Submission to National Health and Medical Research Council discussion paper

'Better informed health care through better clinical guidelines'

Introduction

The Guidelines International Network (G-I-N) Australian and New Zealand Regional Community was established to provide a forum to support the collaboration of organisations and individuals with an interest in guidelines to improve health care across the region.

In January 2016 the ANZ Regional Community Steering Group agreed to develop a collective response to the Australia's National Health and Medical Research Council (NHMRC) draft discussion document *'Better informed health care through better clinical guidelines'.* Survey Monkey was used to collate all responses to the questions which were then transcribed into the NHMRC online submission tool.

The G-I-N Regional Community acknowledges the responses are small in number but consider that that are informative and reflect some views of the regional group. The purpose of the activity was to provide a forum to support a collaborative effort to comment on a discussion paper that will shape the future of guideline activity in Australia

Two additional questions relating to the specific role of the ANZ Regional Community and G-I-N were added to the Survey Monkey tool and are reported on page 8. The general response to these questions supported the G-I-N ANZ Regional Community playing an active role in the guideline network proposed in the discussion paper.

1. Declaration of interest noted;
   Geraint Duggan a member of the G-I-N ANZ Regional Community Steering Group and Director – Clinical Guidelines, Research Policy and Translation for the National Health & Medical Research Council did not contribute to the response or endorse the content of this submission.
2. The discussion paper is available at https://consultations.nhmrc.gov.au/files/consultations/drafts/clinicalguidelinesdraftdiscussionpaper.pdf
3. The process undertaken through the Survey Monkey tool did not request any personal identifying information. The request to participate in the consultation process was sent by email to those individuals who had agreed to join the G-I-N ANZ Regional Community mailing list. Comments were transcribed verbatim with the exception of two question where an interpretation was made:
   a. Would your organisation be interested in participating in a recognition scheme for guideline developers? - the response was mixed
   b. Is the trustworthiness of clinical practice guidelines important to you? – There was agreement across the responses.

Responses to Submission Questions

Do you agree with the key challenges identified in this paper (the NHMRC discussion paper)?

1. Yes, but it is an incomplete list and misses the main underlying problem. The key challenge is the lack of a consistent and assured funding program for guidelines and guideline support. A well administered program would be able to put cost-effective strategies in place to help minimise the challenges noted and to provide support for guideline developers
2. Yes
    a. Final paragraph could be explicit about the lack of Federal Government funding to support a comprehensive national program of clinical guideline prioritisation, development, and maintenance.
    b. The section should also address the need for better implementation and monitoring mechanisms of clinical guidelines.
    c. Although cost effectiveness is mentioned later in the discussion paper, it is infrequently reported in the literature, and costly to demonstrate (cost effectiveness associated with guideline recommendations). This part of the NHMRC standard is difficult to deliver in circumstances of funding constraints.
3. Not fully

    National Framework (page 12)

    a. Funding streams are not identified to support the national framework. Greater investment (dedicated Federal funds) to fund guideline development would be essential.
    b. Guideline documentation should address variations in the terminology. For example, NHMRC LoE (level of evidence) can create confusion in interpretation of evidence and alignment with overseas evidence appraisal.
    c. The role of third party guideline developers requires clarification around: would existing chronic disease guidelines lower the priority for nationally funded clinical guidelines?
        - Funding and governance arrangements for third party developers, including the requirement for feasibility studies on cost-effectiveness of proposed guideline recommendations.
        - Standards for Council approval are needed. By experience, NHMRC Council approval of externally developed guidelines was withheld due to potential consequences on the health services and budget, rather than being trustworthy (evidence-based).

    Implementation (page 13)

    Implementation would be strengthened by performance indicators, investment in reliable data capture and evaluation.

    Building capacity (page 14)

    Elaborate / clarify the use of a CRE (Centre for Research Excellence) framework for funding guidelines.

    Process (page 16)

    The process would need to factor in mandatory public consultation, consumer equivalent recommendations, performance indicators and release (both digital and electronic).

In response to 'poor quality'

a. Some government agencies develop high quality clinical guidelines and
b. Sometimes it may be too difficult to have evidence underpinning a guideline when very little or none exists and this is why some guidance is put together.

Inefficiency

Agree with the need for a national guideline strategy.

Poor quality and lack of capacity

One of the key challenges for guideline development in Australia that is not commented on by NHMRC is the lack of consistent funding for guideline projects. A number of guideline development projects are not funded by government and are therefore produced under considerable financial pressure and often with volunteers doing a considerable amount of the evidence review and writing the guidelines. This tends to lead towards inconsistent standards and makes it hard for developers to meet NHMRC standards.

Inaccessibility

Agree that the proliferation of guideline developers makes it hard to locate and use guidelines. It is an even greater concern that there is currently no established way of ensuring consistency across guideline recommendations on related topics. It is also strange that one of the most widely used set of Australian guidelines - those published by Therapeutic Guidelines - and sold to and used by State governments is not more accessible.

Obsolescence

The 5 year cut-off is arbitrary and not useful. There should be a nationally agreed and funded approach to reviewing the guidelines at least every two years and when new sentinel studies on the guideline area are published.

4. Yes. The key challenges described in the paper accurately represent the challenges facing Australian Clinical Guidelines. There needs to be emphasis on the strategic alignment of funding with the prioritisation of guidelines and also emphasis on the need for guidelines to be a dynamic health care tool that accurately reflects current evidence to enable best practice health care. This also needs to be reflected in clearer funding (esp. ongoing for prioritised guidelines).

Do you agree with the actions proposed in this paper?

1. These kinds of proposals have been flagged for years; the problem is that little action to get practical improvement has occurred. NHMRC funding of CREs to provide a research (and as a by-product an associated service component) in relation to systematic reviews and guideline methods would be a huge practical step that could be of substantial benefit in overcoming many of the problems. The NHMRC could be encouraged to support the current network rather than build a new one.

2. Partly agree with a priority agenda

   a. Agree with transparent and quality focused development processes, but these need to be adequately funded.
   b. Agree with capacity building, but also need to emphasise the importance of developing new approaches to guideline development that address patient centred care approaches, multi-morbidity topics and implementation. Useful to look for technological support for guideline development, but this should be an international approach not just an Australian approach.

3. I think that G-I-N has a role in facilitating international connections across guideline topics and in providing training. I think it would be useful to have only one guideline developers' network operating. G-I-N has stepped in to address that void currently. Could it have a funded role to continue?
   a. Agree on intersectoral support for implementation.
   b. See also comments about the need for addressing multimorbidity and patient centred approaches in implementation.
   c. Agree guidelines need to be more accessible and deal with obsolescence.
4. Yes, the actions proposed are good. With respect to Figure 2, Step 7 ACSQHC Implementation the implementers box (top right) should also include end users (clinicians, administrators, health departments). Links with Cochrane to build competencies is great along with access to services and IT platforms. We also would need to see improvements in NHMRC processes (as outlined by this proposal) before mandating that any funded guideline seek NHMRC approval (p13). Ideas outlined on p14 also need to be carefully considered; e.g. CRE's specific to evidence synthesis is a good idea. Academic institutions which are focused on undertaking research often have a distinct culture which may not fit with expertise in guideline development per se.
5. The discussion paper proposes some excellent strategies to improve the way guidelines are developed and used in Australia. I support the feedback provided from the NHMRC developer workshops.
6. The "Clinical Guidelines Network (CGN)", could be seen to duplicate to role of the G-I-N ANZ regional community, so there should be some consideration given regarding whether this group should be the CGN, or if there are complementary roles they could have if the NHMRC does not want to require guideline developers to be part of G-I-N.
7. I think NHMRC discussion paper could provide better coverage in some areas. These topics should be actively considered as part of guidelines development.
   - While the NHMRC's standards for guidelines mention about resource use, this could be expanded further to explicitly include active consideration of cost utility / effectiveness and affordability of the publicly funded health system.

- Guidelines development should be scoped in a way that covers the entire intervention pathway, including all the possible scenarios that would play out in the real world rather than just a small part of the intervention pathway; e.g. for coronary CT angiogram, guidelines around their use should include consideration of the false positive, the harms and management.
- Over diagnosis and over treatment; ideally guidelines should be developed to provide safeguard against them.
- In area of uncertainties, it would be helpful for guidelines to recommend evaluations that may better inform clinical decision making going forward.

8. Should political aspects influence what is covered in guidelines development? Quality of the draft discussion paper is lacking and the objectives unclear. It focuses on guideline developers that are seeking NHRMRC approval although seems to address guideline developers nationally. Figure 3 on p.16 seems to miss the scoping step for guideline development and includes a strange list of stakeholders (i.e. no general practitioners). This example would probably be better if it were about the process for developing a clinical guideline rather a choosing diagnostic tests.
9. The paper seemed disjointed and difficult to consider as one piece of work. I was unclear about what I was to do with all the information about the various technologies available except being informed of their existence.
10. Was difficult to comment on suggested proposals such as the scheme to support guideline network.

Do you support the draft 2015 Standards for Guidelines?

1. Yes
   a. Principles 1.1 could include target audience for decision making.
   b. Evidence-based guidelines: GRADE, the framework to assess quality of evidence and supported by G-I-N is noted within the document but it is unclear if the NHMRC will fully adopt GRADE in favour of existing NHMRC Levels of Evidence framework.
   c. Also suggest measurable indicators (say performance indicators) are included.
   d. No. The organisation that I work for does not develop guidelines. We are part of a HTA and systematic reviews team
   e. While the NHMRC's standards for guidelines mention about resource use, this could be expanded further to explicitly include active consideration of cost utility / effectiveness and affordability of the publicly funded health system. Guideline development often occurs in silo without active consideration of opportunity cost at a population level; the opportunities that one may forgo elsewhere in different disease or speciality. Recommending unaffordable or low value interventions would result in poor implementation or overall poorer population health outcomes.

f. Yes, the draft 2015 Standards for Guidelines appears straightforward and clearly recognises there would be more information in the detailed descriptions of each step. We advocate for clear directions around the requirements for approval for a 'dynamic updating' model of guideline development. We support the production of updated guideline development handbooks to support the new standards. We also suggest further detail is included for implementation which ideally includes methods and indicators to monitor uptake / adherence to recommended care and support to improve clinical practice (behaviour change strategies). Such activity would ideally be considered in the funding for guidelines to ensure they are used.

g. Appendix 1 about the NHMRC's 2015 Standards for Guidelines is useful, although it may be worth amending the following points: 1.1 - address a health care issue of importance to the intended users; 7.5 recommendations do not always affect the majority of people. A further point could be added: 9.5 Be available electronically

Is your organisation able to develop guidelines in compliance with the draft 2015 Standards? If not, in which areas would your organisation need support or guidance?

1. No. federal funding is needed to support the guideline development program. Federal Government enablers (e.g. national policy, performance measurement, data systems) are also needed to support implementation of clinical guidelines.

Would your organisation be interested in participating in a recognition scheme for Guideline Developers?

1. The response from the GIN ANZ community was mixed.
2. Being a third party developer (and implementer) this would ideally reduce ongoing paperwork with NHMRC.

Has your organisation considered seeking NHMRC approval for its guidelines?

1. Yes. barriers identified: "trustworthiness of the NHMRC?"
   - target audience / users of guidelines view endorsement of guidelines by professional colleges as preferred / equivalent to NHMRC approval
   - cost effectiveness appraisal as a requirement of guideline development in circumstances of financial constraints
   - lack of funding
2. Our funding (federal) dictates we seek approval. The NSF has been producing NHMRC approved guidelines since 2005 and will continue to do so. The NSF recognises the value of NHMRC approval as it lets guideline

users know that the stroke guidelines have been produced in accordance with rigorous evidence-based standards and methodology and are trustworthy.

What resources or training opportunities could be of benefit to members of the Clinical Guidelines Network proposed in this paper?

1. Digital technology; e.g. MAGICapp, Adoption of GRADE, harmonising level of evidence frameworks, transparency and how to manage conflict of interests.
2. Clinical Guidelines Network members would benefit from training in the use of new technology to assist them with guidelines; training in undertaking a systematic review and training in the management of conflicts of interest.

Is the trustworthiness of clinical practice guidelines important to you?

1. As a group the respondents agreed that the trustworthiness of clinical practice guidelines was important.

What problems have you had accessing and using guidelines? How could these problems be solved?

1. Central location for all clinical guidelines like the NICE website; often hard to locate guidelines!!! The NHMRC guidelines portal is not comprehensive.
2. Links to other guideline repositories or a search function to enable access to international guidelines for early exploration of questions that may have already been addressed enabling focus to be applied to other questions that may not be considered if prioritised due to funding constraints. There are many common major health issues where the basic information is being reviewed over and over again. Efficiencies can be gained by establishing a bank of some basic evidence statements pertaining to certain conditions.
3. Difficulty in accessing the associated systematic reviews to published guidelines. Cochrane reviews are available but reviews undertaken by independent groups that have not been through a peer review process are not always available yet are used to inform the guideline development.
4. The format of guidelines is an ongoing issue; finding out what works when and where although there is increasing research interest in this topic.

What factors influence your decision to fund a particular organisation to develop a guideline? Is the ability of the organisation to deliver a trustworthy guideline a factor in this decision?

1. Budget and resource availability. Portfolio of guidelines already deemed to be reasonably "trustworthy" in circumstances of financial constraint.
2. This question was not appropriate for evidence gathering organisations.

Would you consider requiring the guideline developers you fund to be recognised?

1. Section ii) on page 14 requires clarification on proposed framework.

Additional questions asked of the G-I-N ANZ Regional Community

How could the G-I-N ANZ Regional Community work with the proposed guideline network? *The consultation paper mentions working with Cochrane, what could the G-I-N ANZ Regional Community offer.*

1. The GIN regional community could actually provide this service if the NHMRC was willing to provide some support for it.
2. Suggestions:
   a. Digital technology; e.g. MAGICapp; G-I-N library
   b. Adoption of GRADE, and harmonising level of evidence frameworks.
   c. Guidance on managing conflict of interests; a medley of approaches are adopted in Australia.
   d. Shared portal to key Australian journals; e.g. MJA.
3. The consultation paper mentions capacity building, G-I-N ANZ is in the prime position to offer this. G-I-N ANZ can provide / share its expertise / high level advice and needs to be a key player in the proposed guideline network.
4. Offer training in guideline development and implementation, provide international contacts on guideline topics and seek NHMRC funding to run the guideline developers network.

Are there any other options for G-I-N to support the development of high quality guidelines in Australia

1. Develop G-I-N evidence library and guidelines developed by G-I-N members via MAGICapp.