investigator of the RCT comparing two approaches to collaborative prioritization.
7. Participant knowledge of interviewer	Participants were aware of the aims and rationale of the study; they had worked together previously in a research setting where Dr. Elliott oversaw the priority-setting partnership and RCT as a steering committee member.
8. Interviewer characteristics	Dr. Elliott used her first name in all interviews and disclosed her role as a nephrologist, researcher, and graduate student. She also disclosed her role in the previous priority-setting project, and the aims of the present study which included advancing our understanding of stakeholders' experiences as partners in research. Reflexive notes were taken at all stages of this project, to which the interviewer referred during the analysis and interpretative phases to refine our findings.
Domain 2: Study Design	
9. Methodological orientation and theory	Qualitative description, with a constructionist orientation; thematic analysis
10. Sampling	Maximum variation sampling (a purposive sampling strategy) from among 53 eligible stakeholder participants from the original priority-setting project, including CKD patients, caregivers, healthcare professionals, and policymakers. We aimed to sample across all stakeholder roles and engagement types (i.e. steering committee, workshop, wiki).
11. Method of approach	Eligible participants were sent an email inviting their participation in this study. If no response was received, a follow-up email was sent two weeks later. Both emails provided the opportunity to opt out of further correspondence with the study team. The interviewer followed up with interested participants by phone and/or email to schedule an interview.
12. Sample size	23 participants. Sampling continued until data saturation was reached. Six additional interviews were conducted at the expressed interest of participants and to refine evolving analytic insights.
13. Non-participation	5 eligible participants (3 patients, 2 caregivers) declined participation via email response; 4 eligible participants were not reached due to 'undeliverable' email addresses; 21 eligible participants did not respond to our email invitation. As representation across stakeholder roles/engagement types and data saturation were achieved, no further attempts at recruitment were made.
14. Setting of data collection	Telephone interviews were conducted from Dr. Elliott's research office at St. Michael's Hospital in Toronto, ON. Participants contributed to phone interviews from their location of choice, most often from home In-person interviews were conducted in meeting rooms at St. Michael's Hospital and Toronto General Hospital in Toronto, ON.
15. Presence of non-participants	No other non-participants were present during interviews.
16. Description of sample	See Table 1.
17. Interview guide	See Appendix 2. The semi-structured interview guide was developed based on literature review and research team input, including that of a patient partner who

		served as a member of Dr. Elliott's supervisory committee. The interview guide was pilot tested with a researcher experienced in qualitative research and patient engagement. Questions addressed participants' experiences during and subsequent to the CKD research prioritization exercise, including the perceived significance of their involvement in this project and research more generally.
18.	Repeat interviews	N/A
19.	Audio/visual recording	All interviews were audiorecorded.
20.	Field notes	The interviewer kept detailed reflexive notes during and following each interview, in which she documented thoughts related to interview technique (e.g. difficulty with certain questions), tones/inflections, and analytic insights. No direct participant observations or field notes were taken.
21.	Duration	Average interview duration 60 minutes (range 30-120 minutes).
22.	Data saturation	Data collection and analysis took place concurrently. Data saturation was reached after 17 interviews. 6 additional interviews were conducted at the expressed interest of participants who had already been approached about the study, and these interviews were used to refine key interpretive insights resulting from thematic analysis.
23.	Transcriptions returned	Individual interview transcripts were not returned to participants. However, upon completion of the analysis, results were compiled and sent to participants in summarized form. Participants were invited to contact us if they had any questions or wanted additional information.
Domain 3: Analysis and Findings		
24.	Number of data coders	3
25.	Description of coding tree	Codes were derived inductively through repeated readings of initial transcripts. The coders independently generated initial codes for each expressed idea and met after coding the first 3 transcripts to discuss the evolving coding scheme. They then met after coding every subsequent 3-4 transcripts to refine the coding scheme and discuss analytic thoughts. The coding scheme was finalized after having coded the first 10 transcripts, following which minor adjustments were made to code definitions only. 27 codes were derived from the data and were primarily descriptive.
26.	Derivation of themes	Thematic analysis was inductive in that codes and themes were derived from the data. Codes were sorted into preliminary themes, which were reviewed for coherence in relation to coded data extracts and the dataset as a whole. Themes were refined and defined, and relationships between themes were explored. In a final synthesis phase, the meanings of our findings were interpreted in relation to the research questions and contextual factors that may impact them.
27.	Software	NVivo 11 (QSR International Pty Ltd)
28.	Participant checking	The interviewer probed for follow-up on participant comments to elicit complete information. She also verified her understanding of specific comments by repeating or summarizing participant statements and asking for clarification or elaboration, where appropriate. This practice was also to emphasize her active listening and clarify her interpretation. Upon conclusion of each interview, participants were invited to further discuss or provide clarification on any elements of the interview, and to offer additional comments on issues not raised during the interview but that they felt were relevant. Participant validation was not used to establish the credibility of this study's findings, as this technique was felt to be inconsistent with our study's constructionist orientation of multiple, constructed realities.
29.	Quotations presented	Direct participant quotes are provided throughout the results to support each of the 3 identified themes.
30.	Data and findings consistent	Consistent
31.	Clarity of major themes	Three major themes underlying participants' long-term perceived significance in research prioritization were described: (1) Integration of stakeholder communities; (2) Appreciation of the CKD lived experience; and (3) Refocused commitment to

	research and care. The themes are distinct yet interrelated, and address the different accounts for how CKD stakeholders perceive the significance of their engagement in research prioritization. The discussion elaborates on these themes, draws connections among them, and highlights their significance in the context of patient engagement in CKD care and research.
32. Clarity of minor themes	Major themes were not further subcategorized with minor themes. Negative case analysis was conducted to strengthen analysis, whereby data elements that did not support emerging patterns were reviewed to account for alternative explanations, refine themes, and strengthen our resulting interpretations.

Appendix 3. Interview guide

Part 1: Engagement in CKD Priority Setting Project
Tell me about your experiences with research before this particular project, if any.   • Prompt: What was your role in this previous research? How did you become interested in getting involved in research? What type of training do you have in research, if any?
Can you tell me about your experience in this project to determine the top 10 CKD research priorities?   • Prompt: How did you learn about this project? Why did you participate?   • Prompt: What was your role in the project? How involved did you feel? How did you feel working alongside others with different backgrounds? What did you think of the format?

Part 2: CKD Research Priorities
Tell me your thoughts on the final top 10 priorities from your group <<workshop/wiki>>.   • Prompt: How did you feel about the priorities then? How would you rank them now? Why?   • Prompt: When you're thinking about priorities for kidney research, what types of things factor into your decisions (i.e. how do you weigh them)?
What do you know of what has happened with the final priorities since then?   • Prompt: What research projects or initiatives have you heard about using these priorities? How do you feel about the communication with the research team since this project?

Part 3: Long-Term Perceived Engagement
[Patients/caregivers] How would you describe your/patient's kidney disease now? General health?   • Prompt: In what ways is this similar to or different from when you participated in the project? How do you look after your/patient's kidney disease?   [HCPs/policymakers] How would you describe your current scope of practice/position?   • Prompt: In what ways is this similar to or different from when you participated in the project?
Reflecting back, what did you take away from your experience with the priority setting project?   • Prompt: How do you think about health research now? Did you learn anything about kidney disease from this experience? Explain.
Is there anything you are doing differently with respect to your/patient's kidney disease [patients/caregivers] or CKD care/research/policy [HCPs/policymakers] since participating in this project? Explain.   • Prompt [patients/caregivers]: Are you managing your/patient's CKD differently now? If yes, how? Tell me about your experiences with research since then, if any.   • Prompt [HCPs]: Are you caring for people with CKD differently now? If yes, how?   • Prompt [policymakers]: Has your involvement in this project influenced how you determine policy or make decisions related to CKD care? If yes, how?   • Tell me about your experiences with research since then, if any. [HCPs/policymakers] To what extent have you engaged with patients in your research/work since?

Part 4: Other General Engagement
When you think about engaging in research with patients, caregivers, HCPs and policymakers, what are some things that are important to you?   • Prompt: How can we as researchers make it a better experience for you?
How did you use technology to take part in this project (e.g. email, wiki, online communication)?
How did the research team show their appreciation for your time and contributions to this work?   • Prompt: How would you have liked to have been acknowledged? How do you feel about compensating non-researchers (i.e. patients/families) for participating in research?

Part 5: Concluding Questions
Is there anything you would like to add about your involvement in the CKD priority setting project that we haven't already discussed? Do you have any other thoughts about working together with patients and others affected by kidney disease in research?