RESPONSE TO THE INDEPENDENT KHA-CARI GUIDELINES REVIEW PANEL RECOMMENDATIONS

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Responses to Recommendations

KHA-CARI is pleased to provide responses to the recommendations arising from the recent independent review of the KHA-CARI Guideline Process conducted by Professor Carol Pollock and Dr Catherine Marshall. We have listed all of the recommendations arising from the review and have provided a response to each one. In addition:

- We note that the review appears very favourable and that the issues they raise are ones of detail rather than substantive.
- Some of the recommendations are relatively simple (eg concerning governance and representation) and within our existing resource allocation but others require prioritisation (e.g, enhancing implementation activity over guideline production)
- Many of the implementation strategies will need the active involvement of KHA (eg. Consumer representation, KHA representation on the Steering Committee, variability in key items of clinical practice through ANZDATA, development of consumer materials, expansion of the funding base)

1. Governance

The governance of CARI should be strengthened to ensure that:

1.1. *KHA actively exercises its leadership role in CARI through its representation on the KHA-CARI Steering Committee to align and integrate the activities of both groups as in appropriate to provide reliable and consistent evidence-based guidance on kidney health to health professionals, policy makers and consumers.*

Response: KHA-CARI strongly supports this recommendation. There are three KHA positions but usually only one attends. KHA-CARI would welcome stronger linkages with our parent organisation to assist KHA in its other core activities where possible – education, support, advocacy and research.

1.2. *The Steering Committee should include transparent representation from ANZSN ANZDATA, RSA, AKTN at the highest levels on their respective governing bodies. The Steering Committee should include a trained Consumer representative and at least one member from New Zealand*

Response: We agree there is a need to formalise the representation and appointment process for the Steering Committee The Steering Committee does currently include representation from the RSA and one member from New Zealand. In addition current members include individuals in key positions within ANZSN, ANZDATA and AKTN. We would welcome again a consumer representative, and KHA is ideally positioned to assist us in that process. We do not want consumer involvement to be tokenistic but substantive.

1.3. *Where relevant membership of guideline development groups should include nursing (through RSA), allied health (through RSA and defined professional bodies) and consumers / community (through KHA whilst exploring other models of consumer / community engagement in guideline development as proposed)*

Response: Members of guideline development groups are selected to ensure involvement of relevant expertise and ideally key end users. To date, groups have included, nephrologists, surgeons, other specialists (e.g. infectious disease clinicians

and intensivists), nurses and dieticians. Convenors of each guideline group nominate nurses/allied health workers with appropriate expertise. Our current process does not usually involve a consumer representative largely because of the technical process of guideline development. Rather we use a consumer engagement model that is run parallel to guideline development. This model has been published, and we believe offers more effectvive involvement in guideline development than a single consumer on the development group.

1.4. *There are transparent process of appointments (nomination processes, terms of appointment, responsibilities, accountabilities and reporting) of the Steering Committee, guideline topic selection, guideline development committees and accountabilities, and a prior agreed time frames for both the guideline development committees and the KHA-CARI Editorial Office for each guideline under development*

Response: The KHA-CARI Guideline Manual provides a description of roles and responsibilities for all involved in KHA-CARI guidelines and a process for selection of guideline group members. The selection of guideline topics is decided at the Steering Committee meetings. There is currently no formal process for nomination and appointment to the Steering Committee. Timeframes for guideline committees and the KHA-CARI office are addressed through project specific timelines and the KHA-CARI office work plan. Progress against these timelines is reported to KHA and the ANZSN via quarterly reports. We are currently updating the process for Steering Committee member appointments to make this more transparent as recommended.

1.5. *Formal strategic links are developed with Kidney Health New Zealand to better engage the relevant NZ community, recognizing that some guidelines may need to be contextualized to accommodate cultural and health system differences.*

Response: KHA-CARI would welcome links being established with Kidney Health New Zealand. Currently, CARI is listed as a link/resource on their web site but there is no other recognition. For example the document Managing Chronic Kidney Disease in Primary Care National Consensus Statement – makes only passing reference to CARI. This process could be facilitated by KHA.

1.6. *There are transparent arrangements between KHA-CARI, Cochrane and The Centre for Kidney Research regarding attribution of outputs, project ownership, data acquisition and use to support external funding and the governance process for reinvestment into KHA-CARI.*

Response: KHA-CARI operates as a separate financial entity with identified staff within a larger research environment provided by the Centre for Kidney Research. We believe this arrangement is clear but would be pleased to work with the reviewers to identify any specific concerns.

1.7. *Explicit disclosure of Conflicts of Interest (COI) for all those involved at all levels of the KHA-CARI process.*

Response: We have recently reviewed and updated our COI process by adopting the current NHMRC guidance policy (1st August 2012), and this is routinely implemented. We also follow the Institute of Medicine guidelines. Conflict of interest has been identified by the NHMRC as a key area of concern that they will address in their

upcoming review. We suggest that KHA-CARI review our COI process after the NHMRC has completed their review.

1.8. *Formal consideration of succession planning processes should be undertaken by the KHA Board the Dialysis and Transplant Subcommittee of the ANZSN and by the KHA-CARI Steering Committee to ensure that the superb work of CARI continues.*

Response: We would be pleased to work with our parent bodies to ensure this occurs.

2. National and International Linkages

2.1. *KHA and KHA-CARI should closely monitor new guideline initiatives and projects being developed by NHMRC, ACSQHC, State and Federal Departments of Health and the New Zealand Ministry of Health to identify opportunities for funding, access to tools and resources, to create or extend links with other local guideline developers especially in the areas of multi-morbidities. There may also be opportunities to create closer ties with other Australian guideline developers e.g. shared training activities.*

Response: Our staff routinely attend national and international guideline meetings to ensure currency of our operations. KHA-CARI attended the recent Sydney forum at the Australian Commission on Safety and Quality in Health Care, the purpose of which was to introduce the process of review and revision of the NHMRC approach to clinical practice guidelines. This was the first such forum held by the NHMRC. We will maintain close contact with the group undertaking the review. NHMRC are seeking assistance with updating the 'guidelines for guidelines' handbooks and we are considering responding to the request for assistance.

The NHMRC review process provides a key opportunity for KHA-CARI to forge these links as the major guideline groups are also involved in the review. Key groups include The Cancer Council Australia, Cancer Australia, Diabetes Australia, The National Stroke Foundation, and The Heart Foundation. We have worked successfully in the past with Diabetes Australia in the preparation of the Type 2 diabetes guidelines and such partnerships can provide an additional source of funding.

One of the aims of the NHMRC review is to raise the overall standard of guidelines in Australia and to more closely align guideline development with international practice. For example the NHMRC are looking to adopt GRADE as the preferred approach to evidence evaluation. This alignment of processes should facilitate the potential for shared training activities in the future which would be welcomed by KHA-CARI.

2.2. *KHA-CARI should focus its guideline development activities on the areas of practice where there are clear evidence-practice variation in Australia and New Zealand.*

Response: This is the intent of the topic selection process used by KHA-CARI. We will review and amend the procedure to ensure that emphasis on this aspect is clear. Evidence-practice variation should also set priority within our forward work plans. Currently variation in clinical practice is a set criteria for guideline topic selection as stated in KHA-CARI Guidelines Development manual.

2.3. *Continue to collaborate with other English speaking international guideline groups to optimize efficiency of guideline development and to share information and resources where appropriate*

Response: A Memorandum of Understanding (MOU) is being finalised with the European Renal Best Practice group that will facilitate sharing of information such as evidence reviews and minimise duplication of effort when developing forward work plans. The intent is that under the MOU guidelines prepared by the other groups will be edited/adapted by KHA-CARI for Australia and New Zealand and vice versa, rather than each group independently preparing guidelines from first principles. It is hoped that this cooperative approach will extend to other international guideline groups.

2.4. *Commentaries on international guidelines are interesting but not sufficient. Guideline users would prefer to have the advice derived from international guidelines "localised" by a multi-disciplinary group of Australians and have supporting tools and resources provided to facilitate implementation*

Response: We will continue to do this through the adaptation process that we have developed in accordance with the ADAPTE framework. It should be recognised that adaptation of an international guideline is not a trivial exercise and needs to be considered within the context of overall priorities as set in our forward work plan. The work-load is not dissimilar to developing a new guideline de novo. Currently we provide little in the way of implementation tools either for adapted guidelines or our own guidelines, this reflects existing resources and a priority placed on preparation and dissemination of the guideline. Nonetheless we recognise that this is an important area that should be addressed.

3. Priority Setting – Topic Selection

3.1. *ANZDATA provides critical information that should be used to identify areas where practice improvement is required (e.g. unwarranted variation in care, evidence-practice gaps –i.e. areas where there are gaps between what we know from the best available research and what happens in day to day practice)*

Response: We agree with this recommendation and again it is the intent of our topic selection process to access relevant sources such as ANZDATA. This will be emphasised in the review of the topic selection process. In response to this recommendation (and others regarding ANZDATA) we will ensure better coordination with this platform. As a supporter of ANZDATA, KHA would be ideally placed to facilitate this coordination.

4. Form of the Guidelines

Review KHA-CARI processes with a view to ensuring that:

4.1. *Reduce the size and or scope of the guideline topics – concentrate on areas where there is uncertainty and/or evidence-practice gaps. These can be informed by ANZDATA.*

Response: We agree that guidelines should be underpinned by clear clinical questions addressing specific areas of uncertainty and need (as defined during the topic selection process). This is the intent of our process, although we recognise that this requires discipline on the part of the guideline group members to avoid expanding the number of sub-topics during guideline development.

4.2. *Provide training for guideline team chairs especially in the areas of managing the scope of a guideline, the GRADE system and ways to support full participation and contribution of all guideline team members, including elicitation of community member views and managing competing interests.*

Response: An effective guideline convenor is essential to the timely preparation of focussed guidelines. Whilst we define roles and responsibilities for convenors, we do not have a convenor training program. Rather, we provide training in critical appraisal and GRADE to all guideline members in intensive small group sessions. Whilst these training sessions have emphasised the importance of the scope of the guideline, an additional training module specifically addressing this issue is feasible and sensible.

4.3. *Consideration is given to appointment of the guideline chair +/- team for a period of 3-5 years, with the specific responsibility of modifying the guideline on line periodically as new evidence becomes available.*

Response: Updating guidelines is a challenge faced by all guideline groups and this is a high priority issue for the NHMRC. We will review the approaches and recommendations proposed. In addition to the suggestions made by the expert reviewer's, we should review what other groups are doing in this area, for example Cancer Council Australia is using a WIKI platform that may have application for KHA-CARI.

4.4. *Issues of importance to Aboriginal and Torres Strait Islander peoples, Maori and Pacific peoples and other peoples at high risk of kidney disease are addressed where appropriate.*

Response: We agree that this is an area of high priority, to this end we have commenced a feasibility assessment of preparation of chronic kidney disease guidelines for Indigenous Australians and New Zealanders and Pacific Peoples residing in Australia and New Zealand.

4.5. *Consumer / patient areas of concern are considered and guidelines are routinely translated into consumer materials developed by or for KHA.*

Response: We agree that it would be important to prepare and disseminate consumer materials, and will consider how best to do this.

4.6. *Provide supporting tools such as algorithms, guideline summary, apps, checklists and audit tools, to facilitate the implementability of guidelines.*

Response: Many of the KHA-CARI guidelines would benefit greatly from the supporting tools mentioned and also decision aids aimed at assisting communication between

clinicians and patients. Additional funding would however be required if this was to be developed substantively. We seek KHA's advice on this issue.

4.7. *Each guideline should have a targeted communication and implementation strategy agreed.*

Response: We agree that our current communication and implementation strategy is limited. The communication strategy is generic and not guideline specific, and implementation is limited to a prominent but small section of the guidelines. Stronger emphasis could be placed on implementation and audit during guideline preparation, and this we will undertake to do.

4.8. *CARI identifies opportunities to use the guidelines as part of education and training programs and to build capacity in evidence based assessments, systematic reviews and implementation projects.*

Response: We believe this already occurs, but look to ANZSN for providing additional opportunities. Implementation projects have been leveraged, but health technology assessments are beyond our capacity and scope.

4.9. *Identify evidence-based key performance indicators that are applicable to NZ and Australia.*

Response: As noted earlier, this is done to a limited extent as part of the implementation and audit section of the guidelines; although it is often done as an afterthought and with minimal detail. There is a need to change this emphasis and provide some 'model' examples to guide writers. We believe this is a current priority of ANZSN/DNT.

4.10. *Identify areas in each guideline where there is insufficient locally appropriate research data and provide information to the AKN research program, Cochrane Renal Group and other research funders in Australia and New Zealand.*

Response: This is done to a limited extent in two ways:

- the suggestions for research section of the guidelines, however the gaps are not communicated to relevant interest groups.
- the recent development of the AKTN subcommittees addressing the different areas of nephrology (haemodialysis, PD, Acute Kidney Injury etc), which are seeking to link evidence gaps with future research endeavours.

We would need to develop these processes more formally with AKTN.

4.11. *Reshaping the approach to the development of CARI guidelines (e.g. reduced scope, greater participation of expertise, using a medical writer and focus on the development of a broad spectrum of products and tools) should be achieved within current budget or by seeking specific funding for each project e.g. from government funders.*

Response: The most time consuming aspect of guideline preparation is the evidence review process rather than writing and editing. It is not clear that a medical writer would expedite the current process particularly as we publish only small summaries and the full guideline is published online. However, a medical writer would be of great value in the preparation of other forms of publication aimed at consumers, renal nurses etc. This

could not be done within our current resources without reducing core activities of guideline preparation. We would be pleased to work with KHA in seeking leveraged funding but historically this has not be a productive line of enquiry.

5. Implementation Strategies

5.1. *KHA-CARI should identify partners and groups that have a shared interest in promoting and implementing kidney health guidelines including the Renal Society of Australasia, Joanna Briggs Institute, Kidney Health NZ, the Nephrology Educators Network, Therapeutic Guidelines, Federal, State and NZ based Health Departments/ Ministry Renal Networks*

Response: We will seek to implement this recommendation.

5.2. *Targeted involvement of policy makers at different stages of development and review should occur throughout the guideline development and implementation processes*

Response: We suggest that this is a role that could be facilitated by the KHA, particularly making use of the presence of Luke Toy from KHA on the Steering Committee.

5.3. *A review of the functionality of the KHA-CARI website should be undertaken, including enhancing the visibility of KHA-CARI on the KHA website*

Response: The web site was recently revamped. We suggest that a review take place in 12 months including feed-back from members of the ANZSN and RSA.

6. Resourcing of KHA-CARI

6.1. *All funding should be transparent and published.*

Response: This is also an issue being addressed in the NHMRC review. Currently our website provides a list of sponsor logos with no further description provided. We think that this appropriate given KHA is our primary funder.

6.2. *Arms-length arrangements for industry funding should continue to be encouraged*

Response: We agree.

6.3. *Additional options for funding should be explored by KHA including:*

- *Federal and state funding*
- *Subscription from renal units in Australia and NZ and or professional societies*
- *Private insurers*
- *Other industry groups such as those involved in the design and sale of technology used to support kidney health*

Response: We would welcome the opportunity to work with KHA to expand our funding base.

7. Other Recommendations

7.1. *KHA should make contact with the people interviewed as part of this review to provide them with a summary of this report and the decisions made about the CARI program.*

Response: We agree.