

29 June 2012

Mr Simon McKeon, AO
Chair
Strategic Review of Health & Medical Research
PO Box 4226
MANUKA ACT 2603
Via email: mckeonreview@secretariat.com.au

Dear Mr McKeon,

COMMENTARY ON CONSUMER PARTICIPATION IN HEALTH & MEDICAL RESEARCH

Attached is a commentary that may be useful to you in your final deliberations in undertaking the strategic review of health and medical research.

It represents the views of key people who are recognised nationally as those with healthcare consumer advocacy expertise through their appointment to the National Health and Medical Research Council and its principal committees. I should emphasise this commentary does not represent the views of the NHMRC – not for any sinister reason; but for the reason of timing.

We have prepared the document as a commentary, noting that submissions closed a while ago. Unfortunately, the delay in our meeting meant that we did not have the opportunity to discuss key issues amongst ourselves.

We hope you will find this document useful as you work through the key issues.

Yours sincerely,



Anne Cahill Lambert, AM

COMMENTARY ON

CONSUMER PARTICIPATION

IN HEALTH AND MEDICAL RESEARCH

Submitted by:

Ms Anne Cahill Lambert, AM

Ms Margaret Deane

Mr Demos Krousos

Dr Julia Nicholls, OAM

Mr Sebastian Rosenberg

Mr John Stubbs

1 Introduction

The signatories to this commentary are writing in their personal capacity and not representing any organisation. However, each signatory has been recognised nationally as a person with healthcare consumer advocacy expertise through their appointment to the National Health and Medical Research Council and its principal committees. Every six months or so, the signatories have met to discuss key consumer health issues that affect the work of the NHMRC.

We note that the NHMRC has lodged a submission (no. 222) and we endorse that submission. We wish to elaborate on some of the key issues for consumers in the context of the outcomes for health and medical research.

The NHMRC triennium concludes on 30 June 2012.

2 Need for Competitive Research *(term of reference 1)*

Great achievements have been made across the research spectrum from the high-end laboratory experiments into translation to the bedside. There is no better demonstration of this achievement than reviewing Australia's population pyramid over the last century. Such achievement has, of course, built large expectations amongst the Australian community about their longevity and quality of life.

Australians who are diagnosed with what were once terminal illnesses expect that efforts will be made to either cure them or manage their condition so that a reasonable quality of life can be maintained. These expectations require the provision of a high quality, **evidence based**, health care service that is accessible and cost effective.

Australians also expect that considerable efforts will be made to ensure that they are not exposed to any risks or indeed epidemics. They take it as a right that they will be informed about the promotion of good health.

We see these expectations as growing and not reducing.

Thus, it is clear to us that Australia needs to continue to build and retain internationally competitive capacity across the research spectrum. Such capacity needs to embed consumers.

3 Expenditure on Health and Medical Research *(terms of reference 2, 3 and 4)*

Numerous submissions have provided information about levels and sources of funding, including the NHMRC submission. We will not attempt to replicate that information.

However, it should be noted that during the lead up to the 2011 Federal budget when it was suggested that the health and medical research allocation would be slashed, it was predominantly consumers marching in the street and approaching politicians. There were certainly plenty of researchers involved in the campaign, but equally, consumers took a large lead in this activity.

It is our contention that two approaches are required to ensure that Australians can be confident that their health and well being is front and centre at all levels of the Australian health and medical research system:

- a. A proportion of the health budget should be quarantined for research activities under the auspices of NHMRC.
- b. Drug companies who in the past were keen to support individual research activities should be required to contribute to a pool of funding that is managed by NHMRC. This would remove any conflicts of interest that currently prevent them from supporting a system that they often benefit from.

Some process is also required to ensure that there is no duplication and that researchers are encouraged to collaborate across institutions, jurisdictions and countries to achieve the best outcome. One way of achieving this is that all health and medical research applications should be filtered through and/or managed by the NHMRC and that ONHMRC is funded for this. Currently,

researchers can apply through the Australian Research Council, jurisdictional research organisations and other bodies. We need some coordination to ensure that the brightest minds are brought together, within the spirit of competition, but with the focus of improving the health and well being of Australians as the key goal.

It is noted that quite a number of the medical research institutes also receive direct government or philanthropic grants. A mechanism is required whereby those institutes report their priorities for research in advance of NHMRC calling for applications. This may ensure that the health and medical research sector can synchronise priorities with little or no duplication. If they receive government funding, it should be a requirement that their research applications should be managed through the NHMRC.

4 Likely Future Developments (*term of reference 5*)

We are not experts in likely clinical developments, however we are focussed on what it is that Australians expect of their health and medical research activities.

We have seen in the last triennium of the NHMRC considerable demands from consumers who wish to be more involved in the key decisions including priority setting. This is to demonstrate transparency of processes as well as the commitment to the taxpayer that their research dollars are being wisely invested. It is also about that important maxim: *“nothing about me without me”* which includes the research in the laboratory to its implementation at the bedside.

The NHMRC has developed a framework for engaging consumers which is currently being finalised and is unlikely to be concluded before the end of the triennium. That framework will embed consumers in NHMRC processes. The [consumer participation statement](#)¹ outlines NHMRC's commitment in this regard

¹ National Health and Medical Research Council & Consumer Health Forum (2002) *Statement on Consumer and Community Participation in Health and Medical Research*

and is currently being updated. However, it is not well understood amongst researchers and medical research institutes. The important work to be done will be about implementing the revised statement and framework to ensure that health and medical research is not funded through NHMRC unless consumers are genuinely engaged in such research. This is an important approach and should be adopted across the board in all of the health and medical research institutes and agencies.

It is evident that Australia cannot afford curiosity research. Yet, there does not seem to be any process in any of Australia's research organisations (including NHMRC) to clearly educate consumers what it is they wish to have researched. Priorities are set sometimes by governments, but mostly by researchers. Sometimes this is appropriate; often it is not appropriate and consumers are left scratching their heads about the reasons for some decisions.

There is plenty of evidence about differences in priorities and expectations between consumers and researchers² but the burgeoning health system and scarcity of the dollar means that there should be a tighter correlation.

5 Australia's Research Workforce, Governance and Collaboration *(terms of reference 6, 7 and 8)*

One of the significant omissions in Australia's research workforce is access to major grants by female researchers. We know that women and men enter university at roughly even numbers, perhaps skewed towards women lately, but by the time they reach a senior level in the research sector their numbers have dwindled significantly. We are advised by the NHMRC that the success of women who apply for grants at the senior level is about the same as for men. The problem is that very few women are at the senior level applying for grants. We believe that strategies need to be put in place to support women to be able to

² see for example Banfield, MA, Griffiths, KM, Christensen, HM, & Barney, LJ (2011), *SCOPE for Research: mental health consumers' priorities compared with recent research in Australia*. AustNZJ Psychiatry, 45(12), 1078-1085.

sustain a research career. We are not sure that track record in research will ever support the engagement of the other half of the population at the senior level.

NHMRC has instituted a policy that enables consideration of *track record relative to opportunity*. Consumers participate in peer review processes, but only as observers. Thus it is difficult to raise the issue of track record relative to opportunity if any grant review committee has omitted to address this matter.

We have no doubt that universities and MRIs need to become women friendly for researchers and identify strategies to improve the appointment and retention of senior female researchers. They must work cooperatively and collaboratively with organisations such as NHMRC to ensure that the diverse workforce that Australia has is fully utilised.

Of Australia's eleven Nobel laureates, ten have been in the fields of physics (2), physiology or medicine (8) and only one has been a woman. While this is not too different from other countries, nevertheless it does not make it acceptable. Elizabeth Blackburn indeed left Australia and it was her work in the USA for which she was recognised. Australia punches above its weight as far as international recognition and sustainability is concerned, but not as far as engaging women. Significant work is needed to address this shortcoming.

The governance of the medical research sector may be improved by better engaging consumers at all levels. Again, NHMRC has strategies to improve this, but it cannot do this on its own. There are many individuals and organisations that decide upon what research is required, how it is to be managed, and how it is to be implemented. Consumers are an added bonus in supporting essential research to improve health outcomes. They are the greatest advocates for research teams. They are interested in health outcomes, not the egos of who discovers what cure first.

If some of the suggestions addressed at item 3 above are incorporated, the concept of collaboration will be rewarded and the concept of duplication not funded.

6 Health Reform, Health Policy, eHealth and Determinants of Health (*terms of reference 9, 10, 11 and 12*)

The latest health reform processes have seen a plethora of new organisations established that impact upon the work of research funding bodies. Yet little or no links have been established to ensure that their work either complements the work of those involved in medical research or supports that work. We hope that the new organisations as well as the re-vamped organisations work collaboratively with medical research organisations to support the high quality medical research required to ensure a high quality, **evidence based**, health care service that is accessible and cost effective.

eHealth is a key reform that will support improvements in health and medical research and outcomes. Linkages are essential to assess issues such as:

- a. engagement by researchers of all sectors of the population including those from rural, regional and remote Australia, Indigenous people, people from culturally and linguistically diverse backgrounds and children as well as adults. All too often it is easy to include white metropolitan Australian adults in health and medical research activities and this is to the detriment of improving health outcomes of all Australians.
- b. health and medical research needs of Australia – once a system is properly in place, it will presumably include reporting that is able to give a true picture of the impact of any burden of disease, chronic or otherwise. Such a system would therefore obviously identify gaps that should be supported by a rigorous health and medical research base.

We are unclear as to whether any work has been done to enable the collation of population data from eHealth records but we regard this as essential in improving health outcomes.

7 Australia's Role as a Good Citizen *(term of reference 13)*

We know that NHMRC supports a range of initiatives to improve chronic illness and global health, particularly in the developed world. NHMRC's submission itemises its important role in this area. It is unclear to us how priorities are set. We would like to see a more collaborative approach with AusAID to ensure that health and medical research needs are prioritised in a structured way. This might mean a presence from AusAID in NHMRC or ARC, or vice versa.



Signed by: Anne Cahill Lambert, AM on behalf of the following who were members of the Consumer Consultative Group of NHMRC during the 2009-12 triennium:

NAME	COMMITTEE
Ms Anne Cahill Lambert, AM	Council
Ms Margaret Deane	Licensing Committee
Mr Demos Krouskos	Health Care Committee
Dr Julia Nicholls, OAM	Licensing Committee
Mr Sebastian Rosenberg	Prevention and Community Health Committee
Mr John Stubbs	Australian Health Ethics Committee

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