

# **Central Lancashire Online Knowledge (CLoK)**

Title	Best practice for the selection, design and implementation of UK Kidney Association guidelines: a modified Delphi consensus approach
Туре	Article
URL	https://clok.uclan.ac.uk/id/eprint/52001/
DOI	https://doi.org/10.1136/bmjopen-2024-085723
Date	2024
Citation	Burton, James O, Chilcot, Joseph, Fielding, Katie, Frankel, Andrew H, Lakhani, Niraj, Nye, Pam, Parker, Kathrine, Priestman, William and Willingham, Fiona (2024) Best practice for the selection, design and implementation of UK Kidney Association guidelines: a modified Delphi consensus approach. BMJ Open, 14 (6).
Creators	Burton, James O, Chilcot, Joseph, Fielding, Katie, Frankel, Andrew H, Lakhani, Niraj, Nye, Pam, Parker, Kathrine, Priestman, William and Willingham, Fiona

It is advisable to refer to the publisher's version if you intend to cite from the work. https://doi.org/10.1136/bmjopen-2024-085723

For information about Research at UCLan please go to <a href="http://www.uclan.ac.uk/research/">http://www.uclan.ac.uk/research/</a>

All outputs in CLoK are protected by Intellectual Property Rights law, including Copyright law. Copyright, IPR and Moral Rights for the works on this site are retained by the individual authors and/or other copyright owners. Terms and conditions for use of this material are defined in the http://clok.uclan.ac.uk/policies/

# BMJ Open Best practice for the selection, design and implementation of UK Kidney Association guidelines: a modified Delphi consensus approach

James O Burton , <sup>1,2</sup> Joseph Chilcot, Katie Fielding, Andrew H Frankel, Niraj Lakhani, Pam Nye, Kathrine Parker, William Priestman, Fiona Willingham<sup>11</sup>

To cite: Burton JO. Chilcot J. Fielding K, et al. Best practice for the selection, design and implementation of UK Kidney Association guidelines: a modified Delphi consensus approach. BMJ Open 2024;14:e085723. doi:10.1136/ bmjopen-2024-085723

Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (https://doi.org/10.1136/ bmjopen-2024-085723).

Received 23 February 2024 Accepted 04 June 2024

## Check for updates

@ Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by

For numbered affiliations see end of article.

#### **Correspondence to**

Professor James O Burton: jb343@le.ac.uk

#### **ABSTRACT**

**Background** Despite research into how to effectively implement evidence-based recommendations into clinical practice, a lack of standardisation in the commissioning and development of clinical practice guidelines can lead to inconsistencies and gaps in implementation. This research aimed to ascertain how topics in kidney care worthy of guideline development within the UK should be chosen, prioritised, designed and implemented.

Methods Following a modified Delphi methodology, a multi-disciplinary panel of experts in kidney healthcare from across the UK developed 35 statements on the issues surrounding the selection, development and implementation of nephrology guidelines. Consensus with these statements was determined by agreement using an online survey; the consensus threshold was defined as 75% agreement.

Results 419 responses were received. Of the 364 healthcare practitioners (HCPs), the majority had over 20 years of experience in their role (n=123) and most respondents were nephrologists (n=95). Of the 55 nonclinical respondents, the majority were people with kidney disease (n=41) and the rest were their carers or family. Participants were from across England, Northern Ireland, Scotland and Wales. Consensus between HCPs was achieved in 32/35 statements, with 28 statements reaching ≥90% agreement. Consensus between patients and patient representatives was achieved across all 20 statements, with 13/20 reaching ≥90% agreement. **Conclusions** The current results have provided the basis for six recommendations to improve the selection, design and implementation of guidelines. Actioning these recommendations will help improve the accessibility of, and engagement with, clinical guidelines, contributing to the continuing development of best practice in UK kidney care.

#### **BACKGROUND**

The standard for best practice in modern healthcare is based on the ever-expanding body of evidence provided by clinical trials, studies and evidence synthesis. 12 Treatment pathways across many clinical areas are

#### STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study highlights the need for equitable, inclusive and sustainable approaches to guideline development.
- ⇒ Recommendations were developed based on consensus from over 400 clinicians, patients and patient representatives.
- ⇒ Actioning these recommendations has the potential to improve the transparency and accountability of the guideline development process within the UK Kidney Association.
- ⇒ Further research could refine the present consensus statements to try and further explore the variances seen.

directed by the creation of clinical practice guidelines (CPGs), intended to reduce variation of care and optimise patient outcomes.<sup>3</sup> The area of nephrology is no different, with a myriad of national and international guidelines all designed to help healthcare professionals, commissioners and providers of healthcare and people with kidney disease, their families and carers. 4-6 However, the development of CPGs is a complex undertaking, with challenges in selecting areas of review, prioritising their importance, development methodology and implementing the uptake of recommendations into clinical

Many international and national organisations have their own CPG development groups and standards with examples including the WHO, the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Australian National Health and Medical Research Council. There have also been attempts to standardise the CPG development process by the Guidelines International Network (GIN) and the Institute of Medicine



(IOM). Overall, these standards are similar in that they advocate for transparency in the CPG development process, as well as the need for external peer review and stakeholder consultation. However, the exact stepwise process for each differs, with varying stages and processes. Within nephrology it has similarly been highlighted that guidelines can often lack uniformity; importantly this can have a knock-on effect with the development of robust quality metrics, as one of the key components of metric validity is discordance with the latest evidence. Only by producing guidelines that are meaningful to all stakeholders can we then drive meaningful improvements in patient-centred care.

Alongside standards proposed by GIN and IOM, many development and implementation toolkits have been created to measure the strength and quality of CPGs. Internationally recognised models such as Grading of Recommendations Assessment, Development and Evaluation (GRADE) and Appraisal of Guideline Research and Evaluation (AGREE/AGREE II) assist developers in summarising evidence to provide recommendations, and to measure the strength of their recommendations in a structured way. It is GRADE standards are currently recommended by WHO, and used by NICE and SIGN. However, the use of ratification toolkits is not universal and up to 50% of guidelines may be considered unreliable or biased on the basis of having unclear development processes.

Despite the use of more rigorous development tools, many guidelines are still underused, representing a significant guideline-implementation gap. Evidence suggests that implementation can take up to 17 years and ultimately, only 14% of guideline recommendations are translated into clinical practice. As such, some have questioned the effort, relevance and utility of these (often cumbersome) pieces of documentation. However, successful implementation is important, research suggests correct utilisation of NICE guidelines for treating kidney disease has the potential to increase early patient referrals and lower long-term treatment costs. 15 16 Research into implementation strategies report similar barriers to guideline uptake, including lack of time, skills, and knowledge, funding issues, complex and impractical guidelines, and resistance to change within the healthcare community.<sup>3</sup> 14 17 18 However, research does suggest that guidelines can be successfully integrated into clinical practice through the use of multi-faceted approaches to implementation, combining communication, education and practical design strategies. 17-21 Limited research in nephrology indicates that educational interventions have helped to improve guideline adherence, physician competence and kidney function in diabetes patients with chronic kidney disease (CKD).<sup>22</sup>

A key part of CPG development and implementation is engaging stakeholders, including empowering people with long-term conditions like kidney disease to take part in joint decision-making processes.<sup>2 23 24</sup> Previous barriers to this have been identified, including lack of

understanding in how to incorporate the views of those living with kidney disease into guidelines, and how to effectively communicate with, and educate, people living with kidney disease. He 25 GIN has recently developed a toolkit to help developers engage with the public and patients and to try and overcome some of these barriers. In line with this, many now see the inclusion of patient and carer contributions as a fundamental part of the legitimacy and transparency of CPGs. He 18 24 26 It has also been suggested that patient input into CPG development will help improve the impact of guidelines and encourage their use. He 25

Due to the lack of standardised methods to develop CPGs, and the variability with which they are implemented, this research was undertaken on behalf of the UK Kidney Association (UKKA) Clinical Practice Guidelines Committee with the aim to ascertain how pertinent topics in kidney care within the UK should be chosen, prioritised, designed and implemented. The research was designed using a modified Delphi method in order to gather consensus from healthcare practitioners (HCPs) across multiple clinical specialties in primary and secondary care who have input into the management of people with CKD, as well as those people living with CKD, to ensure a breadth of stakeholder opinions were heard.

#### **METHODS**

The study was conducted using a modified Delphi methodology (see online supplemental figure A.1), overseen by an independent facilitator (Triducive Partners) and is reported in accordance with the ACCORD guidelines.<sup>27</sup> Initially, a scoping meeting was conducted in October 2022 between the UKKA Clinical Practice Guidelines Committee and the independent facilitator to agree the aims and scope of the project and discuss potential steering group members. A multi-professional panel of experts in renal healthcare (the study authors) from across the UK were selected on account of their leadership in UK societies, clinical expertise and standing as patient representatives. The group was invited by the UKKA Clinical Practice Guidelines Committee via email. Nine individuals agreed to participate, this number was chosen to ensure the accuracy and reliability of the study by representing all stakeholders without overcomplicating the process.<sup>28</sup>

During round 1, the group convened in January 2023 to discuss challenges in designing and implementing UKKA guidelines, using the nominal group technique. In this session, the panel created a list of problem areas which need to be addressed within guideline development. The panel discussed these areas and consolidated them into a final list covering:

- 1. Value of guidelines to healthcare professionals.
- 2. Value of guidelines to kidney patients.
- 3. Selecting areas of focus for future UKKA guidelines.
- 4. Design of future UKKA guidelines.
- 5. Implementing future UKKA guidelines.

Following the agreement of these domains, the group discussed each area in detail and created a series of 42 draft consensus statements. These were then reviewed anonymously and independently by the panel. This was collated by the independent facilitator. Based on feedback, eight statements were deleted, eight were edited and one new statement was added. The amended statements were then ratified independently and anonymously by the group. This process involved qualitative feedback and comprised round 2 of the process.

The finalised 35 statements provided the basis of a consensus survey, which constituted round 3 of the process. Two separate surveys were created and distributed across the UK. One survey, including all 35 statements, was sent to healthcare professionals in primary and secondary care with any involvement in treating people with kidney disease (not limited to the renal healthcare community). The survey was then streamlined to contain only the most patient relevant statements (n=20), before being sent to patients and patient representatives. This survey was designed to collect quantitative opinion data, as is standard for the Delphi process.<sup>29</sup>

In both surveys, each statement was presented alongside a 4-point Likert scale ('strongly agree', 'tend to agree', 'tend to disagree' and 'strongly disagree') to allow respondents to indicate their level of agreement. While the survey was anonymous, some demographic data was captured for further analyses (role of the respondent, location within the UK and years of experience). The minimum consensus level was set at  $\geq 75\%$ , a widely accepted threshold, <sup>30</sup> with a further category of 'very high agreement' at  $\geq 90\%$ . Instead of aiming for a set response rate, the panel agreed to minimum stopping criteria for the survey. A minimum threshold of 400 responses (distributed between secondary care doctors, general practitioners (GPs), nurses, dietitians and other allied healthcare

professionals) was set. The survey was distributed by the steering group to colleagues, professional and patient societies, and through social media. Respondents were anonymous to the steering group and did not receive incentives for participation.

Completed surveys were anonymously collated and analysed by the independent facilitator to produce an agreement score for each statement, this was calculated by adding the percentage of respondents who agreed or strongly agreed with each statement. This information was then evaluated and discussed by the expert panel in a second group meeting (June 2023, round 4). Analysis was undertaken by the facilitator to assess whether there were differences between respondents by role, experience or location, which was also validated by the expert panel. As the stopping criteria were fulfilled, the group used the results to select key statements from each topic. These provided the basis for draft study recommendations. Following the meeting these were independently and anonymously reviewed and ratified by the group.

#### **Patient and public involvement**

International guideline standards include patient and public involvement as a core principle for developing high-quality evidence-based CPGs. As such, this study was designed to include patient representation at each stage, including the steering panel who co-designed a modified questionnaire for patient respondents and their representatives. Wide distribution of the survey (and the results) was ensured using patient and charity networks.

#### **RESULTS**

The questionnaire was undertaken by 419 respondents, comprised 364 HCPs and 55 patients and patient representatives. Participants came from across the UK

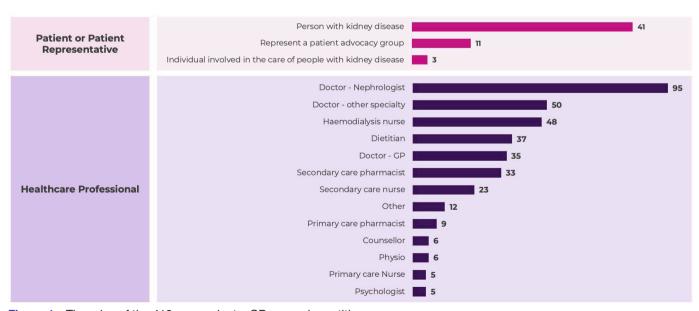
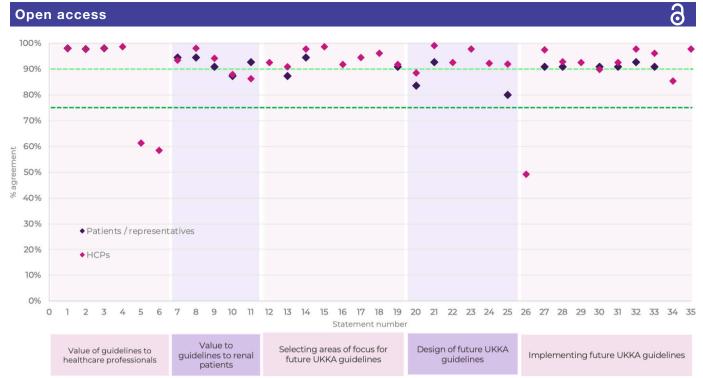


Figure 1 The roles of the 419 respondents. GP, general practitioner.



**Figure 2** The combined consensus across statements from HCPs and patients/patient representatives. The dark green line represents consensus threshold of 75% and the light green line represents the threshold for very high consensus (90%). HCPs, healthcare practitioners; UKKA, UK Kidney Association.

with representation from England, Northern Ireland, Scotland and Wales. Respondents by role are shown in figure 1. HCPs were also asked to provide how long they had been in role. The majority (n=123) had over 20 years of clinical experience, followed by 11–20 years of experience (n=109). Only 55 respondents had less than 5 years of experience.

Consensus among HCP respondents was high (figure 2), with 28/35 (80%) statements achieving over  $\geq 90\%$  consensus, and 4/35 (11%) reaching between < 90% and  $\geq 75\%$  consensus. Only three statements (9%) did not reach the 75% consensus threshold. Among patients and patient representatives, agreement was also high (figure 2), with all statements reaching the consensus threshold. Of the statements presented to this group, 13/20 (65%) achieved  $\geq 90\%$  consensus, 7/20 reached between < 90% and  $\geq 75\%$  consensus.

The results were further analysed by subgroup. There were some variations in the consensus levels for statements between HCPs based on their role, years in role and region (online supplemental figures A.2–A.4). Consensus levels were more consistent when analysed by years of professional experience. However, the only statements to consistently vary from the mean by >10% across role and region were statements 5, 6 and 26. These were also the only statements not to achieve consensus. Among the patient group, differences were noted for two statements (9 and 13), however variation arose due to lower agreement from carers (n=3) and so may not be representative.

Each of the statements and their individual consensus levels are presented in table 1. The consensus score

distribution across the 4-point Likert scale is shown in figure 3A,B.

#### DISCUSSION Value of UKKA guidelines

Across the responses from HCPs there was very high agreement on the importance and utility of guidelines (statements 1–4, 7–11, ≥86%). Responses to statement 4 (99%) also highlight that, while national guidelines are essential, there needs to be capacity for local variations in practice. This is supported by research into CPG implementation, which has found that flexibility and autonomy are key to encouraging HCPs to change their behaviour.<sup>18</sup>

In the past, the UKKA has produced 'commentaries' on guideline documents from other specialist societies (eg, Kidney Disease: Improving Global Outcomes) with specific advice on how these relate to UK practice or require specific considerations around their implementation. Responses to statement 5 (61%) and 6 (59%) (suggesting the UKKA should not provide commentaries and that they are *less* useful than guidelines) did not reach the consensus threshold. This suggests UKKA commentaries on national and international guidelines, along with recommendations for UK implementation, may be an important addition. Figure 3A,B shows a central tendency bias for these statements, with the majority of responses being 'tend to agree' and 'tend to disagree'. A lack of strong opinion on these statements could mean some respondents were unsure of how to respond, particularly as there was no definition provided for what constituted a UKKA 'commentary'. However, the literature repeatedly

repr	esentatives			
No.	Statement	Agreement % HCPs (% patient)		
Topi	c A: Value of guidelines to healthcare professionals			
1	Guidelines help to standardise the level of care	98 (87)		
2	Guidelines help to justify clinical decisions being made	98 (89)		
3	Guidelines should support all healthcare professionals involved in the care of people with kidney disease	98 (89)		
4	Guidelines should acknowledge there may be local variation in practice but should provide the most up to date, evidenced based recommendations regardless of local variation	99		
5	The UKKA should not focus resources of covering 'commentary' of guidelines that have been covered by other professional bodies	61		
6	UKKA commentaries on international guidelines are less useful than full UKKA guidelines	59		
Topi	c B: Value of guidelines to patients			
7	All published guidelines should have a summary of the whole guideline that avoids medical jargon and is understandable to patients with the condition/topic being discussed	93 (95)		
8	Guidelines involving patient care should be easily accessible from a common source	98 (95)		
9	The availability of patient focused guidelines allows for shared decision making and better-informed decisions to be made by the patient	94 (91)		
10	The availability of patient focused guidelines improves patient self-management	88 (87)		
11	The availability of patient focused guidelines improves patient outcomes	86 (93)		
Topi	c C: Selecting areas of focus for future UKKA guidelines			
12	Everyone involved in the management of people with kidney disease should have the opportunity to suggest future UKKA guideline topics for consideration	93		
13	Kidney patients, their families and their carers should have the opportunity to suggest future UKKA guideline topics	91 (87)		
14	Guidelines should be equitable to all and indiscriminate	98 (91)		
15	Guidelines should be developed in priority areas of recognised clinical need or practical importance	99		
16	The UKKA should prepare a rating process (RAG)* to identify priority guidelines	92		
17	The views of different professional groups in relation to priorities for future UKAA guidelines need to be understood and acknowledged	95		
18	The UKKA should involve a multi-professional committee to help identify priority guidelines	96		
19	Any guidelines should be updated with new evidence as soon as possible, rather than at set time intervals	92 (91)		
Topic D: Design of future UKKA guidelines				
20	The simpler the guideline the better	88 (84)		
21	All future UKKA guidelines should include a quick reference of key points at the beginning	99 (93)		
22	All future UKKA guidelines should include authors from the intended audience to ensure relevance	93		
23	Kidney specialists should be involved in guidelines published by other specialist societies that include the management of people with kidney disease	98		
24	All future UKKA guidelines should consider the environmental impact (sustainability) and EDI (equality, diversity and inclusion) agenda	92		
25	Guidelines should accept agreed consensus views where evidence is lacking	92 (80)		
Торі	Topic E: Implementing future UKKA guidelines			
26	Guidelines are difficult to implement	49		
27	Guidelines should be as easy as possible to understand and implement	98 (91)		
28	Guidelines should be such that they are useful during a consultation in order to help guide or explain management plans	93 (91)		
29	All future UKKA guidelines should include practical implementation tips	93		

Continued

Table 1	Continued
---------	-----------

No.	Statement	Agreement % HCPs (% patient)
30	All future UKKA guidelines should include practical tips about engaging hard to reach populations†	90 (91)
31	All future UKKA guidelines should include practical tips about ensuring equity of care	93 (91)
32	All future UKKA guidelines should be accessible to intended audiences seeking them	98 (91)
33	Intended audiences should be proactively notified once future UKKA guidelines are available	96 (91)
34	Intended audiences should be proactively aware through an annual calendarisation of upcoming guidelines	85
35	Where possible, increasing alignment across various professional guidelines and specialist societies is beneficial	98

HCPs graded all 35 statements, while patients/patient representatives graded a targeted subset of 20 statements.

\*RAG: a traffic light system of red, amber, green to determine priorities.

†For example, transient population, do not have regular contact with HCPs, those who have difficulty accessing services.

UKKA, UK Kidney Association.

finds improving CPG visibility through promotion, education and short communications can help to increase their implementation. Therefore, commentaries created by the UKKA could help encourage adoption of new CPGs by simplifying and clarifying their recommendations. Further, where commentaries cover international guidelines, they can give a discussion and interpretation relevant to the UK context.

Patient responses also showed strong consensus on the importance of guidelines, particularly documents which are jargon-free, and person centred. Survey results, alongside input from the lay representative, clearly show that people with kidney disease feel empowered when they have access to resources which they can read and process in their own time outside of appointments. The availability of such person-centred guidelines will help patients to make more informed decisions and potentially lead to improved health communication between patients and their healthcare providers. 24 25 The lay representative also highlighted that people with long-term conditions want reputable information, sourced from the same sites accessed by HCPs, which is reflected in statement 8 (HCPs 98%, patients 95%). A strength of the UKKA guidance is that all documents can be found in a single site and are accessible to people with CKD and HCPs. This is something that will need to continue with future guidelines to ensure these documents remain accessible.

#### **UKKA** guideline selection and design

Following on from aspects of accessibility highlighted in topics A and B, responses to statements in topics C and D emphasised a need for engagement and user-friendliness. Statements 12 (93%) and 13 (91% HCPs, 87% patients) show there is a need to include a variety of stakeholders when selecting potential topics for guidelines, a view strongly supported within the literature. This is reinforced by the agreement to statements 15–18 ( $\geq$ 92%), showing respondents believe a multi-professional approach should be taken to identifying and prioritising

guideline topics. While it has been acknowledged that cross specialty CPGs can be difficult to develop, <sup>32 33</sup> a lack of consideration for comorbidities or age (as a proxy for comorbidity) limits the applicability of CPGs. <sup>34</sup>

When considering the design of future guidelines, statements 14 (98% HCPs, 91% patients) and 20 (88% HCPs, 84% patients) demonstrate the overarching need for guidance to be simple, equitable and indiscriminate. On the basis of this, it is suggested that not only will the UKKA make all guidelines available, but also have a section of their website where all HCPs and people with CKD can suggest topics for future guidelines, as seen in recommendations by Blackwood *et al.*<sup>25</sup> Following this, it is clear there will be a need to prioritise the development of guidelines. The process of this will need to be both rigorous and transparent. Therefore, it is suggested that a 'RAG' (red, amber, green traffic light) system is used to standardise the process by which guideline development is prioritised.

The literature states that CPGs are crucial as they provide management pathways and treatments based on evidence.<sup>12</sup> Currently there is a reliance on clinical trials to provide this evidence base. 35 However, trials may not be available, or even necessary, to back every recommendation. It has been argued that other forms of evidence should be seen as valid when compiling data for guidelines.<sup>26 35</sup> The current research found strong support (statement 25; 92% HCPs, 80% patients) for the use of consensus-based evidence within guidelines. Banno et al have also argued for the value of consensus-based evidence, underlining the need for more Delphi studies to provide clear, documented consensus on the content of guidelines. There needs to be an element of caution here however, consensus based guidelines can generate inappropriately strong recommendations compared with evidence based guidelines and so it is important to ensure appropriate alignment of quality of evidence with strength of recommendations.<sup>36</sup> Wider use of such

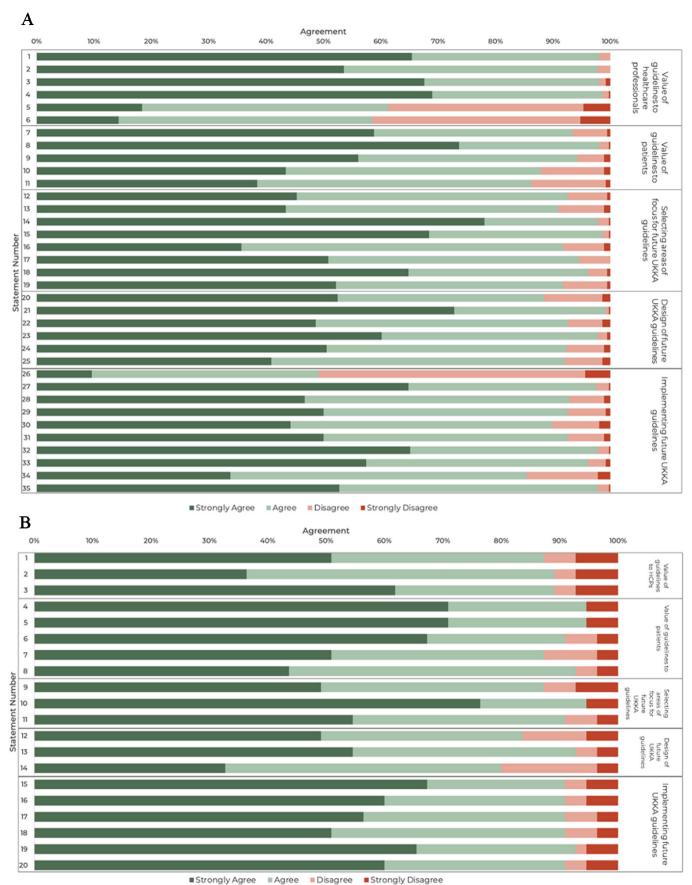


Figure 3 (A) Consensus score distribution across the 4-point Likert scale provided to healthcare professional respondents; (B) consensus score distribution across the 4-point Likert scale provided to patient/representative respondents. HCPs, healthcare practitioners; UKKA, UK Kidney Association.

practice would ensure the quality of guidelines, and allow for more inclusive guideline design, by assimilating patient input with clinical data and HCP recommended treatment pathways.<sup>37</sup>

Consensus with statements 22 (93%) and 23 (98%) show that HCPs are keen to take a multi-disciplinary approach to guideline development. The need for alignment across professional guidelines is further reinforced by consensus with statement 30 (98%). As discussed, developing cross specialty CPGs can be complex, hindered by lack of time, resources and standard CPG development methodologies. 32 33 To ensure that future UKKA guidelines reflect the results of the current research, it is evident that the UKKA's standards for guideline development will need to be updated to reflect this multi-stakeholder approach. When developing future guidelines, the UKKA will need to reach out to other societies and professional bodies for input, strengthening cross-discipline ties and communication. Collaboration across disciplines must be seen as pivotal, and the focus should be on how working together can create more broadly applicable, practical guidelines, by pooling knowledge and resources.<sup>32</sup> We believe that this approach could be a roadmap for optimised clinical management across medical specialties in the UK.

As set out in the Climate Change Act (2008), the UK National Health Service (NHS) has made a commitment to halve greenhouse gas emissions by 2025 and reach net zero by 2050. Within the NHS, the provision of kidney care is a carbon intensive specialty when considered in terms of the numbers of patients treated with renal replacement therapy. The strong consensus with statement 24 (92%) shows the commitment to this agenda, to pay particular attention within guidelines to inform carbon-reduction strategies that live up to the UKKA sustainability agenda; to meet or exceed NHS carbon net zero goals and, the ambition to reduce waste to landfill or incineration by 80%.

#### **Implementing future UKKA guidelines**

The UKKA is committed to reinforcing an agile approach to implementing and updating their guidelines. Although it is positive to see from the HCP response to statement 26 ('guidelines are difficult to implement'; 49%) that many respondents believe guidelines are not difficult to implement, it still does mean that near enough half of the responders feel that guideline implementation can be challenging. There was no difference seen in the agreement levels across experience or geographic region. While literature around guideline implementation highlights potential areas where translating recommendations into practice can fail, it is heartening to see that within nephrology negative beliefs in guideline implementation may not be the central issue. However, it will still be necessary to prepare for other potential implementation pitfalls in the future. In order to address the needs of all HCPs and patients the use of a multi-faceted implementation approach (eg, easy to use and practical guidelines,

combined with promotion, education, monitoring) is recommended.  $^{13\,17\,18\,20}$ 

Consensus with statements 28 (HCPs 93%, patients 91%) and 29 (93%) show there is a need for guidelines to be practical and of use for both HCPs and patients, particularly within consultations. A more efficient structure to guidelines, including a jargon-free summary, could help make guidance more accessible to all audiences. When taken alongside the need for simplicity, it could be suggested that the ideal guideline is delivered in two ways:

- 1. A central guideline designed to educate and support HCPs and people with CKD by providing focused descriptions of healthcare issues and the evidence base for treatments, alongside concise, actionable recommendations.
- 2. A supplementary document with technical details, which enriches the information and evidence provided in the main guideline.

Further to this, promotion of new guidelines could be encouraged by creating a calendar of guideline release dates, as supported by consensus with statement 34 (98%). This approach will keep stakeholders abreast of developments and ensure transparency and accountability in the development process.

#### **Recommendations**

Based on the levels of consensus seen within this study, the steering group were keen that the UKKA's process for creating guidelines should be updated in response to the results of this work. As such the steering group posed the following recommendations:

- 1. A more equitable approach to proposing guideline topics should be adopted, allowing input from HCPs, patients and their representatives.
- 2. UK commentaries on international guidelines that outline regional applicability and more focused implementation are as valued as full UK guidelines.
- 3. All guidance should focus on the end user, with simple and appropriate language to ensure accessibility for HCPs and people with CKD, and encourage engagement.
- 4. Standardised, multi-faceted implementation techniques or 'practice points' to maximise the uptake of their recommendations into clinical practice should be developed and included.
- 5. Connections across disciplines should be fostered, not only to ensure a multi-disciplinary approach to their guideline development but ensure perspectives from nephrology are considered in CPGs created by other professional bodies.
- 6. Guideline groups should outline strategies to address the sustainability agenda, wherever possible.

#### Study strengths and limitations

The large number of experienced specialists that responded to the consensus questionnaire lends weight to the validity of the recommendations proposed by the steering group. The presence of patients and their



representatives in the research, through the steering group and questionnaire respondents, increases the inclusivity and applicability of these findings. It highlights the opinions of these individuals and emphasises the need to acknowledge and act on them throughout guideline development. Responses were sought from both HCPs and patients across the UK in an attempt to reduce geographic bias. While some areas had fewer respondents (eg, Northern Ireland), overall, there was good representation across the UK. The survey was distributed by the steering group, however, data was collected and analysed anonymously by a third party, helping to limit bias.

The 4-point Likert scale was used so respondents had no 'neither agree or disagree' option and had to form an opinion on each statement. However, as discussed, some statements did show a central tendency bias, which could have been due to the language used within the statements. As this study only undertook one round of survey with no adjustments to the statements, it is possible that some of the statements were too agreeable and did not sufficiently challenge the status quo. Further research on this in this area should refine the statements generated herein to determine any greater variance that may exist.

#### CONCLUSIONS

This research explored the views of HCPs, patients and patient representatives on the best practice for selecting, designing and implementing CPGs from the UKKA. Based on the levels of consensus seen across respondents, the steering group were able to develop a strong set of recommendations. Successful implementation of guidelines within nephrology has been shown to improve patient outcomes<sup>22</sup> and is theorised to have long-term cost-effectiveness benefits. 15 16 Actioning the suggested recommendations has the potential to improve the transparency and accountability of the guideline development process within the UKKA, as well as making UKKA CPG documentation more accessible and understandable for all stakeholders. This in the long-term, can only benefit clinical practice and patient outcomes within UK kidney care.

#### **Author affiliations**

<sup>1</sup>Department of Cardiovascular Sciences, University of Leicester, Leicester, UK

#### X James O Burton @drjamesburton

Acknowledgements All authors have undertaken this work on behalf of the UKKA guideline committee and report no conflicts of interest. The UKKA would like to

thank Tim Warren, Dal Singh and Dr Katie Larner for facilitating this project and drafting the current manuscript.

Contributors JOB and KF were responsible for the conception and design of the project and manuscript preparation and act as guarantors. JC, AHF, WP, FW, PN, NL and KP contributed to the design of the study, provided methodological input through the steering group and the interpretation of the results. All authors reviewed the manuscript, had full access to all the data in the study and had final responsibility for the decision to submit for publication.

**Funding** The study was initiated and funded by UK Kidney Association with support from unrestricted educational grants from AstraZeneca UK Ltd, Bayer PLC, Boehringer-Ingelheim Ltd and GSK UK Ltd, who had no input into the design, context or reporting of this work. The UKKA commissioned Triducive Partners Limited to facilitate the project and analyse the responses to the consensus statements in line with the Delphi methodology.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval Ethical approval was not required due to the design of the study, using a completely anonymous survey approach. A statement of consent was included in the survey; consent was implied by completion and submission of responses. There was no collection of personal data nor implementation within the National Health Service structure.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

Supplemental material This content has been supplied by the author(s). It has not been vetted by BMJ Publishing Group Limited (BMJ) and may not have been peer-reviewed. Any opinions or recommendations discussed are solely those of the author(s) and are not endorsed by BMJ. BMJ disclaims all liability and responsibility arising from any reliance placed on the content. Where the content includes any translated material, BMJ does not warrant the accuracy and reliability of the translations (including but not limited to local regulations, clinical guidelines, terminology, drug names and drug dosages), and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

#### ORCID iD

James O Burton http://orcid.org/0000-0003-1176-7592

#### REFERENCES

- Beauchemin M, Cohn E, Shelton RC. Implementation of clinical practice guidelines in the health care setting: A concept analysis. ANS Adv Nurs Sci 2019;42:307–24.
- 2 Guerra-Farfan E, Garcia-Sanchez Y, Jornet-Gibert M, et al. Clinical practice guidelines: the good, the bad, and the ugly. *Injury* 2023;54:S26–9.
- 3 Correa VC, Lugo-Agudelo LH, Aguirre-Acevedo DC, et al. Individual, health system, and Contextual barriers and Facilitators for the implementation of clinical practice guidelines: a systematic Metareview. Health Res Policy Syst 2020;18:74.
- 4 Rossing P, Caramori ML, Chan JCN, et al. KDIGO 2022 clinical practice guideline for diabetes management in chronic kidney disease. Kidney International 2022;102:S1–127.
- 5 National Institute for Health and Care Excellence (NICE). Chronic kidney disease: assessment and management [Ng203]. 2021.
- 6 Roddick AJ, Wonnacott A, Webb D, et al. UK kidney Association clinical practice guideline: sodium-glucose Co-Transporter-2 (SGLT-2) inhibition in adults with kidney disease 2023 UPDATE. BMC Nephrol 2023;24:310.
- 7 Institute of Medicine (U.S). Committee on Standards for Developing Trustworthy Clinical Practice Guidelines., Graham R. Clinical Practice Guidelines We Can Trust. Washington, DC: National Academies Press, 2011.

<sup>&</sup>lt;sup>2</sup>John Wall's Renal Unit, University Hospitals of Leicester NHS Trust, Leicester, UK

<sup>&</sup>lt;sup>3</sup>Department of Psychology, King's College London, London, UK

<sup>&</sup>lt;sup>4</sup>Department of Medicine for the Elderly, Derby Teaching Hospitals NHS Foundation Trust, Derby, UK

<sup>&</sup>lt;sup>5</sup>Imperial College London, London, UK

<sup>&</sup>lt;sup>6</sup>The Willows Health Academy, Leicester, UK

<sup>&</sup>lt;sup>7</sup>UK Kidney Association, Bristol, UK

<sup>&</sup>lt;sup>8</sup>Manchester Institute of Nephrology and Transplantation, Manchester, UK

<sup>&</sup>lt;sup>9</sup>Manchester Academic Health Science Centre, Manchester, UK

<sup>&</sup>lt;sup>10</sup>Heath Lane Surgery, Leicester, UK

<sup>&</sup>lt;sup>11</sup>Social Work and Sport, University of Central Lancashire, Preston, UK



- 8 Schünemann HJ, Wiercioch W, Etxeandia I, et al. Guidelines 2.0: systematic development of a comprehensive checklist for a successful guideline enterprise. CMAJ 2014;186:E123–42.
- 9 Qaseem A, Forland F, Macbeth F, et al. Guidelines international network: toward international standards for clinical practice quidelines. Ann Intern Med 2012;156:525–31.
- Mendu ML, Tummalapalli SL, Lentine KL, et al. Measuring quality in kidney care: an evaluation of existing quality Metrics and approach to facilitating improvements in care delivery. J Am Soc Nephrol 2020;31:602–14.
- 11 Schunemann H, Brozek J, Guyatt G, et al. Handbook for grading the quality of evidence and the strength of recommendations using the GRADE approach. 2013.
- 12 Brouwers MC, Kho ME, Browman GP, et al. AGREE II: advancing guideline development, reporting and evaluation in health care. CMAJ 2010;182:E839–42.
- 13 Gagliardi AR, Brouwers MC. Do guidelines offer implementation advice to target users? A systematic review of guideline applicability. BMJ Open 2015;5:e007047.
- 14 Kredo T, Bernhardsson S, Machingaidze S, et al. Guide to clinical practice guidelines: the current state of play. Int J Qual Health Care 2016;28:122–8.
- 15 Klebe B, Irving J, Stevens PE, et al. The cost of implementing UK guidelines for the management of chronic kidney disease. Nephrol Dial Transplant 2007;22:2504–12.
- Sullivan MK, Jani BD, Rutherford E, et al. Potential impact of NICE guidelines on referrals from primary care to Nephrology: a primary care database and prospective research study. Br J Gen Pract 2023;73:e141–7.
- 17 Pondicherry N, Schwartz H, Stark N, et al. Designing clinical guidelines that improve access and satisfaction in the emergency Department. J Am Coll Emerg Physicians Open 2023;4:e12919.
- 18 Wang T, Tan J-YB, Liu X-L, et al. Barriers and Enablers to implementing clinical practice guidelines in primary care: an overview of systematic reviews. BMJ Open 2023;13:e062158.
- 19 Grimshaw JM, Thomas RE, MacLennan G, et al. Effectiveness and efficiency of guideline dissemination and implementation strategies. Health Technol Assess 2004;8:iii-iv,
- 20 Liu X-L, Wang T, Tan J-Y, et al. Sustainability of Healthcare professionals' adherence to clinical practice guidelines in primary care. BMC Prim Care 2022;23:36.
- 21 Wangler J, Jansky M. What is the significance of guidelines in the primary care setting?: results of an exploratory online survey of general practitioners in Germany. Wien Med Wochenschr 2021;171:321–9.
- 22 Martínez-Martínez P, Cueto-Manzano AM, Cortés-Sanabria L, et al. Can the implementation of clinical practice guidelines improve clinical competence of physicians and kidney function of patients with type 2 diabetes mellitus. Front Med (Lausanne) 2022;9:977937.

- 23 Guidelines International Network. G-I-N PUBLIC Toolkit: Patient and PUBLIC Involvement in Guidelines. Pitlochry, Scotland, 2021.
- 4 Mikdashi J. The meaningful role of patients, and other Stakeholders in clinical practice guideline development. *Rheum Dis Clin North Am* 2022;48:691–703.
- 25 Blackwood J, Armstrong MJ, Schaefer C, et al. How do guideline developers identify, incorporate and report patient preferences? an international cross-sectional survey. BMC Health Serv Res 2020;20:458.
- 26 Grol R, Buchan H. Clinical guidelines: what can we do to increase their use *Med J Aust* 2006;185:301–2.
- 27 Gattrell WT, Logullo P, van Zuuren EJ, et al. ACCORD (accurate consensus reporting document): A reporting guideline for consensus methods in Biomedicine developed via a modified Delphi. PLoS Med 2024;21:e1004326.
- 28 Taylor E. We agree, don't we? the Delphi method for health environments research. *HERD* 2020;13:11–23.
- 29 Shang Z. Use of Delphi in health sciences research: A narrative review. *Medicine (Baltimore)* 2023;102:e32829.
- 30 Diamond IR, Grant RC, Feldman BM, et al. Defining consensus: a systematic review recommends Methodologic criteria for reporting of Delphi studies. J Clin Epidemiol 2014;67:401–9.
- 31 Armstrong MJ, Rueda JD, Gronseth GS, et al. Framework for enhancing clinical practice guidelines through continuous patient engagement. Health Expect 2017;20:3–10.
- 32 Sultan S, Siedler MR, Morgan RL, et al. An international needs assessment survey of guideline developers demonstrates variability in resources and challenges to collaboration between organizations. J Gen Intern Med 2022;37:2669–77.
- 33 Tetreault L, Nater A, Garwood P, et al. Development and implementation of clinical practice guidelines: an update and synthesis of the literature with a focus in application to spinal conditions. Global Spine Journal 2019;9:53S–64S.
- 34 Guthrie B, Thompson A, Dumbreck S, et al. n.d. Better guidelines for better care: accounting for Multimorbidity in clinical guidelines structured examination of exemplar guidelines and health economic Modelling. Health Serv Deliv Res5:1–150.
- 35 Zuiderent-Jerak T, Forland F, Macbeth F. Guidelines should reflect all knowledge, not just clinical trials. BMJ 2012;345:bmj.e6702.
- 36 Yao L, Ahmed MM, Guyatt GH, et al. Discordant and inappropriate discordant recommendations in consensus and evidence based guidelines: empirical analysis. BMJ 2021;375:e066045.
- 37 Banno M, Tsujimoto Y, Kataoka Y. The majority of reporting guidelines are not developed with the Delphi method: a systematic review of reporting guidelines. *J Clin Epidemiol* 2020;124:50–7.
- 38 Connor A, Lillywhite R, Cooke MW. The carbon footprint of a renal service in the United Kingdom. *QJM* 2010:103:965–75.

#### **SUPPLEMENTARY MATERIALS:**

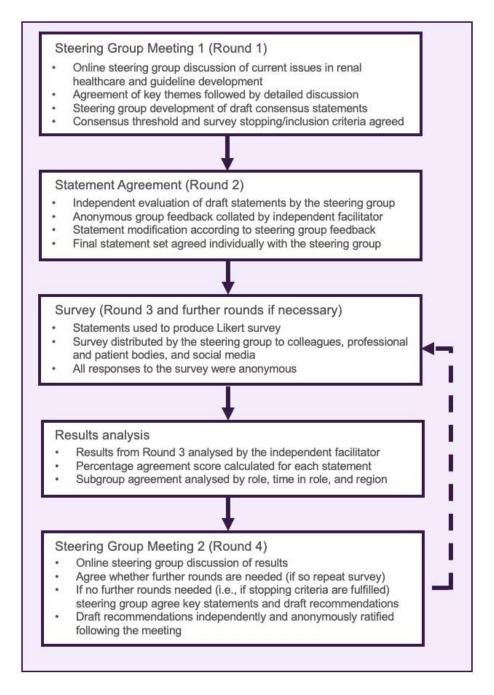
#### LAY ABSTRACT (149 words):

The amount of medical knowledge doubles approximately every 73 days. This makes it hard for healthcare practitioners to keep up to date on the best treatments for people with long term conditions like kidney disease. They rely on clinical guidelines to provide a reliable source of information but the way in which topics and content are selected is not clear.

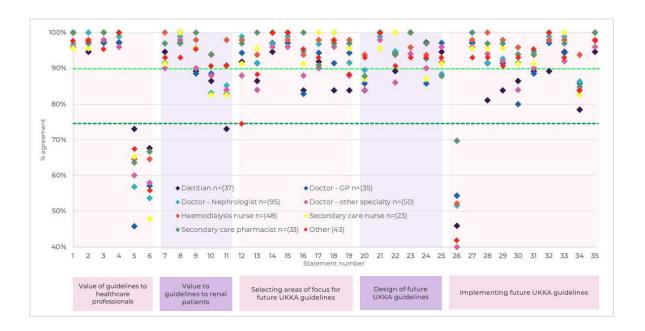
To address this, we undertook a scientific survey with over 400 people in the UK; not just kidney specialists but also doctors and healthcare practitioners from other disciplines that care for people with kidney problems, as well as people with kidney disease and their family / carers.

Based on the replies, we developed six key recommendations that will improve the way guidelines are chosen and written, making things easier for healthcare practitioners to keep up to date and improve the lives of people with kidney, and other long-term disease.

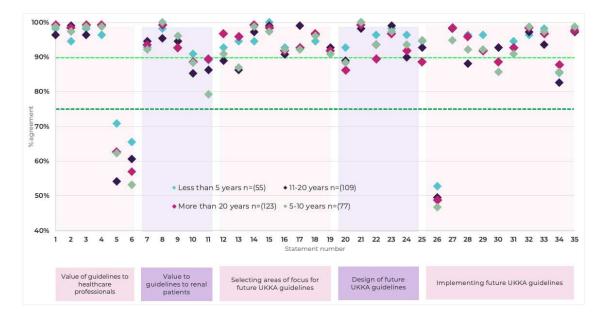
### Supplementary Figure A.1. The modified Delphi method employed in the study.



**Supplementary Figure A.2.** Levels of consensus amongst healthcare professionals analysed by role. "Other" includes roles such as: counsellors, physiotherapists, psychologists, academics, renal technologists, and pharma medics. The dark green line represents consensus threshold of 75% and the light green line represents the threshold for very high consensus (90%).



**Supplementary Figure A.3.** Levels of consensus amongst healthcare practitioners analysed by years of experience. The dark green line represents consensus threshold of 75% and the light green line represents the threshold for very high consensus (90%).



**Supplementary Figure A.4.** Levels of consensus amongst healthcare professionals analysed by region. The dark green line represents consensus threshold of 75% and the light green line represents the threshold for very high consensus (90%).

